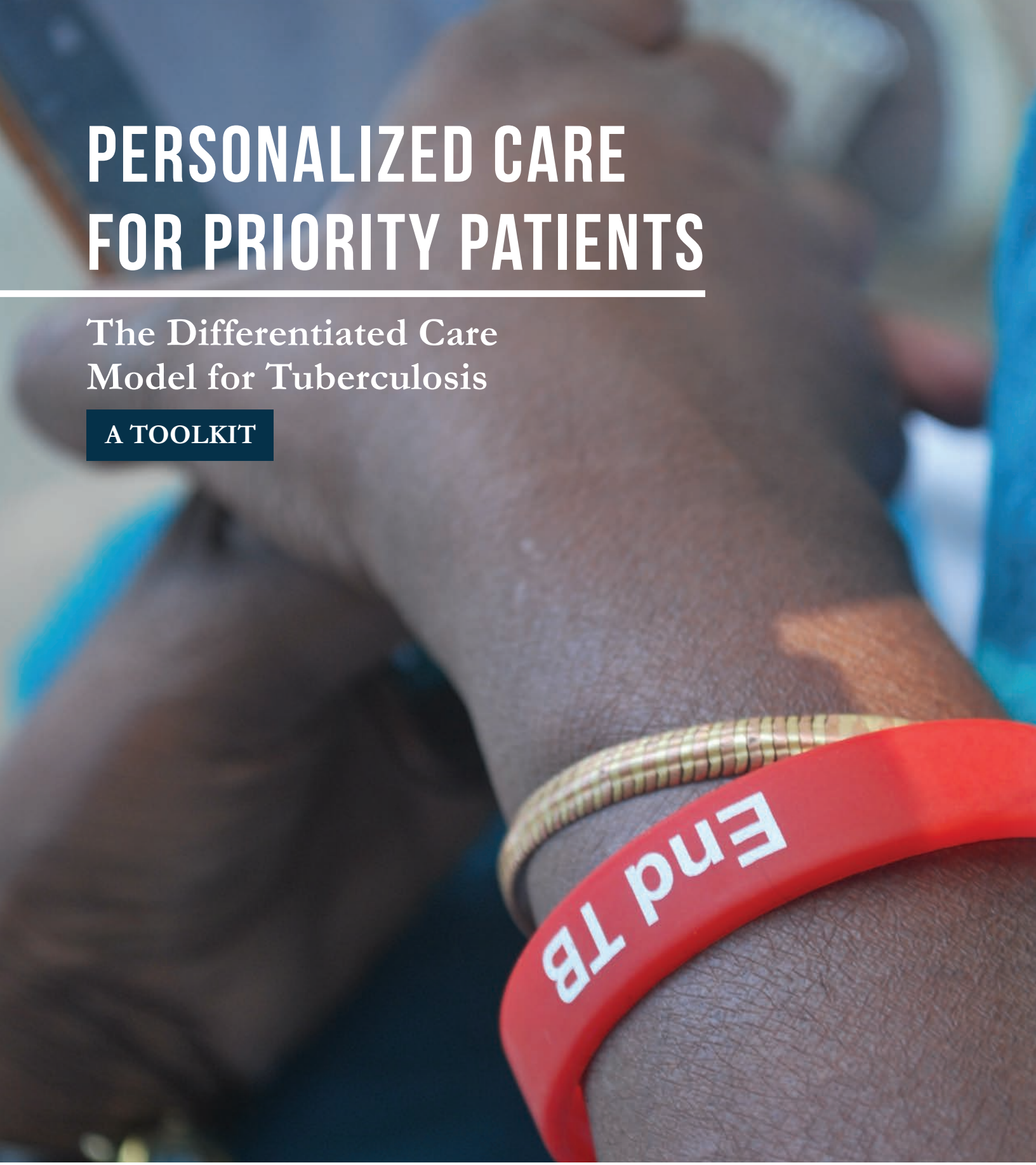

PERSONALIZED CARE FOR PRIORITY PATIENTS

The Differentiated Care Model for Tuberculosis

A TOOLKIT

USAID FROM THE AMERICAN PEOPLE

DOTS Pura course i Pakka ilaaj

TB alert INDIA

NATIONAL HEALTH MISSION

KHPT engage, innovate, empower

Facilitator Guide: Differentiated Care Model with Counselling skills

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OVERVIEW

Tuberculosis, in addition to being the world's top infectious killer, is very much a social disease, the effect and experience of which are determined by social factors. While anyone can get TB, it is a disease the disproportionately affects the poor living in crowded, badly-ventilated settlements, especially those who suffer from undernutrition, have pre-existing health conditions and work in occupations hazardous to the lungs. The journey of a TB patient is a long and difficult one; patients not only have to deal with side-effects over the months-long course of treatment, but often have to face stigma from their families, friends and colleagues who fear that they will get infected or be ostracized for interacting with a TB patient. Stigma from family and friends manifests as isolation from loved ones, and even loss of employment, which often leads the patients to stop taking treatment in the absence of a network of social support. TB care and support, therefore, must be a holistic process which involves not only provision of information on treatment, medication and monitoring, but also includes counselling and psychosocial support to help understand the underlying reasons affecting treatment adherence and address them.

Under the Tuberculosis Health Action Learning Initiative (THALI), a four-project funded by the United States Agency for International Development (USAID), KHPT developed an approach to prioritized patient care on the basis of a risk and needs assessment. This approach, called the Differentiated Care Model (DCM), identified seven categories of patients most vulnerable to unsuccessful treatment outcomes including drug-resistant TB patients, HIV-TB patients, previously-treated patients, TB patients with diabetes, people living alone, those consuming alcohol and the elderly. Each category was offered a tailored package of care and support services, including counselling.

This patient care and support toolkit is designed to help care and support providers, including health facility staff and frontline workers to build the essential skills required to provide prioritized care to high-risk categories of TB patients.

TOOL KIT COMPONENTS

01

Strategy Note on the Differentiated Care Model (DCM)

The strategy note provides a detailed description of the DCM model, including its objectives, key features, tools used, process of engagement and approach to care for each high-risk category of TB patient.

02

Training Module on Counselling

The key objective of the training module is to capacitate health facility staff and frontline workers on communications and counselling skills, and their application to the care and support of TB patients dealing with difficulties in taking medications and sensitive issues such as stigma and disclosure of their TB status.

The training modules have been designed to help facilitators to build capacities of participants over a three-day training, which features structured, participatory and interactive sessions on topics such as active listening, body language, and counselling. The training also includes the assessment of patients' risks and needs and providing medical, economic and psychosocial support through personalized care packages under the DCM model.

The module includes appendices with the tools and communication materials used during the process of assessing patient risk and providing care and support.

03

Stories from the field

These stories from the ground illustrate the implementation of the DCM model through the stories of patients in different risk categories and the types of care and support services they received to help them achieve successful TB treatment outcomes.

STRATEGY NOTE

Differentiated Care Model

A personalized approach to prevention, care and support for TB patients

CONTEXT

Not all tuberculosis (TB) patients are the same, nor do they all have the same type of TB. It is therefore essential to analyse the needs of high-priority patients and plan for a prioritized approach to providing TB prevention, care and support (PCS) services. High priority patients' groups include:

- Elderly patients over 60 years of age
- Patients who are living alone
- Patients who were treated previously, and had taken medication irregularly
- Drug-resistant TB Patients (DR TB)
- Patients consuming alcohol
- Patients co-infected with HIV
- Patients with diabetes

This prioritized approach is termed as the Differentiated Care Model (DCM) for providing PCS services to TB patients and their families for optimal outcomes.

The DCM is aligned with the Integrated Patient-centred Care pillar of the End TB strategy. It aims to synergise THALI efforts with those of the field staff of the National Tuberculosis Elimination Program (NTEP) to provide TB PCS that cater to the specific needs of patients and their families, reducing duplication of efforts in the field, while still ensuring 'Universal Health Care' and reach to all TB patients.

The administration of the risk and needs assessment tool (RANA) is the first step in providing prioritized support services, and is administered at the time of treatment initiation. If the risks and needs are low, patients will be provided the PCS services applicable to all patients, aligning with the national protocol.

KEY FEATURES

The DCM is aligned with the Integrated Patient-centred Care pillar of the End TB strategy.

It is a prioritized approach to treatment of high-priority patients aimed at improving treatment outcomes and reducing mortality.

The Risk and Needs Assessment (RANA) is conducted at the time of treatment initiation to decide which package of PCS services should be provided to each patient.

The DCM has a counselling component to address patients' psychosocial needs.

OBJECTIVES

1 To improve treatment adherence, leading to course completion and cure of high priority patients, thereby reaching more than 90% successful treatment outcomes.

2 To create a specialised cadre of frontline workers who are trained to provide customized PCS services to patients according to their needs.

PRE-REQUISITES TO IMPLEMENTING THE DCM

Presentation/sharing of the DCM with the State and District NTEP teams by the THALI team in Karnataka, Telangana and Andhra Pradesh for consensus.

RANA to be administered to each patient at the earliest, by the time of diagnosis or at least at the time of treatment initiation, while preparing the treatment card for need-based services to all TB patients.

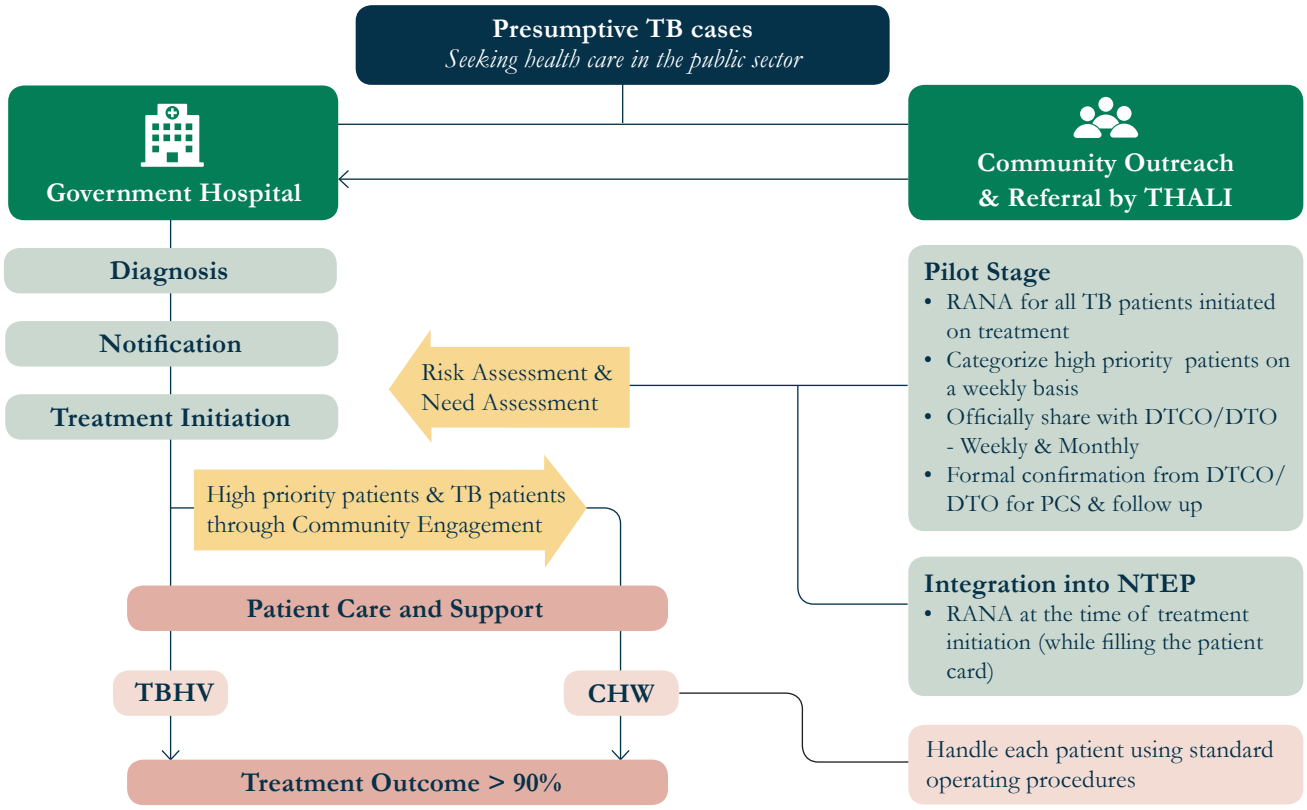
RANA analysis to be done on a monthly basis at the district level, and shared with District TB Officers/ District TB Control Offices (DTOs/ DTCOs), after drawing up the list of high-priority patients in each district.

Capacity building of the project team including the frontline workers (Community Health Workers) on the DCM.

Development of a handbook for Community Health Workers (CHWs) to explain which behaviour change communication (BCC) tools are to be used during each visit for PCS, during the intensive and continuation phases of treatment.

Relevant Information Education and Communication (IEC) and BCC materials to be developed for use among regular care patients and high priority patients, to support behaviour change.

PROCESSES



RISK AND NEEDS ASSESSMENT (RANA)

The RANA form (please see Appendix) was designed to be an easy-to-use tool to help frontline workers create a profile of the TB patient during interactions at the time of diagnosis or treatment initiation and assess the risks which could hinder successful treatment outcomes. The tool assesses:

- A person's knowledge of TB, which may affect his/her treatment adherence, including whether the person has accepted that he/she has TB, and whether he/she has access to treatment.
- The level of social support available to the patient from caregivers and family, and whether he/she has been stigmatized.
- The person's medical history, including co-morbidities such as diabetes and HIV, and whether a patient is a consumer of tobacco or alcohol.
- Whether patients fulfil the criteria for accessing patient benefits such as direct benefit transfer payments, and if they need support to avail support schemes.

The RANA form, once filled, creates a multidimensional profile of the patient which can help the frontline worker personalize a care and support approach based on the person's medical history, as well as psychosocial and financial circumstances. The tool also takes into account whether patients prefer in-person follow-up, or would rather receive remote follow-up through call centres, digital adherence technology, or the TB Careline, an outbound phone-based counselling support service.

The RANA categorizes patients into one or more of the seven high-risk DCM categories, guiding the frontline workers on providing specialized care and support packages developed for each under the DCM model. Patients who do not fall into any of the risk categories receive a standard approach to care and support. The care and support components for each of these categories are listed below.

