ORIGINAL ARTICLE



INTERNATIONAL JOURNAL OF CONVERGENCE IN HEALTHCARE

Published by IJCIH & Pratyaksh Medicare LLP

www.ijcih.com

Introducing Culturally Sensitive Tuberculosis Education and Context Specific Patient Screening

Manjula Datta¹, Mark Nichter², Manjula Singh³

¹Professor & HOD, Department of Epidemiology, The Tamilnadu Dr MGR Medical University, Guindy, Chennai, Tamilnadu, ²Professor of Anthropology, University of Arizona, Tuscon, Arizona, ³Scientist 'F' Division of Delivery Research, Co-ordinator, ITRC ICMR Hqrs., New Delhi

Abstract

This document highlights the importance of culturally sensitive education and context-specific patient screening in enhancing Tuberculosis (TB) Directly Observed Treatment, Short-course (DOTS) programs.

Background: Existing TB education materials are often technically informative but fail to address patient questions and misconceptions. There's a need to address social and practical problems that hinder adherence to DOTS.

Healthcare providers need training to address patient queries effectively.

Research Approach: A multi-site qualitative study was conducted in India to identify common questions and misconceptions about TB. Data collection involved literature review, Key informant interviews, and focus groups. The goal was to create an educational booklet and patient screener to improve DOTS adherence.

Development of Educational Booklet: Candidate responses to common questions were generated in workshops with healthcare providers.

Responses were translated into regional languages and tested with TB patients and their families. booklet has been pre-tested and is ready for pilot testing and evaluation.

Key Considerations for Booklet Use: Adaptation is crucial for cultural relevance, including translation and modification of content. The booklet is not intended for special populations without further adaptation. It should be used as part of a support and counselling package to enhance social and logistical support.

Expected Outcomes of Booklet Use: Increased confidence and ability of DOTS providers and health staff to communicate effectively with patients. Reduced patient and family fears, helping them cope with the illness and its treatment. Improved community understanding of TB, reducing stigma and promoting DOTS.

Patient Screener:

- Used to identify challenges to DOTS completion.
- Helps tailor DOTS to patient needs.
- Demonstrates sensitivity to patient life circumstances.
- Essential Areas for Effective TB Control:

Corresponding Author:

Dr. Manjula Dutta

Professor & HOD, Department of Epidemiology, The Tamilnadu Dr MGR Medical University, Guindy, Chennai, Tamilnadu E-mail: manjuladatta044@gmail.com

- Enhanced education, counselling, and social support.
- Improved patient screening.
- Flexible, patient-centered health system response.
- Addressing structural problems in TB care programs.

Suggestions for Pre-testing and Evaluating the Education Package:

The document provides a 10 step guide to pre-test and evaluate the booklet,

- Translate into the local language.
- Pre-test the translation with key informants and focus groups.
- Adjust the language according to feedback.
- Modify images for local relevance.
- Seek feedback from TB officials.
- Select a pilot test area.
- Consider different procedures for booklet use.
- Hold a workshop for health personnel.
- Decide on a research design to evaluate its effectiveness.
- Collect information on further doubts/questions.

Screening Questions:

Sample questions for screening TB patients are provided relating to:

- Work Migration
- Domestic constraints for women
- Social Support
- Stigma
- Personal habits (smoking and drinking)
- Preferred DOTS supporter

Keywords: Tuberculosis (TB), dots (directly observed treatment, short-course), culturally sensitive education, patient screening, community understanding.

Background

This document contains an educational booklet and patient screener designed to enhance the DOTS tuberculosis program. The educational booklet for TB is based on five years of formative research conducted in India by a team of experienced social scientists and medical doctors working together to address what they saw as a major gap in current efforts to educate TB patients, DOTS providers, and health staff about TB and its treatment. The screener is designed to help identify patients likely to have problems in completing DOTS therapy. A review of educational materials available in India and other South and South East Asian countries in 1999 revealed that existing educational materials were technically informative, but top down in that they did not address common questions TB patients and their families had about the disease or its treatment. Many misconceptions about TB had been reported in the literature as well as social and practical problems likely to undermine adherence to DOTS. Existing educational and patient screening materials did not address these issues nor anticipate how to answer the most basic questions patients were likely to ask DOTS

40

providers or health practitioners. Moreover, the clinical and community experience of the researchers suggested that there was much uncertainty on the part of health care providers about how to address several issues related to TB undermining their confidence in addressing the doubts and queries of patients. The advice they offered about DOTS therapy was technically sound, but their training on how to address the queries of patients was deficient.