STANDARD APPROACH TO CARE AND SUPPORT FOR ALL TB PATIENTS

Steps	Activity	Result/Outcome
Psychosocial counselling	› Reassurance › Counselling » Disclosure » Co-morbidity » Lifestyle/ habits › Family support › Stigma reduction › Support groups	› TB status disclosed › Family/caregiver take care of treatment adherence › Patient attends support group meeting
Nutrition support	› Nutritional advice › Nutritional linkages » Public Distribution Shops (PDS) » Local leaders » NGOs, Civil Society Organisations (CSOs) » Panchayati Raj Institutions (PRI) › Direct Benefit Transfer (DBT) linkage › Family members education on Nutrition	› Nutrition chart made by family, facilitated by CHW (each patient based on their dietary habits) › Patient consume nutritious food daily › Completed formality (prerequisites) for DBT linkage
Infection prevention	› Cough Hygiene › Sputum disposal › Contact screening › INH prophylaxis treatment (IPT) linkage	› Patient follows cough hygiene and sputum disposal › Family members screened › Children <6 yrs receive IPT
Linkages and support	› Social Security linkage › DBT Linkage › Livelihood linkage › Linkages to local philanthropists › Linkages to health insurance	› Patient linked to social security schemes, DBT, Livelihood, Health insurance etc. as required.
Medical support	› Post-diagnosis support › Adherence support and monitoring › Patient status evaluation › Side effect/ symptom management › Tertiary care linkage	› Patient adheres to treatment protocol › Clinical improvement observed. › Weight gain recorded › Side effects are addressed › Patient linked to tertiary care

SERVICE PACKAGE FOR HIGH PRIORITY PATIENT CATEGORIES

Elderly patients over 60 years of age

	Steps	Activity	Result/Outcome
	Counselling	› Understanding and identifying any possible neglect › Identifying and educating primary caregivers on TB disease, drugs and follow up › Ensuring that the primary caregiver understands the importance of providing regular meals to the patient.	› Patient adheres to regular treatment › Patient gains weight
	Medical support	› Verbal screening for other medical illnesses – Diabetes, Hypertension etc. › Ensuring treatment and follow up of medical illnesses with relevant specialists (support in collecting medicines etc.) › Screening of children at home/family for TB	› Patient adheres to regular treatment › Patient gains weight

Living alone/without family support

	Steps	Activity	Result/Outcome
	Counselling	› Understanding the reason for living alone (job-related etc.) and exploring support systems in neighbourhood. › Facilitating support from family or friends or colleagues (respecting the patient's choice) › Assisting in disclosure to caregiver › Working out reminder systems like SMS, alarm clocks, Medication Event Reminder Monitoring (MERM) systems for medicine intake	› Family member/ a friend supports the patient › Patient adheres to regular treatment
	Linkages	› Creating linkages to Careline or support group meetings	› Patient is linked to Careline and adheres to regular treatment

Patients who were treated previously, and had taken medication irregularly

	Steps	Activity	Result/Outcome
	Counselling	› Identifying and understanding reasons for taking medications irregularly previously › Providing appropriate counselling and education support to the patient and family › Ensuring they understand the advantages of regular medicine and disadvantages of irregular medicine (DR TB etc.)	› Patient adheres to regular treatment despite side effects and complete the course of treatment › Sputum conversion
	Medical support and linkages	› Facilitating linkages for getting injections regularly (for patients who have already started injections before modified guidelines) › Ensuring universal drug sensitivity testing, before initiation of treatment. › Ensuring screening for HIV and DM, which may cause repeated episodes of TB	› Patient receive a CBNAAT test to know/ rule out the status of DR TB

Drug-resistant TB

	Steps	Activity	Result/Outcome
	Family/caregiver counselling	› Counselling and educating the patient and family on duration of treatment › Assessing adherence fortnightly and providing need-based counselling to patient and family › Ensuring they understand the side effects of medication and their effective management	› Patient adheres to regular treatment › No complications due to pill burden
	Linkages	› Facilitating linkages for receiving injections regularly › Facilitating tertiary care admissions as and when required	› Patient takes injections regularly › Management of drug reactions/ side effects

Alcohol Dependent

	Steps	Activity	Result/Outcome
	Family/caregiver counseling	› Counselling and treatment literacy for family members › Ensuring that one primary care giver takes the responsibility of giving Anti TB treatment (ATT) daily without fail › Educating the family and primary caregiver on the importance of providing regular meals	› Patient takes ATT regularly › Family/caregivers take care of adherence › Patient and family members attend support group meeting
	Linkages	› Facilitating linkages to de-addiction services and/or higher level medical facilities › Involving Key opinion leaders (KOL) in case of domestic violence etc.	› Patient adheres to treatment regularly › Domestic violence if any, it is addressed.

TB-HIV

	Steps	Activity	Result/Outcome
	Medical support	› Facilitating antiretroviral therapy (ART) initiation	› ART initiation
	Family/caregiver counseling	› Identifying primary caregiver, educating on TB, HIV medications etc., along with other family members › Educating the primary care giver about the importance of Cotrimoxazole in TB HIV co-infection.	› Patient is on regular medication for both TB and HIV › Improvement in CD4 count › Clinical improvement › Patient gains weight, which is a good indicator for both TB and HIV
	Linkages	› Facilitating linkages with other NGOs for social entitlements and nutrition › Motivating patients to attend Patient Support Group meetings	› Patient gets social entitlements › Patient attends support group meetings.

TB-Diabetes Mellitus (DM)

	Steps	Activity	Result/Outcome
	Medical support	› Facilitating linkages with clinical diabetes care › Supporting regular monitoring of sugar levels and ensuring that diabetes under control › Supporting the disclosure of TB status with the doctor treating diabetes for modifications in nutrition/medication if required	› Patient makes changes in diet and has an improved nutrition status › Patient's blood sugar under control › Patient takes diabetes medications regularly
	Family/caregiver Counselling	› Identifying and educating the primary care giver on the importance of providing regular meals (low calorie and high protein), TB medications and diabetic medications	› Patient adheres to regular TB treatment and diabetes treatment. › Patient takes proper diet regularly

SUPPORTIVE SUPERVISION/MONITORING

Minimum one visit during the IP and CP phase by the Community coordinator/ District Program Coordinator (CC/DPC).

During DTO monthly review meeting, review of PCS and RANA data of the high priority patients will be done. A report will be generated and shared with the district NTEP team and CHWs.

Analysis of the monthly progress trend at the district level and sharing it with frontline workers (CHWs). Identification of the cases which need attention and visiting those cases on priority, with the support of the technical team of THALI or NTEP.

Follow-up mechanism to be developed at a micro level for each patient so that the CC/DPC can support the patients periodically.

THE IMPACT OF DCM

763 NTEP staff trained on RANA and DCM

9,595 patients assessed through RANA

4,586 patients assessed by NTEP staff using RANA

4,022 patients identified in THALI intervention geographies

The data is for the July 2019- March 2020 period

14,462 DCM category patients were identified and followed up over the project period

TESTIMONIALS

"We would (earlier) not wait for patients and their caregivers to complete their talk, we would hurry them. In these two days we got to know that we must talk less and support the patient and care givers to talk more. We now know that we need to practice to ask open ended questions rather than close-ended or interrogative questions."

NTEP official attending a counselling training, Bangalore

"The frontline workers of the RNTCP are working hard with each patient for successful treatment completion. Now with this counselling training, they can get challenging patients to complete treatment as well."

Dr Anil, (then) Deputy Director, State Tuberculosis Office, Karnataka

"Since the ASHAs and junior health workers are directly in touch with TB patients, they need more clarity on how to do the follow up of TB patients, and their role is very important in case finding and case holding. This kind of training will help the program."

Dr Indrani, District Tuberculosis Officer, Ballari, on the DCM trainings for ASHAs

"We came here thinking that by attending this (counselling) training our workload will increase, but it has opened up the delicate relationship issues of TB patient and their families. We thought we were counselling patients, we got to know we were only doing health education and not counselling."

A TB Health Visitor from Bagalkot, attending a counselling training

"The Differentiated Care Model as an innovation sounds good to us as it may result in better treatment outcomes among high-priority patients."

Dr Rajesham, State TB Officer, Telangana

FACILITATOR GUIDE

DIFFERENTIATED CARE MODEL WITH COUNSELLING SKILLS

ACRONYMS

AIDS	Acquired Immuno Deficiency Syndrome
ASHA	Accredited Social Health Activist
ART	Antiretroviral Therapy
ATT	Anti-tuberculosis Treatment
BCC	Behaviour Change Communication
CBNAAT	Cartridge Based Nucleic Acid Amplification Test
CC	Community Coordinator
CHW	Community Health Worker
DBT	Direct Benefit Transfer
DCM	Differentiated Care Model
DM	Diabetes Mellitus
DMC	Designated Microscopy Centre
DPC	District Project Coordinator
DR–TB	Drug-Resistant Tuberculosis
DST	Drug Susceptibility Testing
FLW	Front Line Worker
HIV	Human Immunodeficiency Virus
IEC	Information Education and Communication
KHPT	Karnataka Health Promotion Trust
KOL	Key Opinion Leader
MDR TB	Multidrug-Resistant Tuberculosis
NGO	Non-Government Organisation
NTEP	National Tuberculosis Elimination Program
PCS	Prevention, Care and Support
PDS	Public Distribution System
PHC	Primary Health Centre
RANA	Risk and Needs Assessment
TB	Tuberculosis
TC	Technical Coordinator
THALI	Tuberculosis Health Action Learning Initiative
WHO	World Health Organization
ZC	Zonal Coordinator

TABLE OF CONTENTS

SETTING THE STAGE FOR TRAINING

NOTES FOR THE FACILITATOR

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.
› 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.
› 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
› As a facilitator, you should be free from all prejudices or bias relating to persons, ideas or issues.
› Develop the ability and skill to manage dissenting opinions and 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 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.

At the beginning of the training

› Starting the training program on a relaxed and positive note is an important first step. 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.

During the training

› The counselling training module is comprised of technical sessions, and the participants are usually the health systems staff or the community health workers. Some may already have knowledge regarding the content of few sessions while some may not. The facilitator must ensure that he or she strikes a good balance between letting participants share their understanding of the subject while not allowing only those few to "remain in the limelight" all through sessions. Ensuring that there is an environment that allows for learning and listening is important. There must be mutual respect among all participants irrespective of the cadre or the position.
› The facilitator must ensure that all participants are prompted to link theoretical concepts to their practical application in the field and encourage participants to use real life experiences and examples in session discussions.

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.
› 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.

INTRODUCTION

Tuberculosis, in addition to being the world's top infectious killer, is also a social disease, the effect and experience of which are determined by social factors. Patients not only have to deal with side-effects over the months-long course of treatment, but often have to face stigma from their families, friends and colleagues who fear that they will get infected or themselves be ostracized for interacting with a TB patient. In the absence of a network of social support, this stigma often causes the patients to stop their treatment. Underlying mental health problems, including depression and anxiety, also affect TB treatment adherence.

Counselling is an important linchpin in a patient-centric package of support services, to ensure treatment adherence and treatment completion. The National Strategic Plan (NSP) 2017-2025 of the National Tuberculosis Elimination Plan (NTEP) recognizes it as an essential component of a good treatment support plan.

The Tuberculosis Health Action Learning Initiative (THALI) is a patient-centric family-focused TB prevention and care initiative that aims to facilitate vulnerable populations' access to quality TB services from health care providers of the patient's choice. THALI, which is funded by the United States Agency for International Development (USAID), is being implemented in the states of Karnataka, Andhra Pradesh and Telangana by Karnataka Health Promotion Trust (KHPT), in partnership with TB Alert India (TBAI).

THALI recognizes that not all TB patients are the same, nor do they all have the same type of TB or other comorbidities. However, every patient with a successful treatment outcome contributes to the goal of ending TB. Therefore, under THALI, a plan was created for a prioritized approach to providing TB prevention, care and support (PCS) services. For example, TB patients using alcohol or with co-morbidities like HIV or diabetes, need a specialized approach to PCS. This proposed approach is termed as 'Differentiated Care Model' for providing PCS services to TB patients and their families. The Differentiated Care Model (DCM) is aligned with the Integrated Patient-centered Care pillar of the End TB strategy.

This facilitator's manual comprises sections on the DCM and on counselling skills. It focuses on a patient and family-centric approach, keeping in mind that the family plays a big role in supporting the patient's emotional needs and keeps the patient motivated to complete the TB treatment. The training manual also emphasizes the emotional challenges faced by the TB patients and their families, including stigma, fear and non-disclosure of their TB status. These challenges are closely linked to adherence to and completion of treatment, and the module builds the counselling skills of frontline workers (FLWs) who work with patients dealing with these emotions every day. The chapter on linkages seeks to help the FLWs identify the needs of the patients and their families and lead to better treatment outcomes.

The approach in this manual is a hands-on one, with practical sessions for practicing counselling skills on patients who require differentiated care. The manual uses case stories to understand the need for counselling in the field, which gives the FLWs an opportunity to test the counselling skills they have learnt in earlier sessions.

SECTION a

DIFFERENTIATED CARE MODEL

SESSION 1

An Introduction to the Differentiated Care Model (DCM)

Objective

By the end of this session, participants will be able to:

- Understand the Differentiated Care Model and its categories of patients
- Know how to effectively provide care to the different categories of patients

Methodology

Large group discussions

Materials required

Chairs, a quiet and large room, an LCD screen or projector, computer

Duration

165 minutes
(2 hours 45 minutes)

DIFFERENTIATED CARE MODEL

The Differentiated Care Model (DCM) is aligned with the Integrated Patient-centered Care pillar of the End TB strategy. It aims to synergize THALI's efforts with those of the field staff from the National Tuberculosis Elimination Program (NTEP) to provide customized TB prevention, care and support to patients and family. Assessing the patient's risk and needs by using the Risk and Needs Assessment (RANA) tool is the first step in providing a specific package of PCS services to patients and family. In addition to these tailored packages, all patients will be provided standard PCS services in line with the National Strategic Plan for TB Elimination in India (2017-2025).

The facilitator will brainstorm with the participants on the various PCS services provided to the patients and list out the services on a flipchart. The facilitator will then go through a PowerPoint (PPT) slide on this and summarize.

The spectrum of PCS services includes,

Psychosocial support	› Reassurance › Counselling » Disclosure » Co-morbidity » Lifestyle/ habits › Family support › Stigma reduction › Support groups
Nutrition	› Nutritional advice › Linkages to nutrition » Public Distribution System » Local leaders » Nongovernment Organizations, Community Service Organizations » Panchayati Raj Institutions › Linkage to Direct Benefit Transfer (DBT) payments
Infection Prevention	› Cough hygiene › Sputum disposal › Contact screening › Linkage to Isoniazid Preventive Therapy
Financial	› Linkage to Social Security › Linkage to DBT

Financial	› Livelihood linkages and loan access › Linkages to local philanthropists › Linkages to health insurance
Medical	› Post-diagnosis support › Adherence support and monitoring › Patient status evaluation › Side effects/symptom management › Tertiary care linkage › Post treatment follow-up, referral for follow-up sputum microscopy/ cultures › Treatment rupture intervention (when the patient is not traceable)

CATEGORIES FOR INCLUSION INTO THE DCM

The facilitator will discuss with the participants which patients they find difficult to follow up and provide services for. The facilitator will then list out the risks for non -adherence to treatment.

It has been found that TB patients with the following risks have worse treatment outcomes, including death, loss to follow up and treatment failure:


Patients aged more than 60 years


Patients living alone or without family support


Patients who have been treated for TB previously


Drug-resistant TB Patients (DR TB)


Patients consuming alcohol


Patients co-infected with HIV


Patients with Diabetes Mellitus (DM)

THALI Community Health Workers (CHWs) will therefore be trained to focus on these patients and to provide a more intensive package of PCS services, in addition to the spectrum of PCS services mentioned above. All other patients will receive a basic package of services.

The facilitator will then discuss that findings from preliminary RANA analyses were used to select categories of patients who may require differentiated follow-up. However, the basic services for all other patients will continue.

A preliminary analysis of RANA tools from the period June 2018 – June 2019 found that of 11145 TB patients assessed in Karnataka, 5016 patients (45%) required prioritized PCS services. Supporting these patients through the continuum of care, and beyond, so that treatment is successfully completed, will also help the NTEP improve treatment completion and cure to reach successful treatment outcomes of over 90%.

DCM APPROACHES TO PROVIDING CARE TO PATIENTS WITH RISKS

The facilitator will go through the slides in the PPT presentation to orient the participants on the approach to providing care to the different categories of patients. The facilitator will also make it clear that further discussion on the approaches will be dealt with in the upcoming adherence sessions and bring to their notice the handouts that contain the information.

While going through the slides, the facilitator will stress the differences and modifications in the approach for each category. This is highlighted in the relevant slides.

Based on the learnings from the DCM, we emphasize the following points, which have the potential to be significant at the national level:

1. The reduction of negative treatment outcomes using the DCM could result in over 90% successful treatment outcomes
2. There is a need for specialized frontline workers (FLWs) to provide different PCS services for patients with HIV, Diabetes, DR TB, aged above 60 years, living alone, previously treated and using alcohol

TB patients aged more than 60 years

Based on evidence from THALI's RANA analysis, 13% of patients assessed were above the age of 60 years. This group of patients is also at risk for other age-related disorders and risk factors related to habits, lifestyle, and social exclusion. Patients on medication for multiple health problems may have poor adherence due to confusion in taking the regimen, while the presence of other diseases may contribute to negative treatment outcomes.