In the year 2001, this team of researchers associated with the International Network of Clinical Epidemiology (INCLEN) received funding to carry out a small multi site study in four states of India (Kerala, Maharastra, Tamil Nadu, and Uttar Pradesh) to identify the most common questions and misconceptions that TB patients and DOTS providers had about TB and to identify a short list of issues to include in a brief patient screening protocol to assist health staff anticipate likely problems with DOTS adherence. They mined the existing literature and an unpublished data set already collected by the medical anthropologist member of the group for issues identified as relevant for a TB education package. Instruments for open ended interviews were developed and individual interviews and focus groups were carried out in each field site. Table one summarizes the sample of informants interviewed. Details of the research findings can be found in an article soon to be published that looks at both regional differences and similarities in local perceptions of TB and its treatment. The interviews conducted were also designed to capture : a) common questions patients had about TB and TB medication. b) logistical problems patients and DOTS providers had related to following the DOTS protocol, and c) a brief history of the treatment they received before seeking DOTS medication from a government clinic, and the way they were actually taking treatment given life contingencies.

Following two years of data collection and analysis, the group complied a list of issues that they felt needed to be addressed in an educational booklet meant to further the goals of the DOTS program and enhance DOTS adherence. The data collected and the list of issues identified to go into the booklet, and the questions for the patient screener were shared with members of State TB boards and WHO TB coordinators. Their feedback was requested and received.

For the next year, the team focused on developing appropriate responses to the questions identified. This proved challenging and was a multi step process. First a workshop was held where the researchers and a group of experienced health care providers routinely working with TB patients generated candidate responses. Groups from each state worked on how to translate these candidate responses into regional languages and local vernacular understandable to target populations in an area where they wanted to test the Question : Answer TB education booklet. Following the generation of candidate responses each team then carried out a series of key informant interviews and focus groups to test which candidate responses were best understood and most appreciated by TB patients and their families. During this iterative "try and see" process many messages that appeared viable to the research team and health care providers were rejected and new responses were generated and pre-tested.

The responses to the questions presented in this booklet have been pre- tested on samples of local populations in the project sites of the four states. The booklet is now at a stage where it is ready to be piloted by groups working with TB patients and evaluated for effectiveness. We offer suggestions about how groups wanting to test the utility of the booklet might adapt the booklet and screening protocol for local use. The booklet as presented in English, will need to be carefully translated as a first important step toward making it culturally relevant to the population in which it is going to be used. Translation here means not just direct translation, but "conceptual translation" as part of a process of translational research. We anticipate that changes will need to be made in not only the wording, but the ways in which points are conveyed. What we have provided to you in the Question: Answer booklet presented here are a list of responses that appeared to work across project sites in four different areas in India.

A few words about whom this booklet is intended for and how we see it being used is in order. First, we did not develop this booklet to be used with special populations such as TB patients who are HIV positive, young children, or those having MDRTB. The information contained in this booklet will need to be adapted for these populations following additional formative research that addresses their needs and likely questions.

Second, we have no illusions that TB adherence will be improved by simply providing better and more accessible information to patients about TB. This is naïve and certainly not the intent of this research team. The team also does not want to give the reader the impression that we think that most non-adherence to DOTS is related to "cultural barriers", a viewpoint we find misguided and simplistic. We see the use of the education booklet in conjunction with the screener as enhancing the social support and logistical support dimension of DOTS. The booklet needs to be seen as part of a **support and counseling package**. We would emphasize that the booklet's effectiveness should be assessed not just in terms of providing information, but in terms of:

- Enhancing DOTS providers' and health staffs' confidence and ability to talk to TB patients in meaningful ways that address their doubts.
- Putting the patient and family at ease by reducing fears and helping them better cope with the illness (the subjective dimension of sickness) as well as manage the disease and its treatment.
- Providing information to the community about TB and its cure which may serve to help reduce stigma and popularize treatment with DOTS.