Steps to Providing Care (Patients living alone or without family support)

MEDICAL	
Activity	› Look for other medical illnesses – Diabetes mellitus, Hypertension (HTN) etc. › Ensure treatment and follow up of medical illnesses with relevant specialists (support in collecting medicines etc.) › Ensure treatment and follow-up of medical illnesses with relevant specialists (support in collecting medicines etc.) › Make sure that one primary care giver takes the responsibility of giving anti-tubercular treatment (ATT) daily without fail. › Screening of children at home/ family for TB
Intensive Phase (IP)	IP visit – 1,2,3,4
Continuation Phase (CP)	CP visit – 1,2,3,4
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family

COUNSELLING	
Activity	› Understand and identify any possible neglect › Identify and educate primary caregiver on TB disease, drugs and follow up › Support the primary caregiver and address their emotional needs and challenges. Encourage them to cultivate in them the 'identified' strengths during counselling to care for themselves and the people in the family including the TB patient › Ensure that the primary caregiver understands the importance of providing regular meals to the patient
Intensive Phase (IP)	IP visit – 1,2,3,4
Continuation Phase (CP)	CP visit – 1,2,3,4
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family

LINKAGES	
Activity	› Linkages to Careline or support group meetings › Linkages to government schemes for senior citizens (if needed by the patient)

TB patients who are living alone or without family support

THALI's RANA analyses found that 4% of patients were living alone. It was also found that there was an increased presence of other risk factors, including old age, HIV, DM, alcohol consumption and having been previously treated for TB, which may increase the risk for non-adherence to medication.

Steps to Providing Care (Patients living alone or without family support)

MEDICAL	
Activity	› Assist in disclosure to the family to further prevent TB transmission and seeking support for medical care
Intensive Phase (IP)	IP visit – 1,2,3,4
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient, supportive members

COUNSELLING	
Activity	› Understand the reason for living alone (job related etc.) and explore support systems in the neighborhood › Facilitate support from family or friends or colleagues (respecting the patient's choice) › Assist in disclosure – to seek emotional support from the family members/ close friends/ work colleagues/ manager. Support the patient and prepare them for any rejection, stigma, isolation post disclosure. › Offer continued support and extend support to other persons who have received the news too › Work out reminder systems like SMS, alarm clocks for medicine intake
Intensive Phase (IP)	IP visit – 1,2,3,4
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient, supportive members

LINKAGES	
Activity	› Creating linkages to the TB Careline or support group meetings
Intensive Phase (IP)	IP visit – 1,2,3
Continuation Phase (CP)	CP visit – 1,2
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient, supportive members

TB patients who were previously irregular to treatment

Preliminary RANA analyses shows that around 17% of the patients reported having taken treatment previously in an irregular manner. These patients are at risk for non-adherence due to a variety of reasons, including a lack of belief or loss of belief in the treatment itself and persistence of factors that might have led to non-adherence in earlier treatment(s).

Steps to Providing Care (Patients previously irregular to treatment)

MEDICAL	
Activity	› Ensure universal DST, before initiation of treatment.
Intensive Phase (IP)	IP visit – 1,2,3
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

COUNSELLING	
Activity	› Identify and understand reasons for taking medications irregularly previously › Address stigma, interpersonal issues if found, for irregular treatment. Offer regular support whenever required to the patient and caregivers. › Provide appropriate counselling and education support to the patient and family to understand the advantages of regular medicine and disadvantages of irregular medicine (DR TB etc.)
Intensive Phase (IP)	IP visit – 1,2
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

LINKAGES	
Activity	› Ensure linkages for screening for HIV and DM, which may cause repeated episodes of TB
Intensive Phase (IP)	IP visit – 1,2,3
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

TB patients with Drug-Resistant TB

THALI's RANA analyses found that 5% of patients assessed were suffering from Drug-resistant TB (DR TB). DR TB is more difficult to treat, with stronger medications that can cause severe side effects. The course of treatment is longer than the standard course of six months, and may extend up to two years. These factors can hinder treatment adherence.

Steps to Providing Care (Patients with DR TB)

MEDICAL	
Activity	› Ensure the patients and caregivers understand the side effects of medication and their effective management. › Ensure patients take pyridoxine daily during the course of treatment
Intensive Phase (IP)	IP visit – 1,2,3,4
Continuation Phase (CP)	CP visit – 1,2,3,4
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

COUNSELLING	
Activity	› Counsel and educate patients and family on duration of treatment › Assess adherence fortnightly and provide need-based counselling to patient and family › Ensure they understand the side effects of medication and their effective management. If the patient has Cycloserine as part of the drug regimen, it is important to counsel the patient to be vocal about any side-effects and educate the primary caregivers and family members to be supportive and watchful of any difference in behavior, self-harm and suicidal thoughts or attempts. › Keep in touch at regular intervals with the patient › Follow up patients fortnightly to assess adherence
Intensive Phase (IP)	IP visit – 1,2,3,4
Continuation Phase (CP)	CP visit – 1,2,3,4
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

LINKAGES	
Activity	› Leverage resources (nutritional support, finance, de-addiction center, mental health etc.) for higher-level medical management (surgery etc.) › If the patient requires admission into an in-patient facility, provide help for the same with the support of other team members. › Counsel the patient after an initial assessment and facilitate linkages to already-existing care and support systems for DR TB patients, such as the Tata Institute of Social Sciences for counselling.
Intensive Phase (IP)	IP visit – 1,2,3,4
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

TB patients using alcohol

Based on the evidence from THALI's RANA analysis, 13% of TB patients in Karnataka consumed alcohol, which may affect their adherence to treatment. There is little documentation of TB drug interactions with alcohol. However, alcoholism is a known factor which can hinder adherence to Anti-Tuberculosis Treatment (ATT), and can aggravate liver toxicity associated with ATT and gastritis. Alcoholism is a disease and should be treated by a team of health professionals including the doctor, nurse, counsellor and peer counsellor. Management of withdrawal symptoms and detoxification are important components of the medical management of alcoholism. The patient's own motivation and decision, as well as family support, is important for success in an alcohol de-addiction program. Additionally, there are also challenges that are faced by the patient's family, which need to be acknowledged.

CHALLENGES FACED BY FAMILY

The family can feel pressurized if the alcoholic patient is not willing to reduce consumption or abstain from alcohol. Convincing the patient to adhere to treatment, eat on time and follow a normal routine can create stress in the family. Eventually, in some families which are facing continuous challenges, negligence can build and family members may become indifferent.

Alcoholic patients may move around and this can make it difficult for the family to search for them and give them their ATT on time. Similarly, as there are concerns about adherence, ATT is not given to alcoholics on a monthly basis. Instead, patients have to go and collect ATT on a daily basis or twice a week.

Many times, it is the patient's wife or caregiver who collects the medicines from the dispensary. However, as they also have to go for work, this can mean that medicines are not collected on time as they do not want to lose their daily wages. Some of the patients and/or their family members depend on the local health worker to collect ATT. However, by the time the health worker collects and gives them the medicines, a few doses may have already been missed.

Steps to Providing Care (Patients using alcohol)

MEDICAL	
Activity	› Facilitate linkages for pyridoxine tablets

COUNSELLING	
Activity	› Ensuring that TB medications are taken regularly, is the primary goal and not de-addiction › Counsel and educate the patient and family regarding treatment › Make sure that one primary care giver takes the responsibility of giving ATT daily without fail › Educate the family and primary care giver on the importance of providing regular meals and link it to nutrition and adherence to medication › Facilitate linkages to de-addiction services and/or higher level medical facilities › If the patient is completely intoxicated throughout the day and **is not taking medicines**, then, taking the factor of affordability and support into account, assist the family members in admitting the patient to a de-addiction center. However, this is completely at the discretion of the family members.
Intensive Phase (IP)	IP visit – 1,2,3
Continuation Phase (CP)	CP visit – 1,2,3
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

LINKAGES	
Activity	› Involve Community Leaders in case of domestic violence etc. › One such measure to empower a woman in these circumstances is to link her with a friend or female community leader, a neighborhood 'sister' or 'Sakhi,' in whom she can confide.
Intensive Phase (IP)	IP visit – 3,4
Continuation Phase (CP)	CP visit – 1,2
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

TB patients with HIV

Patients with both TB and HIV can have unfavorable outcomes. TB can be difficult to diagnose and treat in persons living with HIV owing to challenges related to presentation of symptoms, comorbidity, pill burden, co-toxicity and drug interactions. The mortality in this group is very high; 9700 people living with HIV and TB died in India in 2018, according to the WHO's Global Tuberculosis Report. THALI's RANA analysis found that 3% of TB patients assessed were HIV-positive.

Steps to Providing Care (Patients with HIV)

MEDICAL	
Activity	› Facilitate Antiretroviral Therapy (ART) initiation › Identify primary caregiver, educate on TB, HIV medications etc., along with family members › Facilitate linkages for pyridoxine tablets as and when required › Ensure that the patient is regularly followed up by ART medical officers › Educate the primary care giver about the importance of CPT (Cotrimoxazole) in TB-HIV co-infection

COUNSELLING	
Activity	› Identify primary caregiver, and counsel on regularity of TB, HIV medications etc. along with family members › Motivate the patient to attend patient support group meetings › Support the family in making a patient-friendly medication schedule, as pill burden (number of pills to be consumed) will be high
Intensive Phase (IP)	IP visit – 1,2,3
Continuation Phase (CP)	CP visit – 1,2
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

LINKAGES	
Activity	› Facilitate linkages with other NGOs for social entitlements & nutrition › Facilitate linkages with other NGOs working for HIV, based on the patient's requirements. › Motivate patients to attend Patient Support Group meetings
Intensive Phase (IP)	IP visit – 2,3
Continuation Phase (CP)	CP visit – 1,2,3,4
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

TB patients with Diabetes Mellitus

Diabetes is a chronic disease which tends to weaken the immune system. The chances of a person with DM getting TB are therefore 2-3 times higher, when compared to non-diabetics. About 10% of TB cases globally are linked to diabetes. 8% of TB patients were found to have diabetes, according to THALI's RANA analysis.

Steps to Providing Care (Patients with DM)

MEDICAL	
Activity	› Facilitate screening for diabetes in all TB patients › Facilitate linkages with diabetes clinics and ensure TB and diabetes medications are taken regularly › Support regular monitoring of blood sugar levels to ensure that diabetes is under control

	› Support the disclosure of TB status to the doctor treating diabetes for modification in nutrition /medications if required
Intensive Phase (IP)	IP visit – 1,2,3
Continuation Phase (CP)	CP visit – 1,2,3,4
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patients and family members

COUNSELLING	
Activity	› Educate and support screening for diabetes in all TB patients › Counsel on linkages with diabetes clinics and ensure TB medications and diabetes medications are taken regularly. › Tell the patient and care giver the cons of being non-adherent to both the medications. › Regular counselling to support regular monitoring of blood sugar levels. Ensure that diabetes is under control. This is needed as elderly patients may have issues at home and may not be interested in taking care of themselves. › Support in the disclosure of TB status to the doctor treating diabetes for modification in nutrition /medications if required › Identify and educate the primary caregiver on the importance of providing regular meals (low calorie and high protein), TB medications and diabetes medications.
Intensive Phase (IP)	IP visit – 1,2,3
Continuation Phase (CP)	CP visit – 1,2
Materials (IEC/BCC)	Relevant IEC/BCC in accordance with the needs of patient and family members

LINKAGES	
Activity	› Facilitate linkages for pyridoxine tablets

COMMON ACTIONS FOR ALL CATEGORIES OF PATIENTS

In addition to the specific actions for different categories of patients, it is important to note the following:

› Ensure HIV and diabetes screening for all TB patients
› Ensure that every patient in the field is periodically assessed clinically by a doctor
› Establish referral linkages to tertiary medical care facilities
› Organize support group meetings frequently, which provide an opportunity for the patients to interact with those patients who have successfully completed treatment
› Educate the patient and the family on sputum disposal methods and cough hygiene
› Assist the primary caregiver in understanding the importance of providing regular meals to the patient
› Mobilize support based on the patient's nutritional, emotional and economic requirements through KOLs, other NGOs or government schemes, where possible
› **Seek support from Community Coordinators/District Project Coordinators/Zonal Coordinators/Treatment Coordinators when there is difficulty in providing services to such patients. Bring to their notice all bedridden patients.**

The facilitator will summarize, saying that the DCM aims at reducing negative treatment outcomes and improving positive treatment outcomes for TB patients. The facilitator will emphasize how to effectively deliver these PCS services during the following sessions.

SECTION b

COMMUNICATION SKILLS IN COUNSELLING

SESSION 2 Communication skills in Counselling

Objective

By the end of this session, participants will be able to:

- Understand the difference between verbal and non-verbal communication
- Understand the process of communication and its importance in counselling

Methodology
Interactive activities and large group discussions

Materials required
Flip charts, marker pens, chairs, a quiet and large room, an LCD screen or projector, computer

Duration
60 minutes

Communication is an important part of the counselling process. Before we learn the skills of counselling, an introduction to the process of communication and barriers to effective communication in counselling, will be discussed and demonstrated.

The facilitator asks participants 'What does communication mean to you?'
The facilitator writes down all the responses on the flipchart. After all participants have responded, the facilitator will explain that communication is a two-way process by which two or more people exchange ideas, facts, feelings, or impressions, so that each gains a common or mutual understanding the message.

The facilitator asks participants to demonstrate the process of communication.

Activity 1 - Interactive Activity

This activity will demonstrate the process of communication.

1. Ask any two persons to come and talk to each other about how they reached the training venue to attend this training (encourage the volunteers to start the conversation from the time they heard about the training until they reached the training venue) or anything else they wish to talk about.
2. Give them 2 to 5 minutes to talk to each other. The tone and voice must be audible to all in the training hall.
3. Tell the other participants to observe how the conversation is going and the communication that is taking place.
4. Once the conversation between the volunteers is over, ask the participants what they observed. Write their responses on a chart.
5. Compare the responses on the chart with the responses to the earlier discussion under this session. **Tick** the responses common to both charts.

The facilitator then explains the process of communication based on what actually transpired during the activity.

THE COMMUNICATION PROCESS

Sender (source) – A person talking

Message – What is spoken or told, put in words

Receiver – The person who is listening

Filter – The person listening comprehends the message according to their understanding, their perceptions, and/or their current mood

Feedback – The receiver replies with what they have understood

The sender determines what they would like to communicate to the receiver, then composes it into a message (words), and transmits it through a channel or medium (often by speech and body language in counselling) to the receiver, who then interprets the message and its meaning according to their life experiences and understanding. Filters like personal perceptions or environmental disturbances affect the understanding of the message by the receiver. By providing feedback, the receiver of the message can let the sender know they have heard and correctly understood what was being communicated.

Effective communication means that transmitted information is received and understood by the receiver in the way it was intended by the sender of the message.

Activity 2 - Interactive Activity

This activity will demonstrate verbal communication, how communication can be understood differently and possible misinterpretation of a message.

1. Ask the participants to make a big circle either in the training hall itself or outside the training hall if there is place (if the venue is small, make them stand where they are).
2. Tell the participants that the neighboring participant will whisper a message in their ear and they in turn have to pass on the message in a similar way to the person next to them and so on.
3. They are told to listen and observe the tone of the voice while they receive the whispered message.
4. Call one of the participants and whisper the following message in their ear – 'Any cough that lasts for 2 weeks accompanied by fever can be TB, but there is no need to fear. TB can be completely cured by completing the TB treatment.'
5. Now instruct the participant to whisper the above statement into their neighboring participant's ears.
6. The person after them must not hear what is being whispered.
7. The participants will continue whispering the sentence as they have understood it into the next person's ear, until the last participant has heard the whispered message.
8. Ask the last participant to say the whispered message **aloud**.
9. Draw the attention of all participants and ask every participant to listen.
10. If the last participant says the exact sentence as told to the first participant, brainstorm with the participants on the process involved in receiving the right message, unchanged, and refer back to the process of communication and explain.

11. If the last participant shares a different sentence from the original one, brain storm on the process involved, refer back to the process of communication and explain the barriers which may have affected the communication process.

12. Discuss the tone of the whisper – was it pleasant, hurried, curt, rude, happy etc., as this also impacts communication.