We emphasize this because the way in which the booklet is used is as important as its content. We encourage you to think through the process of how you can best use the booklet to advance the objectives noted above. We provide an example of one way the booklet might be used, but alternative ways of using the booklet should be considered in context.

Let us say a final word about the importance of the screener. We see the screener being used as both an assessment tool as well as part of an interview process that tailors DOTS to the special needs of the patient. As an assessment tool, the screener identifies likely challenges to successful completion of DOTS treatment. These challenges need to be identified by health staff and DOTS providers and addressed early. The screener can also be used as a means of letting the patient and family know that DOTS providers are sensitive to their life contingencies and habits that may make adhering to DOTS difficult. Use of patient centered interviews for TB has been shown to improve DOTS outcomes. We see more effective TB control as requiring the following four areas of effort:

- More effective education leading to better understanding of TB as well as enhanced counseling and social support.
- Better screening of patients such that more challenging cases will be provided more appropriate support.
- More flexible and patient centered health system response to patient needs based on real world contingencies.
- Acknowledgment and ongoing critical assessment of structural problems in the program for provision of

care to TB patients leading to creative problem solving attentive to local context.

We hope that groups outside India will also find these materials useful and a base upon which to build their own culturally sensitive tuberculosis education packages and context sensitive patient screeners.

Research Team

Technical Advisor

Dr. Mark Nichter, Medical Anthropologist Health Social Science Advisor, INCLEN

PRINCIPAL INVESTIGATOR

Chennai

Dr. Manjula Datta, Pediatrician

Project Staffs:

Mrs. S. Kalpana, Technician

Ms. Shanthi Sankaralingam, Social Scientist Ms. Bhuvaneswari Rajaraman, Asst. Statistician

CO-INVESTIGATORS

Trivandrum

Dr. Sudheendra Ghosh, Pulmonologist

Dr. Rajan, Lecturer in TB and Chest clinic, Trivandrum

Nagpur

Dr. Archana Patel, Pediatrician

Ms. Smitha Pupulwar, Social worker

Vellore

Dr. K.R. John,Community Medicine Jerrymose Joseph, Reasearch Trainee

Mr. Muruga Periyar, Asst. Reasearch Officer

Lucknow

Dr. Rajendra Prasad, Pulmonologist Dr. Ramesh C Ahuja, Internal medicine Mr. Ajay Srivatsava, Social Worker

TECHNICAL ASSISTANCE

Mr. Ravi Datta

Mr. N. Valladurai, Research Scholar

TABLE ONE: SAMPLE

The following interviews were conducted during stage one formative research when baseline data was collected. Each group conducted an equal number of interviews in each informant category.

Category of Patient/Provider	Total Number Interviewed	Total Male	Total Female	Total Literate	Total Illit
Less than 2 weeks in DOTS program	22	12	10	18	4
4-6 weeks	24	12	12	20	4
3-5 months	24	12	12	18	6
Early defaulters	14	9	5	9	5
Late defaulters	12	8	4	10	2
Doctors	24	12	12	24	-
Multi purpose health workers	40	20	20	40	-
Lay DOTS providers	40	20	20	40	-
Total	200	105	95	179	21

Fifteen focus groups with patients, family members and DOTS providers were also conducted as well as community and clinic based participant observation.



EDUCATIONAL BOOKLET

Tuberculosis (TB) is curable: Learn more about TB



Produced by: Clinical Epidemiology Unit, The Tamil Nadu Dr. MGR Medical University on behalf of The INCLEN TB Working Group





• Who gets TB?

- Anybody can get TB.
- Those who are weak, have too little to eat, those with weak immunity have a higher chance of getting TB.
- Many people think those who get TB have bad habits or poor hygiene. This is not true. Many people who get TB have good habits and have good personal hygiene.
- What causes TB?
 - TB is caused by a germ and it spreads through the air when an infected person coughs, sneezes, and talks loudly.



Many people think TB is caused by other things. Most of this is not true.