13. Conclude the activity with an explanation of how TB patients and caregivers/family understand messages given to them. The TB patients and caregivers/family would be hearing about the messages of TB for the first time and might not completely understand the messages given to them. While concluding, also mention that the receivers will understand and perceive the message according to their understanding, attitudes, life experiences and background.

Activity 3 - Interactive Activity and Group Discussion

This activity will demonstrate non-verbal communication (gestures, facial expression, and body language).

1. Ask two, three or four participants to volunteer for this activity.

2. Tell the volunteers to go to one of the farthest ends of the training hall or outside the training hall, so that the discussion with the facilitator is not heard by rest of the participants.

3. Tell the volunteers that one of them will play a TB patient who smokes and drinks along with their treatment, one will be a healthcare provider and the others will be playing family members of the patient.

4. Instruct one of the volunteers playing the role of a health care provider to give out dos and don'ts to the volunteer playing the TB patient. Ask them to inquire about whether the volunteer-patient is eating healthy food. He/she must not talk verbally but communicate everything in gestures (non-verbally). The other volunteers will observe and respond in a similar way (non-verbally using hand gestures, facial expressions).

5. Ask the participants to keenly observe the volunteers.

6. Once the volunteers have finished the activity, ask the participants what they observed – encourage participants to focus only on the non-verbal communications.

7. List down all the observations on a chart.

8. Compare the responses to verbal and non-verbal communication on a chart paper and explain that any communication between two or more people involves verbal and non-verbal communication, and that both are an integral part of counselling skills.

Barriers to communication can be:

› Message – too complicated, difficult language, too much information or false information (similar to the whispered message)
› Medium (Verbal) – unclear words or physical disturbance while listening (give example of disturbances that happen when the phone network is bad or when there is background noise)
› Medium (Non-verbal) - no eye contact, casual posture
› Receiver – lack of interest, feeling tired, anxious, hungry, angry
› Filters – lack of privacy, noise, personal prejudices
› Feedback – not given, not clear or ignored by the sender

IMPORTANCE OF INTERPERSONAL COMMUNICATION IN COUNSELLING

The facilitator brainstorms asking the participants, 'Do you know the purpose of counselling?' The facilitator awaits the responses of the participants and writes them on a chart.

Depending on the responses received, the facilitator clarifies the purposes of counselling between the counsellor, the patient and the patient's family.

These include the need to:

› **Advocate** - Encourage the patient by explaining the benefits of a certain behavior or behaviors, including eating healthy, taking medicines on time and adherence to treatment.
› **Educate** - Provide specific TB information so that the patient is motivated to adopt a behavior change.
› **Counsel** - Assist the patient in making an informed decision based on all the facts and information available in the context of their own personal situations.

Emphasize that the importance of effective communication between the counsellor and the client cannot be underestimated. For counsellors, communication skills are required in order to encourage their clients to feel comfortable while talking about their problems and to ensure that they understand the message. Barriers to effective communication should be minimized.

Next, the facilitator asks the participants 'What do you understand by interpersonal communication?'

The facilitator explains that "interpersonal communication" is the act of passing on information, thoughts, opinions and/or feelings through speech, facial expressions, gestures and tone of voice from a sender to a receiver (from one person to another/many).

Interpersonal communication in a client-counsellor relationship involves both verbal and non-verbal communication.

Counselling is a special form of interpersonal communication where feelings, thoughts, experiences and attitudes are explored, expressed and clarified. Counselling is the act of helping a client make her or his own decisions by providing unbiased information and asking questions about what the client wants and what the client thinks that he or she can do.

The counselling relationship is a space for building the confidence and self-esteem of a client to enable him or her to make lifestyle changes in light of their TB diagnosis and treatment. In a supportive atmosphere, clients can express their needs and challenges in completing the treatment regimen, and then make realistic decisions about what they can do to overcome the challenges. It takes time to build a trusting relationship with a client; counselling is not a one-time act, it happens over time and takes a while to grow.

Communication in counselling, both verbal and nonverbal, are important tools of a counsellor. In a counselling session, the counsellor and the client sit facing each other. Even if there is a small twist in the face, a soft sigh, or expressions of like or dislike,

this can be observed by the other. The counsellor has to be especially clear and careful because any negative communication, either verbally or non-verbally, can break the rapport and trust.

Having said this, **what should effective communication be like**?

Clear and simple – The counsellor's words should be audible. The counsellor should use simple statements or questions so that the client can easily understand them.

Direct communication – The counsellor should directly ask and get any information he or she needs from the client. If the client does not give a direct answer or tries to change the subject, the counsellor has to help the client stay on the topic that is being discussed.

Body posture - The counsellor should ideally sit leaning slightly towards the client. The arms and legs of the counsellor should not be crossed, or the client may misread the counsellor to be a closed person or a person with no interest in the client's problem.

The counsellor should not try to assume what the client is trying to say or put words in the client's mouth when the client is unable to express what they want to say.

Throughout the session, the counsellor should maintain eye contact with the client. This helps the counsellor observe the non-verbal gestures of the client.

SESSION 3 Counselling skills

Objective

By the end of this session, participants will be able to:

- Understand the skills of counselling
- Demonstrate counselling skills
- Use counselling skills in accordance with the needs of the TB patient and family

Methodology

Role playing, group activity, case study and discussions

Materials required

Flip charts, marker pens, chairs, a quiet and large room, an LCD screen or projector, computer or laptop

Duration

120 minutes (2 hours)

The facilitator starts with an activity with the participants. The objective of this activity is for participants to imagine what it would be like to be diagnosed with a serious disease and to envision how persons diagnosed must feel to help them better empathize with the patients they work with. These steps must be explained as given below for the activity's objective to be achieved.

Activity 4 - Group Activity and Discussion

1. Ask each of the participant to tear a sheet of paper and keep their pens ready to write.
2. Tell each of the participants to write the name of only one disease, which they believe is dreaded, on the sheet of paper which they had torn.
3. Give then one or two minutes to write.
4. After writing, ask the participants to fold the paper up as small as possible.
5. After the participants have written on and folded up the paper, use a deep bowl to collect it from each of them.
6. Once all the folded papers are put in the bowl, shake the bowl until they are mixed well.
7. Pass the deep bowl around and ask each participants to pick up just one folded sheet of paper.
8. Next, ask each of the participants to read out loud the disease that has been written on the sheet of paper.
9. After each of the participants have read, in a gentle, soft, assertive voice tell the participants that each of them has been diagnosed with the same disease they had read out.
10. After telling them the above, stay quiet for a minute.

Allow and observe the participants' reactions – some of them laugh, some stay quiet, some argue etc.

11. In the same gentle, soft, assertive voice, ask the participants that in all the reactions they just noticed, what were the thoughts and feelings in the split second, after you told them that they were diagnosed with the disease on the sheet of paper.

12. Allow the participants to share their feelings. They may have been worried, thinking about what would happen to their family; they may have been fearful or scared, thinking that they may face stigma, isolation and discrimination; they may have thought that they would not be able to live, and thought of ending their lives; they may have thought where they could get the money for treatment, or how they would live with this kind of disease (in case of HIV infection, mental disorder). They may have though that they will get through it (for being diagnosed with DM), thinking that it is a curable disease and so they will be fine (for being diagnosed with TB).

13. After they share their thoughts and feelings, explain to them that their thoughts would be similar to those of the patients diagnosed with TB and their family members. This is the very reason that the patients, their caregivers and family members will need to be supported emotionally as well as clinically.

> After points 7 to 10 have been discussed with the participants, it becomes important to 'de- role' the participants from the 'diagnosis' they have received.

14. Request each of the participants to tear the sheet in their hands into as small pieces as possible. While they are tearing, ask them to tell themselves as many times as possible, **'I am healthy and I don't have any disease.'** Ask them to put the pieces of sheet into the bowl. These will then be dumped into a waste basket.

15. Ask the participants, 'Now what are your thoughts and feelings?'

16. The participants will share that they feel lighter, are happy, have no worries now, and are relieved. One or two participants may say they are still feeling heavy. It's important to 'de-role' the participants and ease the thoughts and feeling they went through.

> **Note:** Take some time off and talk to the participants about the reasons for feeling heavily, and assess if they need to be referred to a counsellor/psychologist.
>
> Explain to the participants, this is the journey of thoughts and feelings which the person diagnosed with TB will have too, until they are tested TB-negative after the completion of treatment. However, some TB patients may have challenges in completing the treatment. Such patients and family members will need counselling.

COUNSELLING

Counselling is a process that makes a difference to people's lives. Many people from various walks of life have sought counselling and as a result feel happier, more content and are more effective in their lives. Counselling offers clients the opportunity to explore and heal their past and present difficulties in a confidential and supportive environment by dealing with life issues.

The main purpose of counselling is to learn more about ourselves, about the way we think and the way we view ourselves in life. To a large extent, counselling is an educational process; an education in the art of living. Once we know ourselves better, we can then take action to make positive changes.

In counselling sessions, clients will learn techniques for making changes and how changing their thinking can positively affect their lives. In other words, they are not given advice about what to do, but rather are helped to find their own solutions in a supportive and confidential environment.

The purpose of counselling is to help clients achieve their personal goals, and gain greater insight into their lives. One hopes that by the end of this process one will be more satisfied with his or her life. Counselling is NOT a process through which the counsellor tells the client what he or she should do or decides choices for the client to make. Rather, it is an opportunity for the client to come to a greater understanding of the person that he or she is, with the help of the counsellor.

Need for counselling in TB

The facilitator reveals the purposes of counselling for TB.

- Motivating TB patients to complete treatment
- Providing technical information about TB to patients and family members
- Providing emotional support to TB patients and care givers
- Helping patients make informed decisions about their behavior and helping patients carry out their decisions
- Preventing TB transmission

The facilitator lists the counselling skills that are required by a counsellor on a chart paper and demonstrates each of the skills.

The facilitator will create a scenario where the health worker is on a visit to the TB patient's home. The facilitator acts as a health worker. Throughout the counselling skill session, the facilitator will ask one or two participants to volunteer for the demonstration.

Each of the counselling skills will be demonstrated and practiced. The facilitator will continue asking for more volunteers to come forward and practice each counselling skill.

COUNSELLING SKILLS

1 RAPPORT BUILDING

This becomes the first step in counselling. This skill is an easy one to develop. It starts with the health provider (doctor/nurse/ Senior Tuberculosis Laboratory Supervisor/Senior Treatment Supervisor/Tuberculosis Health Visitor). Smile, establish eye contact and greet them as per the local norm. This is non-verbal communication, which passes a message of acceptance and non-judgement.

Activity 5 - Demonstration

Demonstrate the following

1. Meet the TB patient or caregiver and wish them with a smile.
2. Ask them if you can talk to them.
3. Introduce yourself (be cautious if there are people other than the TB patient and caregivers when you are introducing yourself, introduce yourself only as a 'health worker.' It is important to be neutral).
4. The health worker (still with a small smile) asks them how they are feeling with the initiation of TB treatment.
5. When the TB patient/caregiver talks, lean forward a little, make eye contact, and nod when listening to them.

2 EMPATHIZING

Empathy means that the counsellor places himself or herself in the patient's situation in order to understand the patient and be sensitive. This shows two of the qualities of the counsellor: acceptance, which means accepting the person as they are, along with their feelings, and being non-judgmental of what they are sharing, how they are dressed and their economic background.

Activity 6 - Demonstration

Demonstrate the following

The facilitator asks each of the participants to secretly write a difficult activity for their neighbor. Once they have finished writing, tell each of them to read it out loud (there will be laughter among the participants). Once everyone finishes reading out loud, tell the participants to come forward and complete the activity which they had written for their neighbor. Ask them how it makes them feel now. Once they all finish talking about how this made them feel, explain that empathy is understanding how the other person is feeling. This is a counselling skill and a quality of a counsellor.

3 OPEN-ENDED QUESTIONS

Asking open-ended questions will yield the health worker more information from the TB patient or caregiver.
Example: What do you eat through the day? (Keep the questions short and ask them one at a time).

Activity 7 - Demonstration

Demonstrate the following

As a frontline worker (FLW), ask the TB patient or caregiver what their diet has been. After this question is answered, ask the next question, which is about what they include in their everyday eating. Continue maintaining eye contact and keep a small smile on your face while asking open-ended questions.

4 ACTIVE LISTENING

It requires processing what is being communicated through encouraging body language, attentive listening, clarifying, paraphrasing and giving feedback to the patient.

Activity 8 - Demonstration

Demonstrate the following

Ask a participant (playing a TB patient/caregiver) to sit opposite to you (playing a health workers) on a chair. The health worker asks the person opposite what happens to them if they have side effects of TB treatment and still have to go to work? When the person starts talking, the health worker makes eye contact, nods, seeks and clarifies.

If there is time during the training, one demonstration of non- active listening can be done, which is exactly opposite to the above demonstration.

5 SEEKING CLARIFICATIONS

Seeking clarifications will help get additional information and will help the patient explore the problem, if any.

Activity 9 - Demonstration

Demonstrate the following

The health worker asks the TB patient or caregiver, while maintaining eye contact and a small smile, *'How many times do you include greens, sprouts and eggs in a week's diet?'* This clarifies the quality of diet they are eating and also the health workers will get to know if the family needs any nutrition support.

6 PARAPHRASING

This involves using different words to restate what the client has said to show that the counsellor has understood what is being stated and to allow the client to give clarifications if required.

Activity 10 - Demonstration

Demonstrate the following

The health worker restates what the TB patient or caregiver has been including in their everyday eating. This skill will help the TB patient or caregiver know if the health worker has listened to them. If there are parts which were not said or understood by the health worker, the receiver gets an opportunity to clarify them.

7 SUMMARIZING

The main points of the discussion are summarized so that focused action can be decided upon.

Activity 11 - Demonstration

Demonstrate the following

The facilitator (as health worker) will summarize everything that was said until the end. The health worker will highlight the need to eat three to four nutritious meals every day. The health worker will also reiterate that the TB patient should continue the TB treatment in spite of the side effects, and that he or she should get in touch if there are any other problems or they need help.

This marks the end of the counselling skill-building sessions and demonstrations. The same will be practiced by all the participants during the training.

CONFIDENTIALITY

One of the important principles in counselling is maintaining confidentiality.

Why is it important to maintain a patient's confidentiality?
As TB is often associated with stigma, TB patients or caregivers often ask the health workers to maintain confidentiality if they are sharing personal details during counselling.

When the patient is diagnosed with TB, it is important to reassure them that TB is curable and that they should not blame themselves or feel guilty about their diagnosis. While the counsellor may encourage the patient to tell his/her loved ones about their diagnosis so that they can receive their support during treatment, it is important for the counsellor to tell them that they will not disclose their condition or any part of their discussions to anyone.

This is an essential part of any counselling or supportive relationship. Information is shared by the client with the implicit and explicit understanding and expectation that it will not be revealed to others.

One of the essential components of counselling is trust between the counsellor and the client. Without this mutual trust, the client may not be able to disclose personal and sensitive information to the counsellor. TB patients are not only suffering from an illness; they will have many other issues which could be related. They may find it much more difficult to share information due to the fear of being judged, criticized or exposed to more harm and pain. Therefore, it is crucial for a counsellor to inform the client that whatever he or she is sharing in the session will be kept confidential and will not be revealed to anyone.

The following measures can be taken by the counsellor to ensure confidentiality of the information discussed by the client,

- See the client alone for individual sessions. This creates a comfortable atmosphere for the client to discuss his or her issues openly and helps in maintaining confidentiality.
- Conduct the session in a room where the counsellor and the client will not be disturbed. Do not discuss in a corridor, reception area, or in front of others.
- Ensure that nobody is overhearing the conversation between the client and the counsellor.
- Keep the records under lock and key. Make sure that the record of a client is not available to anybody without the permission of the counsellor.
- Do not discuss any issue with his or her spouse or other family members without the client's permission. The client's family may try to persuade the counsellor to disclose information shared by the client, but the counsellor has to be careful not to disclose any information to anybody about the client or the issue at hand.

CHALLENGES IN MAINTAINING CONFIDENTIALITY

- When there is a possibility of a client harming himself or herself, or other people, maintaining confidentiality poses a challenge. For example, if the client informs the counsellor that he or she is feeling low and wishes to kill or harm himself or herself, the counsellor can break confidentiality to make sure that the client is safe.