NONE OF THESE CAUSE TB

- Contaminated water
- Sharing food with the sick person
- Stepping on urine or sputum
- Contact with blood
- Depression, mental worries
- Sexual relations
- Cold food and cold climate
- Is TB hereditary?
 - TB is not hereditary.
 - It does not spread through the blood
- Is TB just a disease of adults or can children get TB?
 - All men, women and children can get TB
 - Even young children **can** develop TB.
- Can TB be cured?
 - YES. Medicines are available to cure TB.
 - If the medicines are taken as prescribed the disease will be cured

 The medicines for TB are given in blister packs. All the medicines you will need for a complete cure are in this blister pack.



- Where can I get these medicines and how much does it cost?
 - TB medicines are available in all government hospitals, PHCs, and TB clinics. These medicines can be collected from these places or even the hospital can arrange for some known people, relatives, or friends to provide these medicines to the patient.
 - These medicines are provided free of cost by the government. There are no hidden costs.
 - A complete supply of medicines is reserved for each patient with their name on the box the day they begin treatment.



- Is government medicine for TB as good as the medicine available in private shops?
 - The medicines available in private shops are in no way better than the ones provided by the government. The government provides the very best medicines available to cure this disease.
 - These medicines provided by the government are costly. A full six month course of medicines contained in the blister pack costs the government RS 700.

|44|

- The government provides these medicines free to its citizens. The government is committed to controlling TB in the community so that it does not spread.
- It is the duty of the government to provide effective medicines to its citizens, and the duty of all patients to take these medicines as recommended for a complete cure of tuberculosis.
- For how long does a tuberculosis patient have to take medicine?
 - All people with TB have to take minimum of 6 months medication to be cured. Taking medication for less time leads to relapse.
 - For most TB patients, six months of medication is enough for a complete cure.
- Why do medicines have to be taken for such a long time?
 - TB is like a tree with deep roots. It has to be uprooted completely; otherwise it grows back very quickly with greater strength.
 - It takes six months to kill all of the TB germs in the body, to remove all the phlegm from the lungs, for the body to become strong, and for the appetite to return to normal.
 - Taking medicines for less than 6 months will result in the TB coming back once again and the germs to become stronger making it very difficult to cure the disease.
- Do all TB patients need to take the same amount of medicine?
 - Although the symptoms of the disease vary from person to person, the germs causing TB are the same.
 - To kill the germs all the tablets in the blister pack must be taken together for a minimum of 6 months by ALL people having TB
- Why do we have to take so many tablets at one time?
 - More than one tablet is needed to kill the germ.
 - Each of the medicines in the blister pack serves different purposes.
 - The medicines are meant to be taken together and work together to cure the disease. So do not take these medicines in split doses.
 - The medicines work together to kill the germ, increase appetite and weight, decrease phlegm and cough, and prevent the disease spreading from one person to other.



- What are the important medicines in the blister pack?
 - All medicines are important whether it is capsule or tablet, small or big, red or white.
- Does a TB patient also need injections or tonics?
 - Everything needed to cure a TB patient is in the blister pack.
 - Taking injections will not cure the disease faster.
 - Tonics are not required for a cure if medicines in blister pack are taken properly
 - Injections are needed only for patients who have not taken TB medicines properly for six months. For these people, the germs have become stronger and are harder to kill.
- When should a tuberculosis patient take the medicines?
 - The best time to take the medicines is in the morning.
 - The Medicine can be taken on empty stomach or half an hour after taking morning food.
 - If you are unable to take the medicine in the morning or have forgotten to do so, the medicines can be taken in the night, but half an hour after food.
 - It is best to take the medicine at the same time everyday.
- What if I experience side effects like burning sensation of the stomach or if my urine turns reddish?
 - Don't worry, this is common when one first starts taking medicines for TB
 - It takes some time for the body to get adjusted to the medicines.
 - These symptoms do not mean that these medicines do not suit (put in a local term as an example-English does not do the idea justice) the body.
 - After four to six weeks the symptoms will decrease and appetite will increase.

- Do not be alarmed at the color of the urine. It is nothing to do with the heat in the body. It is a harmless effect of the drugs.
- What if I find these symptoms intolerable?
 - If you can not tolerate taking the medicine in the morning, try taking it in the evening half an hour after meals
 - If the symptoms persist, consult your doctor immediately
 - Do not wait some days without taking medicine before seeking a consultation.
- What if rashes occur after I have taken the medicine?
 - If the rash is similar to the one in measles, see the doctor immediately
- Is there any time anyone should stop taking medication for TB?
 - What if somebody suffers from diarrhea, fever, headache? Do they need to stop medication?
 - Don't stop taking TB medications even if illness occurs.
 - If the illness is serious consult a doctor. If the doctor is not your TB doctor, inform them that you are taking TB medication and show him/her the blister pack.
 - ·
- Do TB medicines react with any other medications?
 - No, TB medications do not react with any other medications. They may be taken with other medications. There is no harm in doing so.
- What if I miss a day of medicine?
 - If you are unable to take medicine on the correct day for any reason then it is okay to take the medicine on the following day.
 - You should never take a double dose on the same day. There should be at least one day gap.
- What if I am feeling healthy, appetite is good, and I can work? Can I stop medication?
 - Even though you may feel healthy, do not stop taking medicines in the blister pack till you complete all six months of medication. TB is like a tree with deep roots, and it has to be uprooted completely.
 - Don't gamble with your life at this time, just because you are feeling better. Stopping medication at this time is very dangerous! If you stop the medication, the TB will surely come back.

- Family members should encourage the patient to complete the medication for all 6 months.



- Will a TB patient be able to work hard again?
 - Yes, if they take the medicine regularly
 - and eat enough food they can work hard again.
 - After a few weeks of medication the patients' hunger increases and weakness reduces. They will regain their health.



- Sometimes a TB patient has to go outside their residence for work or to visit or help relatives. How would they get medication?
 - There is a full box of medicine reserved for each patient and kept by the DOTS provider with the patients name on the box
 - If the patient goes away from home for a short time, one or two weeks, they should contact the provider so that medicines may be provided to them while they are away from their home.
 - If the patient goes away from home for more than one or two weeks, they should contact the DOTS provider and provision will be made for them to continue treatment
 - Comment: At present the DOTS guidelines for transfer of the medicine box are very vague. The previous system of providing the patent with a referral slip that specified the category of case and the number of doses that he had already taken, is not being followed. This operational problem has

to be addressed for both patients leaving their residence for short, medium and long times.

- Is it alright for a woman to become pregnant while taking tuberculosis medicine?
 - While a woman is taking medications for tuberculosis it is best if she avoids becoming pregnant
- If a pregnant woman develops tuberculosis can she take tuberculosis medications during her pregnancy?
 - If a tuberculosis patient becomes pregnant, she should continue taking all the medicines in the blister pack
 - Inform the doctor that you are pregnant.
 - The TB medicine in the blister pack does not cause abortion.
 - If a mother takes the medicine regularly, both mother and the baby will be healthy.



- What if a woman is breast-feeding will taking the medicines harm the baby?
 - Do not stop breast feeding while taking TB medicines
 - A woman can breast feed her baby while taking TB medicines.
 - The medicine in the blister pack does not harm the baby.
 - Taking TB medicine will not reduce breast milk. Breast milk will in fact increase as a woman's health improves.



- Does taking medication prevent the spread of TB to other family members?
 - After starting medication, the patient becomes less and less contagious.
 - After 2 weeks, contagion is less and after 2 months the doctor checks the patient's sputum to see if the patient is still contagious. If they are still contagious, the doctor will tell the patient and medicine will be adjusted.
 - After two months of taking medication, there is little chance of the disease spreading as long as the patient continues to take the medicine for six months.
- How do I prevent others from getting TB?
 - Remember TB spreads through air, so follow a few simple rules to prevent others from getting TB.
 - Cover your mouth with a cloth while coughing or sneezing
 - Be careful where you spit because TB spreads through the air.
 - Remember. TB does not spread because of sharing food, bedding or clothes. It only spreads through the air.
 - Anyone having TB and not taking medication can infect other people..



- If a TB patient stops taking medication before six months, can they infect others with the disease even if they are feeling well?
 - Yes. If a patient stops taking medication it is possible for them to infect others with the disease.
 - Medicine in the blister pack prevents the patient from infecting others with TB.
 - Medicine must be taken for all 6 months. The government goes to great expense to provide free medicines to cure the patient as well as protect others from getting the disease.