- When there is a legal problem, maintaining confidentiality becomes a challenge. In some situations, where the client is injured badly or in situations where children are involved, the counsellor might have to break confidentiality and share some information with lawyers or in a court of justice.

- In some situations, it may be difficult to intervene. If the counsellor feels it necessary and important to discuss the problem with a co-worker, senior doctor or professor, then the counsellor can breach confidentiality. However, the counsellor has to ensure that the information disclosed will not be used for any purpose other than its intended purpose.

- Sometimes, a database is created to use client information for research work. Under such circumstances, the client's identity need not be disclosed.

› If the client is referred by a third party, handling queries by them could become a problem. In Indian culture, most women do not approach the counsellors alone. Sometimes they are accompanied by a well-wisher who refers the case to the counsellor. It's only natural for the well-wisher to ask the counsellor about the client. However, the counsellor should not break confidentiality in this scenario. The counsellor can politely refuse to share information on the grounds of principles of counselling. The well-wisher can be appreciated for the referral and affirmation can be given by telling them that they will definitely be contacted in case additional help for the client is required.

› The counsellor has to inform the client if he or she has to break confidentiality. The counsellor should inform the client at the very beginning of the session that his/her confidentiality will be maintained at all costs and that the safety of the client is important to the counsellor. He or she should also mention situations (if the client is planning to harm himself or herself, or attempt suicide) where confidentiality will not be maintained, so as to help the client and inform members of the family or anyone the client indicates. The counsellor must promise the client that he or she will be informed before any information is shared with others.

› Tell the participants that counselling is a special process. It is a confidential dialogue between a counsellor and a patient which helps a patient define his or her feelings and cope with a situation.

The goal of TB counselling is to help a patient make informed decisions and, ideally, to follow the Medical Officer's recommendations for the completion of TB treatment. These decisions will affect a patient's life, so it is very important that they are the patient's decisions, not the counsellor's. Informed and voluntary choices are the foundation of effective counselling. A well-informed patient who voluntarily chooses to complete treatment is more likely to be satisfied and continue the treatment. To be informed, patients need to have clear, accurate, and specific information. The treatment team (the Medical Officer, Senior Treatment Supervisor, DOTS providers and the counsellor) determines informational needs, provides information, and helps patients to make decisions. Counselling is different from education, although education is an important part of counselling. Counselling is not solving the problem for the patient or giving advice. In the counselling process, the counsellor avoids telling the patient how to solve the problem or what decision or action to take. Instead, the counsellor, and other providers, enable the patient to reach a better understanding of their situation and help the patient decide what they may want to do to move towards treatment completion.

EFFECTIVE WAYS TO COUNSEL A TB PATIENT OR CAREGIVER

While improving ones counselling skills is an ongoing process, it will be helpful to keep certain points in mind as a patient is counselled.

Counselling is most effective when the counsellor,

› Makes the patient feel comfortable.
› Conducts the session in a quiet, private space with little to no interruptions.
› Makes it an interactive dialogue where both parties listen to each other and speak to each other with respect and concern.
› Makes the session client-centered, individualized and tailored to the specific needs of the patient.
› Talks at a moderate pace and appropriate volume.
› Establishes eye contact, is pleasant and reassuring, and has an open and relaxed body language.
› Presents messages that are clear and simple.
› Asks questions to make sure that the listener has understood the message.
› Is patient when the listener has difficulty understanding.
› Helps patients identify solutions for their personal problems that are acceptable to them.

DOS AND DON'TS IN COUNSELLING

Confidentiality is the protection of personal information. Confidentiality means keeping a client's information between you and the client, and not telling others including co-workers, friends, family, etc.

Not maintaining confidentiality,
Not disclosing or telling other people what has been disclosed to the counsellor/community workers during counselling.

Supportive verbal communication
Asking open ended questions
Paraphrasing
Reflecting feelings

Non-supportive verbal communication
Advising
Criticizing/ scolding/ threatening
Discussing your personal problems
Interrupting
Imposing your own values
Curiosity
Asking questions in a direct and embarrassing manner
Arguing
Controlling the client
Labeling
Encouraging dependence
Unwarranted assurance
Talking too much by the counsellor

Supportive non - verbal communication
Active listening
Maintaining eye contact
Having an attentive body posture
Nodding appropriately
Keeping an appropriate facial expression
Using silence appropriately.

Non-supportive non-verbal communication
Looking away frequently
Looking bored or irritated
Yawning
Looking at one's watch/mobile phone
Writing while counselling the person
Using an unpleasant tone of voice

Activity 12 - Role Play

The facilitator reminds the participants to start the role play with the first skill of rapport building and continue using counselling skills, concentrating on verbal and nonverbal communications.

Case Story 1: Ms. S. is married and earns Rs.3000 per month. She has been diagnosed with TB and cannot work for a few weeks. Her husband discriminates against her and there comes a point when he asks her to leave her home. One day, she is pushed out of her house, but later in the morning her husband allows her back in the house.

Case Story 2: Ms. K is a 45-year-old widow who is suffering from TB. She has two daughters who are 25 and 22 years of age. Ms. K is working at a garment factory. They come along with their mother for counselling. They don't allow her to talk. They tell the counsellor that she is taking medications for TB and has severe side effects. They want her to stop taking treatment, and say that even if she dies it's fine, but they can't see her suffering.

Case Story 3: Mr. S. has been diagnosed with TB. He has not been taking his TB treatment regularly. When the health worker visits his house, he says that his wife has taken the children and gone to her parents' home, and he has no one to support him at home. He is a daily wage laborer and he has not been irregular to work.

SESSION 4

Stigma and its effects on TB treatment and adherence

Objective

By the end of this session, participants will be able to:

- Identify different types of TB stigma in different contexts
- Understand how stigma in affects individuals and treatment adherence

Methodology

A PowerPoint presentation and large group discussion

Materials required

Flip charts, marker pens, chairs, a quiet and large room, an LCD screen or projector, computer

Duration

60 minutes

STIGMA WITH TB

Tuberculosis (TB) is one of India's most important public health problems and accounts for nearly one-fourth of the global TB burden. TB is a classic example of a disease with both medical and social dimensions, characterized by its close relation to poor socio-economic conditions. Any person facing health issues without any social or family support may experience psychosocial issues, and this includes TB patients.

The stigma attached to TB adds to the burden of disease for both men and women, and even more so if they are of marriageable age. While men have to deal with the stigma at their work place and at the community level, women are faced with ostracism within the household and in the immediate neighborhood. Stigma is a barrier towards health seeking behavior and treatment adherence. Fears of being socially avoided result in TB patients choosing not to disclose their TB status to family or friends. This raises the risk of treatment failure and the rise of drug-resistant TB, which is more difficult and expensive to treat. This has consequences on patients' finances, adding to emotional burden and relationship issues with family and others.

In some cultures, TB can be considered a 'curse' on a family, as the illness often affects multiple generations – we know that this is simply because TB is an airborne illness, which is more likely to be spread among people living in close proximity.

The most common cause of TB stigma is the perceived risk of transmission from TB-infected individuals to susceptible family/community members. Depending on geographic region, however, persons with TB are also stigmatized because of its associations with HIV, poverty, low social class, malnutrition, or disreputable behavior. TB-related stigma has a more significant impact on women, the poor, less-educated community members, which is especially concerning given that these groups are often at higher risk for health disparities. Such stigma may, therefore, worsen pre-existing gender and class-based health disparities.

TYPES OF STIGMA[1]

SELF-STIGMA	ANTICIPATED STIGMA	EXPERIENCED STIGMA	INTERNALIZED STIGMA

[1] https://www.who.int/chp/knowledge/publications/adherence_full_report.pdf?ua=1 [accessed on Feb 21, 2019].

SELF-STIGMA	ANTICIPATED STIGMA	EXPERIENCED STIGMA	INTERNALIZED STIGMA

Self-stigma is when persons believe they are weak because of an illness - in this case, TB. This kind of negative attitude can be harmful because it may stop them from seeking or receiving treatment for TB and its symptoms. Self-stigma is the biased, negative judgment that we impose on ourselves.

Self-stigma may be present if the person with TB have ever,

- Caught themselves overthinking the words, actions, and nonverbal behavior of others, "knowing" that they're not measuring up to people's expectations or to their own
- Noticed self-insulting thoughts running through their minds
- Found themselves agreeing with their self-deprecating thoughts
- Felt that they're not good enough for someone or something
- Felt worthless

When a TB patient stigmatizes themselves, they are seeing themselves unevenly. They may do this because they have experienced others stigmatizing them or because they fear being socially outcast.

SELF-STIGMA	**ANTICIPATED STIGMA**	EXPERIENCED STIGMA	INTERNALIZED STIGMA

This involves difficulties faced in disclosing their TB status due to the fear of negative reactions by others. Anticipated stigma is the belief that prejudice, discrimination and stereotyping will be directed at oneself from others in the future.

People living with TB who anticipate stigma, expect that others will devalue them based on their TB illness. Research has demonstrated that anticipated stigma undermines the physical and mental well-being of people living with TB. Anticipated stigma, expected experiences of prejudice, discrimination and stereotyping puts undue pressure on TB patients which affects their self-confidence or their ability to stay positive, adhere to treatment and have aspirations for their future.

TB patients who do not have adequate psychological, physical, economic and/or social resources to handle these demands will experience increased stress. For example, they may perceive social rejection from friends and family, discrimination from work colleagues and poor caregiving from healthcare workers as demands that they do not have the resources to handle.

SELF-STIGMA	ANTICIPATED STIGMA	**EXPERIENCED STIGMA**	INTERNALIZED STIGMA

Experienced stigma occurs when persons with TB are treated differently by relatives/neighbors/friends after their disclosure of TB, for example, facing ridicule, insulting remarks, discrimination, social exclusion, and/or isolation.

Social exclusion is often triggered by the idea that TB is highly infectious and manifests in dining and sleeping separately from the patient, avoidance of sexual intercourse, and exclusion from activities in school and/or at work.

Married women are often expelled from their house and forced to go to their maternal home, more so than men. This is also holds true for unmarried men and women, who experience stigma even after being cured and find difficulty in getting married.

SELF-STIGMA	ANTICIPATED STIGMA	EXPERIENCED STIGMA	**INTERNALIZED STIGMA**

The already stigmatized TB patients internalize stigmatizing ideas and, consequently, they believe that they are less worthy than others. This belief is expressed by either fear, shame, hopelessness, guilt and/or a loss of self-esteem. Moreover, the internalization of devaluating beliefs alters TB patients' expectations of life and hampers TB treatment adherence.

All types of stigmas have emotional and mental repercussions which show up in a patient's day to day life. Some of the effects of stigma are:

- At a personal level: Shame, self-blame, isolation, loneliness, loss of status, loss of self-esteem, loss of hope, depression, stress, denial, anger, violence, alcoholism, suicidal tendencies, tobacco dependency.
- At the familial level: Family quarrels, mutual blame and conflicts, being driven away from home, divorce or separation, property-grabbing, abusive relationships
- Patients may avoid getting tested and disclosing their status to partners and family and thereby, denying themselves a probable support system. They may also avoid accessing TB services, or stop their treatment, which results in the spread of TB.
- Patients may also be discriminated against and disowned by their families or evicted from their accommodation or fired from work etc.

SIGNS OF STIGMA

This list is for the person counselling TB patients to help the patient overcome stigma using counselling skills and by building awareness on TB. This is not an exhaustive list and will grow as one counsels patients.

Signs of stigma	Skills to be used (Counselling skills learnt during the counselling skills session training)
Non-adherence to TB treatment	› Use empathy › Probe reasons for non-adherence to TB treatment › Build awareness on health when TB treatment is not consistently taken
Non-compliance with regular medical check-ups at the facility	› Ensure confidentiality › Probe reasons for not getting regular check-ups
Excuses for not eating a nutritious diet	› Build awareness on a nutritious diet › Show the patient the chart on nutritious diets and link it to overall health and recovery
Lacking confidence to come alone for regular check ups	› Accept the person's issues and empathize › Explore how this is affecting their daily life and jointly plan for the support needed to come alone to the health center and in to manage in daily life › If needed, involve any family member(s) in planning, with prior permission of the TB patient
Talking about reduced social life and lack of interest	› Accept the person's issues, and empathize › Explore how this is affecting their daily life › If needed, involve any family member(s) in planning, with prior permission of the TB patient › Probe for any violence faced within the home or house, alcohol dependency and other issues
Showing low self-care	› Explore the past of the TB patient and the pattern of their daily life › Ask when the TB patient became uninterested in self-care and why they think this happened › Explore what small steps they would take to be interested in themselves (especially with women who are thinking of everyone at home, except themselves) › Encourage and tell the patient to note the difference it has made (even if it's a small difference), how they felt and what they thought when they cared for themselves
Denial or non-acceptance of TB	› Empathize with the patient › Show them the hard copy of the report confirming the TB infection › Explore what they are feeling and accept them › Explore what would help them accept their TB infection. Just be with the person. › Inform the patient of the advantages of accepting their TB status and taking treatment

A person diagnosed by TB may be already going through one or more, of the above stigmas. TB diagnosis can further cause low self-esteem and the patient can suffer from other psychological conditions. It becomes imperative that the health worker identifies the signs and symptoms and counsels the patient. It will help the patient to be self-aware and with the help of the health worker, the patient can support themselves to work towards overcoming stigma. This will help the patient in adhering to TB treatment. Furthermore, the patient can lead a confident life after TB treatment.

SESSION 5 Adherence to TB treatment

Objective

By the end of this session, participants will be able to:

- Understand treatment adherence, its components and approaches and strategies to promote it
- Understand the barriers to adherence and opportunities to improve it
- Practice adherence counselling through simulations

Methodology

Small group activity and large group discussion

Materials required

Flip charts, marker pens, case stories, chairs, a quiet and large room, an LCD screen or projector, computer or laptops

Duration

300 minutes (5 hours)

DEFINITION OF ADHERENCE BY THE WHO

In terms of TB control, adherence to treatment may be defined as the extent to which the patient's history of therapeutic drug-taking coincides with the prescribed treatment. It is important for patients to take the right drugs of the right dosage at the right time to have successful treatment outcomes.

Adherence may be measured using either **outcome-oriented** or **process-oriented** definitions. Outcome-oriented definitions use the end-result of treatment, e.g. cure rate, as an indicator of success. Process-oriented indicators make use of intermediate variables such as appointment-keeping or pill counts to measure adherence. The extent to which these intermediate outcomes correlate with the actual quantities of prescribed drugs taken is unknown.

The point that separates "adherence" from "non-adherence" would be defined as that point in the natural history of the disease which makes the desired therapeutic outcome likely (adherence) or unlikely (non - adherence) to be achieved. There is as yet no empirical rationale for a definition of non-adherence in the management of TB. Therefore, the definition of adherence to TB treatment needs to be translated into an empirical method of monitoring both the quantity and timing of the medication taken by the patient. At the individual level this is desirable, but at the population level a more pragmatic approach is needed. Thus, the success of treatment, that is, the sum of the patients who are cured and those who have completed treatment, is a pragmatic, albeit a proxy, indicator of treatment adherence.[2]

FACTORS THAT INFLUENCE ADHERENCE TO TREATMENT

Many factors have been associated with adherence to TB treatment, including patient characteristics, the relationship between health care provider and patient, the treatment regimen and the health care setting. One author has defined non - adherence as "an unavoidable by-product of collisions between the clinical world and the other competing worlds of work, play, friendships and family life."

FACTORS THAT ARE BARRIERS TO ADHERENCE TO TB TREATMENT

A Economic and structural factors

TB usually affects people who are hard to reach such as the homeless, the unemployed and the poor. The lack of effective social support networks and unstable living circumstances are additional factors that create an unfavorable environment for ensuring adherence to treatment.

[2] https://www.who.int/chp/knowledge/publications/adherence_full_report.pdf?ua=1 [accessed on Feb 21, 2019].