- It is the duty of the tuberculosis patient to complete the full course of medication
- When should the patient visit the doctor during the treatment?
 - The patient should visit the doctor at the end of 2nd,
 4th and 6th month of the treatment.
 - These visits allow the doctor to check and see if the medication is effective by doing a sputum test.
- Why are sputum examinations important?
 - Only by doing sputum test can the doctor decide whether any change in the medication is required.
- Does the tuberculosis patient need to be on a special diet ?
 - The TB patient should eat whatever food is available that suits their body.
 - Special food is not necessary.
 - One can take medication with whatever food is available.
 - If available, foods like egg and milk that give strength and are easily digestible should be taken
 - After 4 6 weeks of medication the patient's appetite will increase and they feel very hungry, this is a very good sign.



- Can a TB patient smoke?
 - It is very unhealthy for a TB patient to smoke.
 - TB affects the lungs and produces phlegm.
 - Tobacco corrodes the lungs and increases cough and phlegm making it difficult for the lungs to heal.
 - If the tuberculosis patient cannot give up smoking, reduce the habit as much as possible.
 - Even if the tuberculosis patient smokes, they should continue taking medication.





- Is drinking alcohol harmful for the tuberculosis patient?
 - While ill with tuberculosis, it is not advisable to drink.
 - If you cannot stop drinking, reduce as much as possible.





- If I drink alcohol, can I still take medication?
 - Even if you have consumed alcohol, continue taking TB medications regularly.
 - Take the medication as scheduled even if you have consumed alcohol that day – just leave a gap of a few hours.
- Is it harmful for the tuberculosis patient to have sexual relations?
 - While weakness is there, sexual relations should be avoided.
 - There is no harm in having sexual relations when the patient is feeling stronger.

|48|



- Is it harmful for the partner to have sexual relations with a tuberculosis patient?
 - It is advisable for the TB patient not to kiss their partner or children until they have taken medications for at least two months
 - tuberculosis does not spread through sexual relations..
- Is a TB patient cured for life if they take medicines properly?
 - There is now a very effective medicine that can cure TB provided free by the government. There is no reason to suffer with tuberculosis.
 - 98 out of 100 TB patients who take the full 6 months of medication in the blister pack will be completely cured and be able to return to work.
 - The government has provided you the best medicines to become well. It is now up to you to take these medicines properly.



Take the medicines and get a cure. It is your duty. Tell others how to get cured!

Suggestions for pre-testing , and evaluating the effectiveness of the community based TB education package

THE 10 STEPS

- Read over the education booklet and translate the questions and answers into the regional language. The language used should be appropriate for the local population. Vernacular terms used should be easily understandable to this population. Translate the best you can and adjust ideas if and when necessary.
- 2. After a first translation has been done and run by your staff, the material **must** be pre- tested. We advise that this be done in two stages.
 - a. Key informant interviews: sample 10
 - i. Read the questions to five patients who are illiterate and five patients who are literate. Read them the questions one by one and ask how they understand the question – have them repeat to you what they have been told in their own words. Next, read them the answers to the question and check to see that they understand the answers and if the language and ideas contained in the answer are easy to follow. Ask if they have any doubt about what has been said. Also ask if there is a better way of conveying the meaning of the answer in the local language.
 - ii. Have five Dots providers who are literate read the questions and answers and ask them what each question and answer means and if they have understood the questions and responses. Ask if the language is clear. Ask if they have any doubts about what is contained in the booklet.
 - b. Focus group: two focus groups of health center staff
 - i. Assemble a group of 5 staff members and repeat the procedure noted above. Have one person read out loud and others discuss each question and answer.
- **3.** Make adjustments to the language in the booklet according to information collected from pre-test experiences.
- **4.** Modify images in the booklet to match the local culture.
- 5. Show a mock up of the booklet to the following people for their feedback
 - a. State TB officials