B Patient-related factors

Ethnicity, gender and age have been linked to the lack of treatment adherence in various settings. Knowledge about TB and a belief in the efficacy of the medication will influence whether or not a patient chooses to complete the treatment. In addition, cultural belief systems may support the use of traditional healers rather than taking allopathic medicine. In TB patients, altered mental states caused by substance abuse, depression and psychological stress may also play a role in treatment adherence.

C Regimen complexity

The number of tablets that need to be taken, as well as their toxicity and other side-effects associated with their use, may act as a deterrent to continuing treatment.

D Supportive relationships between the health provider and the patient

Patient satisfaction with his/her healthcare provider is considered to be an important determinant of adherence, but empathic relationships are difficult to forge in situations where health providers are untrained, overworked, inadequately supervised or unsupported in their tasks, as commonly occurs in countries with a high burden of disease.

E Pattern of health care delivery

The organization of clinical services, including the availability of expertise, links with patient support systems and flexibility in the hours of operation, also affects adherence to treatment. Many of the ambulatory health care settings responsible for the control of TB are organized to provide care for patients with acute illnesses, and staff may therefore lack the skills required to develop long-term management plans with patients. Consequently, the patient's role in self-management is not facilitated and follow-up is sporadic.

GROUP DISCUSSION TO UNDERSTAND BARRIERS TO TB TREATMENT

The facilitator begins by splitting the participants into two groups (depending on the number of participants). This is done by asking the participants to call out 'one' and 'two' and grouping them according to their number.

Next, the facilitator distributes case studies to each group. Each group will get 15 minutes to discuss the case study and write down their observations on a chart. Both groups will get back with these points and present their charts to all the participants.

Activity 13 - Group Discussion

B is a 40-year-old man present with chronic cough. He was diagnosed with TB. He is the prime earning member in his family. He is afraid he may now be removed from work or not given work if people at his work place get to know his TB status. His family members are supportive to some extent.

1. What could be the patient's fear at work?
2. What are his support systems?
3. What could be the barriers to treatment adherence?
4. What support could B get to complete his treatment, and from whom?

Activity 14 - Group Discussion

Ms. X, a 30-year-old single woman earning daily wages, has been diagnosed with TB and referred to your Primary Health Centre by the ASHA worker for frequently defaulting on treatment. She has defaulted on TB treatment previously, and has now been re-enrolled to the TB treatment regimen. She has come to the hospital now with the local health worker, who tells you that the patient's father died of TB and her only living relative is her sister who lives in a nearby village. She has no close friends or care givers in the village. She has not been able to get a job due to her frequent ill-health, which does not allow her to work regularly.

1. What are the potential factors that could lead to non-adherence in this patient?

2. Apart from the factors contributing to non-adherence in the given case study, what other factors could contribute to non-adherence to TB medication?

After each group presents their discussion points, the facilitator summarizes them and concludes the group activity with the points given by the group. The facilitator then wraps up the session with a summary.

Note: Alternatively, these case studies can also be used for conducting adherence counselling sessions for practice during the training.

MEANS OF IMPROVING ADHERENCE

Psychological and emotional support to improve adherence

Any chronic disease can be emotionally debilitating, more so when one is diagnosed with TB, which is a stigmatized disease. Not only does the person diagnosed go through the experience, but his or her family and close social circle also suffer. Stigma may lead to non-adherence to TB treatment, and/or being intermittently irregular to TB treatment.

Informal support can be provided by physicians, nurses, TB Champions (if available in the area of the patient living), and family members. Most programs use a multidisciplinary support team of social workers, nurses, health educators, companions, and doctors. Support may focus on problems related to the different stages of treatment, stigma and discrimination, treatment adherence, side effects, socioeconomic difficulties, treatment failure, and death. The establishment of support groups may allow patients with TB to meet, socialize with other patients, and provide emotional support to each other.

Socioeconomic interventions (incentives and enablers) to improve adherence[3]

Socioeconomic problems, including hunger, homelessness, and unemployment, both short term and long term, are common among TB patients. They should be addressed to help patients to adhere to TB treatment.

These problems have been successfully tackled through socioeconomic interventions that include the use of possible provisions in the form of "incentives" and "enablers." Incentives are rewards that encourage patients to adhere to treatment. Enablers are goods or services that make it easier for patients to adhere to treatment, such as the provision of transportation vouchers. Social workers or other designated professionals can help assess the patients with the most need and monitor delivery of quality and timely services.

Monitoring adherence

TB patients are often asked if they are adhering to treatment, but the answer is more complicated than a yes/no. Telling a patient that they must adhere to treatment if they want to get better is not a satisfactory response. The counselor must probe as to why a person is not taking medication. Asking the right questions and responding in a constructive manner is useful.

[3] https://TBnetwork.org/135-socioeconomic-interventions-incentives-and-enablers [accessed on Feb 21, 2019].

The facilitator may use the following table to understand different scenarios and skills employed in counselling and communication, and apply them to the following activities.

Scenario/Cues	Counselling skills and Communication
"Are you becoming frustrated with the adverse effects of the medication?"	"We can manage your adverse effects if you keep communicating with the clinical and community teams. Many adverse effects improve with time." The counselling skill to be used here is Empathy.
"Are you feeling better?"	"Even though you feel better, your TB is not cured. You must keep taking drugs for the entire treatment period." Here, the skill is effectively imparting TB health education on treatment completion.
"Are you planning to travel soon?"	"We can make arrangements so that you will not miss any doses." Here, the health worker is supporting the TB patient to continue the TB treatment even during travel.
"Are you planning to go back to work?"	"We can make arrangements so that your treatment is more convenient at your workplace. We can also talk to your employer if you agree." The health worker understands that eating breakfast and taking TB tablets while going to work, especially after a break from work, may be hard. This may be harder if the patient is suffering from side effects due to TB treatment. The health worker explores the possibility of support at work for the patient for treatment adherence.
"How is your relationship with your clinical team/ community health worker?"	"If anyone on the clinical or community team is disrespectful, we apologize. Please let us know how we can treat you better." The health worker makes sure that there is no discontinuation of TB treatment due to the arrogant/ negligent behaviors of medical and para medical team. This support, even from one health worker, goes a long way in helping the patient to complete the treatment.

(Source: https://TBnetwork.org/112-common-adherence-problems-and-their-solutions, accessed on Feb 21, 2019)

Note: It is important to be aware of potential problems with adherence before they occur—before a dose or appointment is missed. Ask open-ended questions at every evaluation.

The facilitator further uses the following case studies to ensure that participants practice counselling skills learnt. This learning will help participants counsel non-adherent patients for completion of TB treatment.

Activity 15 - Role Play

1. The facilitator asks for volunteers to take part in the role plays. The facilitator reads out the case stories and asks volunteers to assemble in front of participants before beginning the role play.
2. After each role play activity is over, the facilitator collates responses from the observing participants about what they saw during the role play.
3. Each role play addresses the issues of TB patients from the social, gender and economic perspectives.
4. After wrapping up the discussion following the role play, the facilitator briefly presents on each of the issues dealt with in the role play.

Alcohol dependence and TB

Raju is 38 years old. He lives alone, and is dependent on alcohol. He works in a bar and at the end of the day, he is given a bottle of alcohol. His wife, fed up of this, has taken their child and left him. He used to live in Mangalore, where he was diagnosed with TB and put on treatment for nine months. He is currently living in Bagalkot, where he has been diagnosed with TB again.

Please note: This may not be a one-time effort. Here, the TB patient is living alone, is dependent on alcohol, and has TB. Raju's social standing is low because of his alcohol consumption and because he is not earning. He does not have anyone's respect, and thus is neglected. Being a man with family, he is expected to earn and be responsible for himself and his family. All of these qualities are lacking in Raju. His motivation for restarting TB treatment and completing it will be low due to these factors.

The health worker who visits his home will have to explore and provide support for the following:

1. Build a rapport (during the first meeting and the following meetings)

2. Explore by asking open ended questions. The questions below are basic open-ended questions to support the TB patients and their family members. The health worker asks more open-ended questions relevant to the situation during patient visits.
   a. As he is living alone, from whom does he seek support when in need?
   b. On what issues does he seek support?
   c. What kind of support does he receive from the people from whom he seeks support?
   d. Explore his motivation to restart his TB treatment.
   e. What are his activities in a day? (This will give the health worker an idea about the time Raju starts drinking, and help plan the medication timings.)
   f. During every visit, help him understand the advantages of quitting alcohol.
   g. After having built good trust and rapport, find out the aspirations and dreams of his childhood and youth. This will help to find out if he had any dreams and aspirations which can serve as a clue to the health workers to motivate him to be healthy and realize at least part of his aspirations. This can also give clues as to why he is reaching for alcohol. During the visits, educate him about de-addiction centers and motivate him join them.

3. The health worker must explore the available social entitlements for Raju and link him to them. This includes linking him to services so that he can get food on time, and to a shelter or short-stay home in case he has no shelter.

4. The health worker will explore if they can contact his wife or any family members to help Raju complete the TB treatment and to support him emotionally when in need.

5. The family member or the support person(s) will be educated on TB and build awareness on TB, adherence to TB medication and completion of treatment.

6. The health worker also explores if there is a need to support the family members or the support person(s) as they motivate Raju to complete his treatment.

TB, Diabetes and HIV

Ratna is a 42-year-old woman who was once married and separated from her husband more than a decade ago. She was diagnosed with diabetes 15 years ago and is on medication for it. Five years ago, she was started on insulin. She has also been diagnosed with the HIV infection and recently started taking ART. She has also started TB treatment. She complains of blurred vision and a cough. She was advised to get baseline chest radiographs and an eye examination, followed by an ophthalmic consultation. Since she is diabetic, she needs her weight to be monitored regularly. She lives with her young daughter.

Please note: Ratna is living alone with her daughter, who is not earning. She is the only earning member. It is important to help Ratna understand that HIV and diabetes are lifelong diseases. Both conditions will need lifelong medication to manage their long-term effects and progress. The health worker should involve her daughter in supporting Ratna to complete TB treatment, with Ratna's permission. The health worker's primary goal is to ensure adherence and completion of TB treatment.

The health worker who visits his home will have to explore and provide support for the following:

1. Build rapport (in the first meeting as well as the following meetings).

2. Explore by asking open-ended questions. The questions below are basic open-ended questions to support TB patients and their family members. The health worker asks more open-ended questions relevant to the situation during patient visits.

3. After building awareness on TB, and the need to complete TB treatment, build her awareness on the importance of a nutritious diet, encourage her to follow a diet regime, and exercise once she gets some energy. Educate her about the HIV infection and link her to an ART center for further counselling on HIV and to understand the precautions she needs to take if she is sexually active, to avoid a re-infection or the development of a resistant strain of the virus.

4. The health worker will have to ask about support mechanisms available to her. She can ask *"As you are not keeping well, who else can you ask for support, apart from your daughter?"* This support can take the form of taking her to the hospital for check-ups, or to get things done at home.

5. Since she is the only earning member, the health worker has to explore the need for further linkages other than the linkages to ART and diabetes treatment. These include ration cards, nutrition, skill building and income generation for herself and her daughter.

6. From this case, Ratna's motivation to take care of her health and complete TB treatment is her daughter. However, she will need regular counselling to manage her current ill health, to continue to be healthy and live well.

7. The health worker will involve her daughter, as she lives with her mother, to take care of the wellbeing of both of them. She will need regular counselling support to raise her hopes about her mother's health and also to continue and complete her education (short-term financial linkages can be explored here).

Note: The facilitator can ask the participants to also share any difficult cases they have or are currently facing. These cases can be used for practicing adherence counselling using counselling skills. This practice session will not give solutions to solve difficult cases, but will give multiple perspectives to approach the cases in few different ways. This sharing can also bring about cross-learning, if someone among the participants has dealt with a similar case.

SESSION 6 Referral and linkages to TB services

Objective

By the end of this session, participants will be able to:

- Identify medical and non- medical needs of TB patients and their families
- Identify the TB patient's and family's needs, refer and link them, accordingly

Methodology

Small group activity and large group discussion

Materials required

Flip charts, marker pens, copies of the case stories, chairs, a quiet and large room, LCD screen or projector, computer or laptop

Duration

60 minutes (1 hour)

The facilitator brings back the Prevention, Care and Support (PCS) services components for the patient and their family members from section A and connects them to the current session on referrals and linkages. Revisiting the table below and case studies provided, the participants map the need for referral and linkages for the patient and their family to ensure holistic and uninterrupted support for the completion of the TB treatment.

The spectrum of PCS services includes,

Psychosocial support	› Reassurance › Counselling » Disclosure » Co-morbidity » Lifestyle/ habits › Family support › Stigma reduction › Support groups
Nutrition	› Nutritional advice › Linkages to nutrition » Public Distribution System » Local leaders » Nongovernment Organizations, Community Service Organizations » Panchayati Raj Institutions › Linkage to Direct Benefit Transfer (DBT) payments
Infection Prevention	› Cough hygiene › Sputum disposal › Contact screening › Linkage to Isoniazid Preventive Therapy
Financial	› Linkage to Social Security › Linkage to DBT › Livelihood linkages and loan access › Linkages to local philanthropists › Linkages to health insurance

Medical	› Post-diagnosis support › Adherence support and monitoring › Patient status evaluation › Side effects/symptom management › Tertiary care linkage › Post treatment follow-up, referral for follow-up sputum microscopy/ cultures › Treatment rupture intervention (when the patient is not traceable)

When a person is diagnosed with TB, the person's needs are not limited to just getting treatment. Studies have shown that being infected with pulmonary TB and extra pulmonary TB has led to unemployment, depriving patients of their daily basic needs until they get back to health. TB patients lose up to 20-30% of household income from the initial months of treatment until two months after treatment.[4]

TB and poverty are closely linked, and this creates a situation where the family cannot fulfil their basic needs, including daily nutritional needs. Co-morbidities with HIV and/or diabetes take away time from work and result in additional out-of-pocket medical expenses. Families of persons who die from the TB lose about 15 years of income. A majority of patients are wage-earners, and their illness leads to 30% decline in average productivity.6 When the main earning member(s) is infected with TB, it affects the daily routine of each family member, children's education and the emotional health of these families. The family may also face stigma due to TB, which can bring down the emotional morale of the TB patient and family members.

It is important to assess the needs of the patient and family during counselling and home visits.

It is a good practice to map the services available in the patient's vicinity and link them to these services.

When linkages to medical and non-medical needs of the TB patient and their family members are created, it motivates the patient to complete treatment. The need for linkages increases if more than one person is diagnosed with TB within the family.

The referrals and linkages can be made to service providers, who can provide patients benefits and social entitlements. The service provider could be a public or private hospital, an NGO, a network, a government department, a local business, skill building and income generation institution, a self-help group, an organization which fulfils educational needs of the children, psychiatric needs, or nutritional needs, or even another project within the same NGO.

The health workers (during the counselling skill training) can be encouraged to keep track of TB patients, who successfully completed TB treatment after they were referred and linked to benefits and services.

The following case studies will help participants understand the importance of linkages for the TB patients and their family members. We need to understand that with many patients, there will be many different needs. These case studies only depict a sample of needs of the TB patients and linking them to the relevant services.

[4]Fonkwo P. N. (2008). Pricing infectious disease. The economic and health implications of infectious diseases. EMBO reports, 9 Suppl 1(Suppl 1), S13–S17. https://doi.org/10.1038/embor.2008.110 [accessed on Feb 21, 2019]

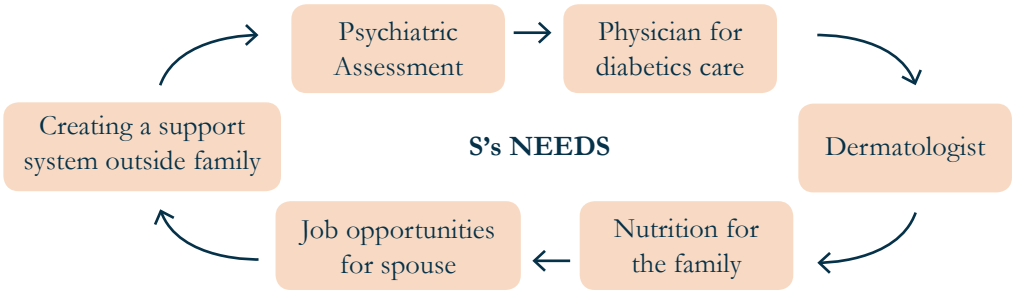
Activity 16 - Group Activity

1. Divide the participants into small groups. Each group should comprise 5-6 members.
2. Give each of the small groups a case scenario (given below) and 10 minutes to discuss.
3. Let the small groups discuss and make notes in accordance with the questions under each case study.
4. Each group will then choose a representative from their group to present to the larger group. The facilitator jots down the points presented and at the end of each presentation, more discussions will follow around the missed points. The facilitator concludes, saying that each case will vary according to the needs of the patient and family.

Case Story 1

S is a 40-year-old home maker; she has a daughter studying in high school. Her husband was working in a garment showroom. Their first daughter died 3 years ago due to fever. Presently, S has been diagnosed with pulmonary TB. Her husband has been very supportive. He was the one to take his wife to hospital, which took many trips until the diagnosis was done and treatment was started. He lost his job as his long absence was affecting his employer's business. S also has diabetes and is on medication for that. She has skin rashes all over her body and is unable to sleep at night.

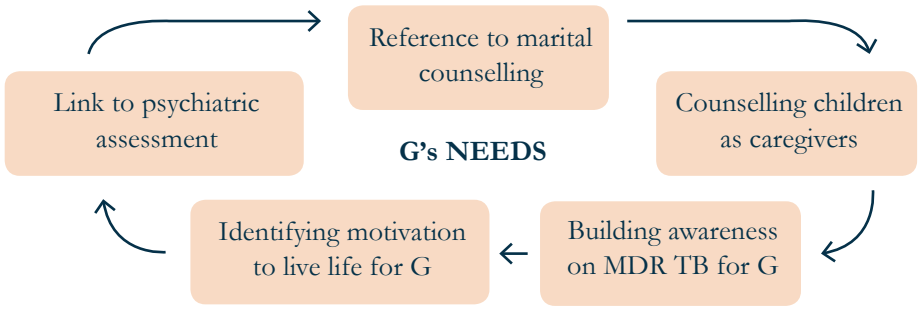
What are the needs of S and her family and with whom/ with which services would the linkages be created?



Case Story 2

G is living with his wife and unmarried son. His daughter is married and visits them often. G has been diagnosed with Multi Drug-Resistant TB (MDR TB) of the lungs. He used to previously smoke beedis and even now secretly smokes without his family's knowledge, although he sometimes gets caught smoking. He is on MDR TB treatment. He has finished the intensive phase of treatment. His relations with his wife and children are strained. They try their best to be patient with him and tolerate his demands. He complains that his wife and children ill-treat him as he is not an earning member of the family anymore. His family complains that even after they put the tablets in his mouth, he acts like he has swallowed and then goes out and spits them all out. They say that they have tried their best to convince him to consume his tablets, but in vain.

What are the needs of G and what are the possible linkages?



SNAPSHOTS OF A COUNSELLING TRAINING SESSION FOR NTEP STAFF, BENGALURU

ANNEXURES

Annexure 1:
Schedule for Training on Differentiated Care Model with Counselling Skills for Frontline Health Workers of the Tuberculosis Program

Date: ..... Venue: .....

S. No	Time	Topic	Facilitator
DAY 1			
1.	9.30 to 10.30am	Introduction/ice-breaking, pre-test and standard training rules	
2.	10.30 to 11.30 am	Refresher - Components of PCS	
3.	11.45 to 1.30pm	Differentiated Care approach	
		Lunch	
4.	2.30 to 3.30pm	Differentiated Care approach	
5.	3.30 to 5.00pm	Communication skills	
		Every day from 11.30am to 11.45am and 3.30 to 4.15pm – Tea break for 15 minutes	
DAY 2			
6.	9.30 to 10.00am	Recap and plan for the day	
7.	10.00am -12.30pm	Counselling skills	
8.	12.30 - 1.30pm	Stigma	
		Lunch	
9.	2.30 - 5.30pm	Adherence to TB treatment	
DAY 3			
10.	9.30 to 10.00am	Recap and plan for the day	
11.	10.00am - 12.00pm	Adherence to TB treatment	
12.	12.00 -1.00pm	Referrals and linkages	
		Lunch	
13.	2.00 -2.30pm	Summary	
14.	2.30-3.30pm	Post-test and Feedback	

Annexure 2:
Pre/ Post Training Questionnaire

Date: ..... **Venue:** .....

Please answer all questions.
Your answers will provide us an understanding on how to plan and implement this training better.

Name: ..... Gender: .....

Pre / Post training (circle as applicable) Date: .....

1. In your opinion, who are the persons most likely to become infected with TB in India?
   Please tick all that apply.
   - ☐ Homeless persons
   - ☐ Children under 5 years
   - ☐ Senior Citizens
   - ☐ People living with HIV/AIDS
   - ☐ Health care worker treating a confirmed case
   - ☐ Family members of a confirmed case
   - ☐ Prison Inmates

2. Can someone become infected with TB more than once in their lifetime?
   Please tick the right answer.
   - ☐ Yes
   - ☐ No
   - ☐ Do not know for certain

3. Do open windows and the use of fans increase the chance of TB infection?
   - ☐ Yes
   - ☐ No
   - ☐ Not sure

4. Do many people infected with TB face self-stigma?
   - ☐ Yes
   - ☐ No

5. Which of the following statements best describes Counselling?

- [ ] Supportive relationship between a patient and a skilled worker
- [ ] Giving advice to a patient or client
- [ ] Interrogating a client
- [ ] All of the above.

6. Write True or False (T/F) in the space next to the following statements.

a. You should never ask close ended questions to the patients _____

b. Probing means asking more questions and it is a bad habit _____

c. The counsellor should be able to look at the patient and judge if the patient is likely to default. _____

d. The counsellors should put words in the clients' mouth if they find it difficult to express themselves _____

e. The patients don't know much, hence the counsellor should do the talking _____

f. Active listening is more than just hearing _____

7. What are the ways to show you are listening to a client?
(Please tick your response)

- [ ] Making eye contact
- [ ] Having a blank facial expression or staring
- [ ] Using minimal encouragers (mmmh, ah ah etc.)
- [ ] Interrogating, using 'why' questions
- [ ] Summarizing (paraphrasing) information the client has told you and repeating back to check that you have understood

8. Empathy is more important than sympathy in counselling

- [ ] True
- [ ] False

9. Name three qualities of a counsellor.

a) _____

b) _____

c) _____

10. You are counselling a gentleman at the hospital. His test for TB is positive. During the conversation, he tells you not to mention it to his wife sitting outside, for the fear of losing her respect and because she can tell others in the family. After the counselling, you walk the gentleman to the door. His wife is sitting outside. She happens to be the mother of your child's classmate. She has become your friend as you both go to school to pick up your children. You feel that you

should tell her about her husband's TB result. As a counsellor, should you tell this woman of her husband's TB positive report?

- ☐ Yes
- ☐ No

11. What are three reasons for non-adherence to treatment in persons with TB?

a) _____

b) _____

c) _____

12. RANA is the first step to PCS:

- ☐ Yes
- ☐ No

13. Improvement in patients' condition can be assessed by weight gain:

- ☐ Yes
- ☐ No

14. Read each statement and determine whether it is an open-ended or closed question by placing a tick in the correct column.

Is it an open-ended or closed question?	Open	Closed
a. How do you feel now?		
b. Do you have any side effects due to the medicines you are taking?		
c. Do you have any children?		
d. What kind of thoughts come to your mind when you take these medicines?		
e. Could you please tell me your reasons for coming?		
f. Will you agree to take the treatment for two long years?		
g. How do you think you can protect your family members from TB?		
h. What have you heard about this treatment?		
i. Are you aware that TB can spread through coughing and sneezing?		
j. What questions do you have about Tuberculosis?		

Annexure 3:
Pre/ Post Training Questionnaire with keys

Date: ..... **Venue:** .....

Please answer all questions.
Your answers will provide us an understanding on how to plan and implement this training better.

Name: ..... Gender: .....

Pre / Post training (circle as applicable) Date: .....

1. In your opinion, who are the persons most likely to become infected with TB in India?
   Please tick all that apply.
   - ☑ Homeless persons
   - ☑ Children under 5 years
   - ☑ Senior Citizens
   - ☑ People living with HIV/AIDS
   - ☑ Health care worker treating a confirmed case
   - ☑ Family members of a confirmed case
   - ☑ Prison Inmates

2. Can someone become infected with TB more than once in their lifetime?
   Please tick the right answer.
   - ☑ Yes
   - ☒ No
   - ☒ Do not know for certain

3. Do open windows and the use of fans increase the chance of TB infection?
   - ☒ Yes
   - ☑ No
   - ☒ Not sure

4. Do many people infected with TB face self-stigma?
   - ☑ Yes
   - ☒ No

5. Which of the following statements best describes Counselling?

- [x] Supportive relationship between a patient and a skilled worker
- [ ] Giving advice to a patient or client
- [ ] Interrogating a client
- [ ] All of the above.

6. Write True or False (T/F) in the space next to the following statements.

a. You should never ask close ended questions to the patients ..... False

b. Probing means asking more questions and it is a bad habit ..... True

c. The counsellor should be able to look at the patient and judge if the patient is likely to default. ..... False

d. The counsellors should put words in the clients' mouth if they find it difficult to express themselves ..... False

e. The patients don't know much, hence the counsellor should do the talking ..... False

f. Active listening is more than just hearing ..... True

7. What are the ways to show you are listening to a client?
(Please tick your response)

- [x] Making eye contact
- [ ] Having a blank facial expression or staring
- [x] Using minimal encouragers (mmmh, ah ah etc.)
- [ ] Interrogating, using 'why' questions
- [x] Summarizing (paraphrasing) information the client has told you and repeating back to check that you have understood

8. Empathy is more important than sympathy in counselling

- [x] True
- [ ] False

9. Name three qualities of a counsellor.

a) Being non-judgmental

b) Patience

c) Good listener

10. You are counselling a gentleman at the hospital. His test for TB is positive. During the conversation, he tells you not to mention it to his wife sitting outside, for the fear of losing her respect and because she can tell others in the family. After the counselling, you walk the gentleman to the door. His wife is sitting outside. She happens to be the mother of your child's classmate. She has become your friend as you both go to school to pick up your children. You feel that you

should tell her about her husband's TB result. As a counsellor, should you tell this woman of her husband's TB positive report?

- [x] Yes
- [✓] No

11. What are three reasons for non-adherence to treatment in persons with TB?

a) Migration

b) Alcoholic

c) Severe side effects

12. RANA is the first step to PCS:

- [✓] Yes
- [x] No

13. Improvement in patients' condition can be assessed by weight gain:

- [✓] Yes
- [x] No

14. Read each statement and determine whether it is an open-ended or closed question by placing a tick in the correct column.

Is it an open-ended or closed question?	Open	Closed
a. How do you feel now?		✓
b. Do you have any side effects due to the medicines you are taking?		✓
c. Do you have any children?		✓
d. What kind of thoughts come to your mind when you take these medicines?	✓	
e. Could you please tell me your reasons for coming?	✓	
f. Will you agree to take the treatment for two long years?		✓
g. How do you think you can protect your family members from TB?	✓	
h. What have you heard about this treatment?	✓	
i. Are you aware that TB can spread through coughing and sneezing?		✓
j. What questions do you have about Tuberculosis?	✓	

Annexure 4:
PowerPoint Presentation on Differentiated Care Model

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THALI

Tuberculosis Health Action Learning Initiative

Jan 2016 to Jan 2020

Differentiated Care Model

Introduction -1

ALL persons diagnosed with TB need counselling and support to address their concerns:

- to initiate TB treatment,
- to be adherent to the medication and
- to complete their treatment.

Introduction -2

- There are certain patients who have a higher risk of not being initiated on, adhering to or completing their TB treatment.
- These patients need a prioritized approach.
- This group constitutes about approximately 40% of total TB patients.
- The differential approach for these patients is referred to as 'Differentiated Care Model'.
- This aligns with Pillar 1 of the 'End TB strategy'

Introduction -3

- Risk and needs assessment tool (RANA) administration, is a first step for providing prevention care and support (PCS) services to patients.
- Assessing risks will help to provide differentiated care to patients in addition to the basic PCS services
- Differentiated Care Model will help RNTCP to improve treatment completion and cure to reach more than 90% successful treatment outcomes.

Basic components- Prevention, care and Support

Psycho Social	Nutritional	Infection Prevention	Financial
•Reassurance •Counselling Disclosure Co-morbidity Lifestyle/ habits •Family support •Stigma reduction •Support groups	•Nutritional advice • Nutritional linkages PDS Local leaders NGOs, CSOs PRI •DBT linkage	•Cough Hygiene •Sputum disposal •Contact screening •IPT linkage	•Social Security linkage •DBT Linkage •Livelihood linkage, loan access •Local philanthropies' link •Health insurance link

Medical

- •Post diagnosis support
- •Adherence support & monitoring
- •Patient status evaluation
- •Side effect/ symptom management
- •Tertiary care linkage*
- •Referral for follow-up sputum microscopy/ cultures
- •Treatment rupture intervention (when patient not traceable)
- •Post treatment Follow up , Screen for DM and HIV

Categories of patients

1. Elderly (> 60 years)
2. Living alone/ without family support
3. Previously treated patients
4. DR TB
5. Alcohol use
6. TB HIV
7. TB DM

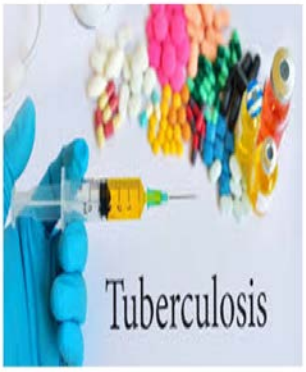
Elderly patients (>60 Yrs. of age)

- Understand and identify any possible neglect
- Identify and educate primary care giver on TB disease, drugs and follow up
- Ensure that primary care giver understands the importance of providing regular meals to patient.
- ***Look for other medical illnesses – Diabetes, Hypertension etc…***
- Ensure treatment and follow up of medical illnesses with relevant specialists (support in collecting medicines etc..)
- Screening of children at home/family

Living alone/ without family support

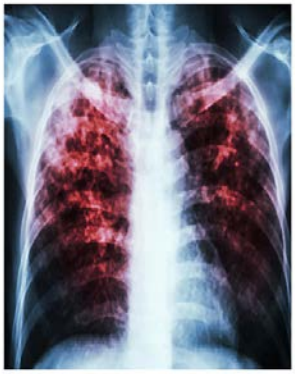
- ***Understand the reason for living alone (job related etc..) and explore support systems in neighbourhood.***
- Facilitate support from family or friends or colleagues (respecting patient's choice)
- Assist in disclosure
- Linkage to Careline or support group meetings
- Work out reminder systems like sms, alarm clock for medicine intake, MERM

Previously treated, irregular



- ***Identify and understand reasons for irregular medications***
- Appropriate counselling and education support to patient and family
- Facilitate linkages for getting injections regularly
- Ensure universal DST, before initiation of treatment.
- Ensure screening for HIV and DM, which may cause repeated episodes of TB

DR TB

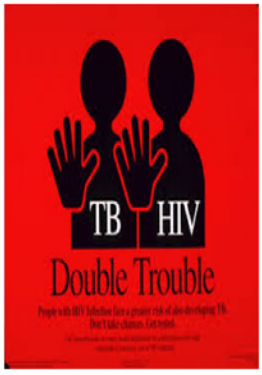


- ***Counselling and education to patient and family on duration of treatment***
- Assessing adherence fortnightly
- Facilitate linkages for getting injections regularly
- Facilitate tertiary care admissions as and when required
- Leveraging resources for higher level medical management (surgery etc…)

Alcohol Use

- ***Ensuring TB medications are taken regularly, is the primary goal and not de-addiction.***
- Counselling and treatment literacy to family members.
- Make sure that one primary care giver takes the responsibility of giving ATT daily without fail.
- Educate the family and primary care giver on the importance of providing regular meals.
- Facilitate linkages to de-addiction services and/or higher level medical facilities
- Involving KOLs in case of domestic violence etc…

TB HIV



- ***Facilitate ART initiation***
- Identify primary care giver, educate on TB, HIV medications etc.. Along with family members
- Educate the primary care giver about the importance of Cotrimoxazole in TB HIV co-infection.
- Facilitate linkage with other NGOs for social entitlements

TB DM

- Facilitate screening for diabetes in all TB patients
- ***Linkages with diabetic clinical care and ensure TB medications and Diabetic medications are taken regularly***
- ***Ensure regular monitoring of diabetes and ensure good control of diabetes (no need for insulin)***
- Identifying and educating the primary care giver on importance of providing regular meals, TB medications and diabetic medications.(low calorie and high protein diet)

Common actions for all of patients

- Regular clinical assessment by a medical doctor
- Establish referral linkage for tertiary care
- Organise support group meetings
- Educate patient and family on cough hygiene and sputum disposal measures
- Provide regular meals to patients
- Mobilize support through KOLs , govt schemes etc., based on needs
- All TB patients can be screened for DM and HIV

✓ ***Seek support from line managers in case of any difficulty in providing services to patients***

✓ ***Bring to their notice all bedridden patients***

Anticipated learnings….

(1) The reduction of negative treatment outcomes, resulting in >90% successful treatment outcomes, by using differentiated care model.

(2) The need for specialised front line workers in providing prioritized PCS services for patients with HIV, Diabetes, Alcohol use.

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Annexure 5:
DCM reminder cards for frontline workers

WHERE I SHOULD FOCUS

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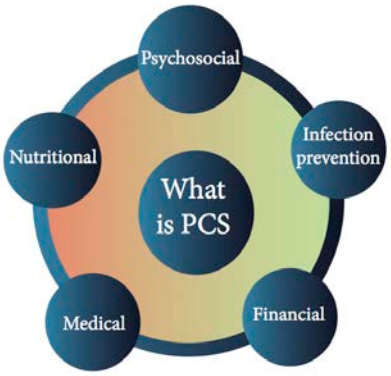


Psycho Social
- ❖ Reassurance
- ❖ Counselling
  - Disclosure
  - Co-morbidity
  - Lifestyle/habits
- ❖ Family support
- ❖ Stigma reduction
- ❖ Support groups

Nutritional
- ❖ Nutritional advice
- ❖ Nutritional linkages
  - PDS
  - Local leaders
  - NGOs, CSOs
  - PRI
- ❖ DBT linkage

Financial
- Social Security linkage
- DBT Linkage
- Livelihood linkage, loan access
- Local philanthropies' link
- Health insurance link

Infection Prevention
- Cough Hygiene
- Sputum disposal
- Contact screening
- IPT linkage

Medical
- Post diagnosis support
- Adherence support & monitoring
- Patient status evaluation
- Side effect/ symptom management
- Tertiary care linkage
- Referral for follow-up sputum microscopy/cultures
- Treatment rupture intervention (when patient not traceable)
- Post treatment Follow up

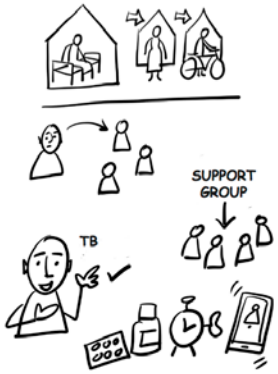
WHO SHOULD I PRIORITISE FOR CARE AND SUPPORT?

- ✓ Elderly (> 60 years)
- ✓ Living alone/ without family support
- ✓ Previously treated patients
- ✓ DR TB (Drug Resistant TB)
- ✓ Alcohol use
- ✓ TB HIV
- ✓ TB DM (TB-Diabetes)

ELDERLY PATIENTS (>60 YRS. OF AGE)

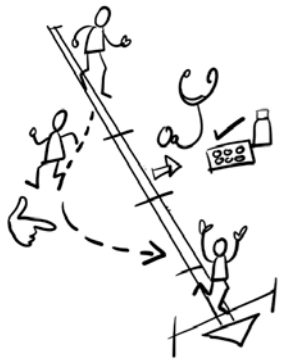
- ✓ Understand and identify any possible neglect
- ✓ Identify and educate primary care giver on TB disease, drugs and follow up
- ✓ Ensure that primary care giver understands the importance of providing regular meals to patient.
- ✓ Look for other medical illnesses – DM, HTN (Hypertension) etc…
- ✓ Ensure treatment and follow up of medical illnesses with relevant specialists (support in collecting medicines etc..)
- ✓ Screening of children at home/family

LIVING ALONE/ WITHOUT FAMILY SUPPORT



- ✓ Understand the reason for living alone (job related etc..) and explore support systems in neighbourhood
- ✓ Facilitate support from family or friends or colleagues (respecting patient's choice)
- ✓ Assist in disclosure
- ✓ Linkage to Careline or support group meetings
- ✓ Work out reminder systems like sms, alarm clock for medicine intake.

PREVIOUSLY TREATED, IRREGULAR



- ✓ Identify and understand reasons for irregular medications
- ✓ Appropriate counselling and education support to patient and family
- ✓ Ensuring they understand the advantages of regular medicine and disadvantages of irregular medicine (DRTB etc.)
- ✓ Facilitate linkages for getting injections if they require
- ✓ Ensure universal DST, before initiation of treatment.
- ✓ Ensure screening for HIV and DM, which may cause repeated episodes of TB

DR TB

- ✓ Counselling and education to patient and family on duration of treatment
- ✓ Assessing adherence fortnightly
- ✓ Ensuring they understand the side effects of medication and their effective management
- ✓ Ensuring patient takes pyridoxine tablet daily during the course of treatment
- ✓ Facilitate linkages for getting injections regularly
- ✓ Facilitate tertiary care admissions as and when required
- ✓ Leveraging resources for higher level medical management (surgery etc…)

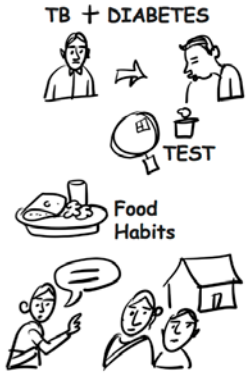
ALCOHOL USE

- ✓ Ensuring TB medications are taken regularly, is the primary goal and not de-addiction.
- ✓ Counselling and education of patient and family regarding treatment
- ✓ Make sure that one primary care giver takes the responsibility of giving ATT daily without fail.
- ✓ Facilitate linkages for pyridoxine tablets
- ✓ Educate the family and primary care giver on the importance of providing regular meals.
- ✓ Facilitate linkages to de-addiction services and/or higher level medical facilities
- ✓ Involving KOLs in case of domestic violence etc…

TB HIV

- ✓ Facilitate ART initiation
- ✓ Identify primary care giver, educate on TB, HIV medications etc.. Along with family members
- ✓ Facilitate linkages for pyridoxine tablets as and when required
- ✓ Ensuring that the patient is regularly followed up by ART medical officer
- ✓ Educate the primary care giver about the importance of CPT (Cotrimoxazole) in HIV TB co-infection
- ✓ Motivating patient to attend patient support group meetings
- ✓ Facilitating linkages with other NGOs for social entitlements & nutrition

TB DM



- ✓ Facilitate screening for diabetes in all TB patients
- ✓ Linkages with diabetic clinics and ensure TB medications and Diabetic medications are taken regularly
- ✓ Supporting regular monitoring of blood sugar levels & ensuring that diabetes is under control
- ✓ Facilitate linkages for pyridoxine tablets
- ✓ Supporting in the disclosure of TB status to the doctor treating diabetes for modification in nutrition /medications if required
- ✓ Identifying and educating the primary care giver on importance of providing regular meals (low calorie and high protein), TB medications and diabetic medications.

COMMON ACTIVITIES FOR ALL PATIENTS

- ✓ Ensure HIV and diabetes screening for all TB patients
- ✓ Regular clinical assessment by a medical doctor
- ✓ Establish referral linkage for tertiary care
- ✓ Organise support group meetings
- ✓ Educate patient and family on cough hygiene and sputum disposal measures
- ✓ Provide regular meals to patients
- ✓ Mobilize support through KOLs , government schemes etc., based on needs

- ❖ Seek support from line managers in case of any difficulty in providing services to patients
- ❖ Bring to their notice all bedridden patients

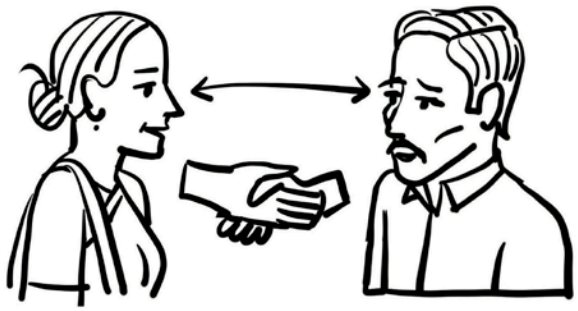
Annexure 6:
Counselling skill cards for frontline workers

Do Remember!

Counselling Skills
Qualities of a Counsellor

USAID FROM THE AMERICAN PEOPLE KHPT

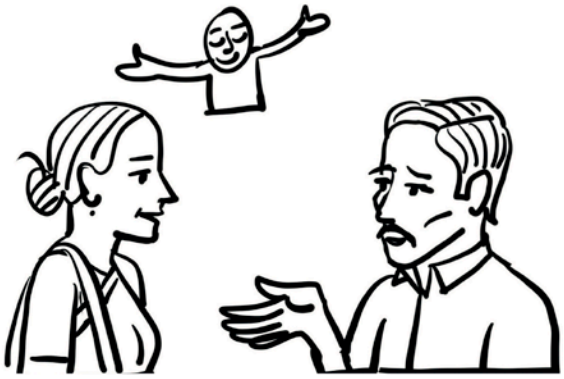
Rapport Building



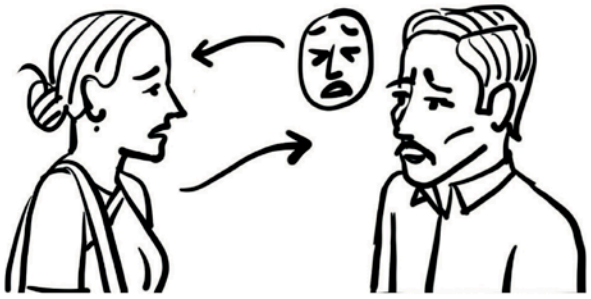
Respect the Client, TB Patient/ Member of the Family

Confidentiality

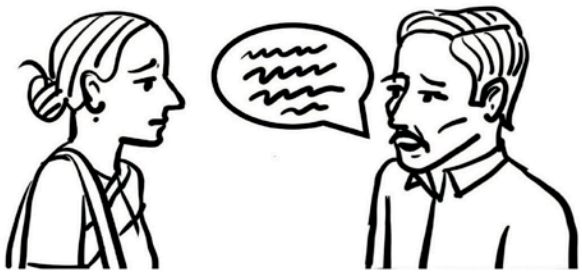
Non Judgemental



Empathy



Active Listening

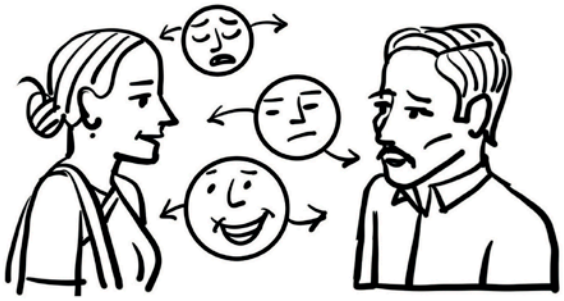


Questioning – Close Ended

Questioning – Open Ended

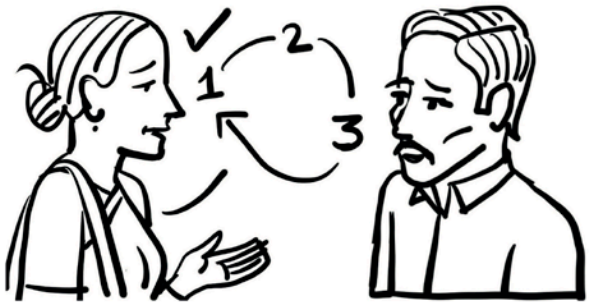
Using silence

Reflecting Feelings



Paraphrasing

Summarizing



Annexure 7:
Risk and Needs Assessment (RANA) format

Risks and Needs Assessment (RANA)

District name: _____ **TU Name:**_____ **DMC Name:**_____ **Facility Name:**_____

NIKSHAY ID: _____ **Date of RANA:** _____ **Date of treatment initiation:** _____

Patient's full name: _____ **Age:** _____ **Gender (M/F):** _____ **Assessment done by (Name & Designation):**_____

A) DCM Category – tick (√)								
	Yes	**No**		**Yes**	**No**		**Yes**	**No**
1. Elderly patient (age ≥60 years)			**4.** Patient consuming alcohol			**7.** Patient with Diabetes		
2. Patient living alone &/or without family support			**5.** DRTB patient					
3. Previously treated patient			**6.** Patient co-infected with HIV					

B) Ask relevant questions and screen for following risk factors – tick (√)	**Yes**	**No**	**C) Ask relevant questions and screen for following social needs – tick (√)**	**Yes**	**No**
1. Does the patient understand TB disease and/or treatment?			**1.** Does the patient have Aadhaar card?		
2. Does the patient accept TB disease and/or treatment?			**2.** Does the patient have bank account?		
3. Patient is experiencing discrimination or denial of rights because of TB			**3.** What type of ration card does the patient have? a) BPL ☐ b) APL ☐ c) None ☐		
4. Patient is Migrant/Frequent traveller					

	Yes	**No**
Does the patient fall under any DCM category? (Tick based on section A):		

Details of In-person care – Differentiated Care Model (DCM)

Visit/contact number	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**								
Date of visit/contact	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM	DD/MM
Type of contact (In-person=1; care giver=2, telephonic=3)																
Percentage of adherence as per NIKSHAY																
Risk code (codes to be mentioned here itself)																
Action code (codes to be mentioned here itself)																

Codes to be used for recording risk/s identified and action/s taken during patient visit/contact

Risk code	**Risk factors**
A	Refusal for in-person care
B	Regular travel/migration
C	Plan of social event in near future
D	Recently faced crisis (**anything that prevents treatment adherence**)
E	Disease status not disclosed to immediate family
F	Persisting symptoms/no clinical improvement
G	Side effects/appearance of new symptoms
H	Bed ridden
I	Blood sugar not under control
J	No weight gain
K	Tobacco use
L	Lack of family support
M	Problem with access to drugs
N	Financial difficulties for daily living
O	Difficulty in getting DBT

Person may have multiple risk and multiple actions may be taken. Therefore, more than one option in risk and action is possible

Action codes for risk specific actions taken (along with adherence counselling to all patients)
A. Linked to careline /support group meetings
B. Facilitated linkage for medications **C.** Reminder system for medicine intake/ IDAT in pilot districts
D. Supported for disclosure
E. Reassurance and referral to a medical doctor for symptom relief
F. Ruled out DRTB
G. Tested for CD4/viral loads in case of TB-HIV
H. Reassurance and referral for management of side effects
I. Facilitated linkages to relevant specialist and/or tertiary care admission
J. Facilitated linkage to diabetic clinic/NCD clinic
K. Educated patient on diabetic diet and importance of regular physical activity
L. Nutritional counselling
M. Nutritional support/linkages
N. Educated the patients on disadvantage tobacco use
O. Identified primary care giver/explored support from neighbourhood
P. Educated patient on TB and treatment
Q. Family level counselling and support provided
R. Linked to RNTCP medications (as per patient's convenience) including injections (if required)
S. Facilitated livelihood support, assisted in getting ration card
T. Linkage to health-related schemes established
U. Assisted for DBT linkage
V. Facilitated action on DBT/Linked to DBT

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