b. Other TB personnel such as local DOTS officer attached to WHO

You now have a booklet ready to be piloted and evaluated

- 6. Select pilot test area for the booklet
- 7. Consider alternative procedures for how to use the booklet and when to use it. For example, the booklet might be introduced in the clinic at the same time instructions are being given on how to take the medication and screening questions are asked.
 - a. The provider might flag a few messages that seen particularly relevant for discussion with a particular patient and then ask the patient and accompanying family members if they have any questions they would like to ask.
 - i. When they answer the questions posed, they may refer to the booklet.
 - b. They may encourage the patient to consult them at the next visit to the clinic (during the intensive phase) if they have any doubts about TB and its treatment. Or they may suggest that they talk to their DOTS provider in their neighborhood.
 - i. Doubts may be addressed and the booklet referred to when relevant. This may increase the credibility of the DOTS provider.
- 9. Have a one day workshop in pilot test area for health personnel on how to use the booklet. Discuss and role play procedures on how to use the booklet as a tool to enhance the counseling of patients and their families.
- **10.** Decide on a research design for testing the effectiveness of counseling using the booklet.
 - a. Decide on sample frame and size of patients and providers for the intervention and control arms of the study, if a case control design is adopted.
 - b. Conduct pre-post education test on selected questions included in educational package in both case and control groups.
 - i. Pre test might be given to patients in the intervention group before the education session on a few key points, and post test may be given on the same points the next time they are seen.
 - ii. The increase in knowledge in both intervention and control groups may be compared.
 - iii. Questions for such assessments should be appropriate to gender of patient
 - c. Beyond evaluating tests of improved knowledge and adherence as an outcome measures, consider

measuring patient and provider satisfaction with the booklet

- i. Did use of the booklet improve communication and interaction between patient and DOTS provider:
- Are you better able to answer the questions your patients ask you?
- Did use of booklet improve your confidence to offer advise?
- Has the booklet cleared any doubts you have had about tuberculosis or its treatment?
- Has using the booklet improved communication between you and the patient or their family members?
- ii. Did information reduce fear and stress of patient and family members –

What information in the booklet was most helpful?

- **iii.** Did the doctor find booklet useful in interactions with patients?
- **11.** Collect information on further doubts and questions not presently in the booklet, that might be included in a revised booklet in the future.
 - a. DOTS providers should be encouraged to keep a list of questions not contained in the booklet as well as any doubts people have voiced about what is written in the booklet.
 - b. These questions should be collected

If you use the booklet or screener, please acknowledge INCLEN as the source of this information. We would be most interested in hearing about experiences and welcome comments regarding the booklet and how we could improve it.

For further information, help or advice on how to conduct an effectiveness trial using an adaptation of this booklet, please feel free to contact INDIACLEN@ touchtelindia.net

Methodology

SCREENING QUESTIONS FOR IDENTIFYING TB PATIENTS

Providers should ask TB patients the following set of questions in order to assess problems likely to interfere with adherence to DOTS.

Work Migration

- How often do you leave your place of residence for work
- How long do you leave for at a time
- When is this likely to happen

|50|

 Do you have to leave at short notice will you know before hand

Note: You are trying to capture information about long term migratory labor as well as shorter term work related travel

Domestic constraints for women

- Are you able to leave the household to attend a clinic
- Can you come to the clinic by yourself or do you need someone to accompany you –is this a problem for you
- How many children do you have and how able are you to leave the home to fetch medicine?

SOCIAL SUPPORT

- Do you have someone to accompany you to the clinic or someone who can help you get your medicines if you are unable to do so yourself
- Do you feel neglected by your family Stigma
- Are you worried about other people coming to know you have tuberculosis

PERSONAL HABITS

- Smoking or tobacco use
 - Do you smoke or use tobacco in any form?
 - What do you use and how often
 - Are you able to leave the smoking/tobacco habit completely or is this too difficult for you to do?
- Drinking (check with family members)
 - In a week on how many days do you drink
 - In a typical day that you drink, how many drinks do you take
 - Ask family members whether they will be able to assure that the patient takes medicines regularly. How much control do they have over the patients because of his drinking habits.

Preferred DOTS supporter

• Please identify one person who can best help you during their illness

They should be someone who can attend an education session, and encourage and remind you about medicine taking.

 Who would they like this person to be: a family member, friend, neighbor, anganwadi worker, or health worker?

References

1. Amir Khan, John Walley, James Newell, and Naghma Imdad. Tuberculosis in Pakistan: socio-cultural

constraints and opportunities in treatment Social Science & Medicine 2000 Jan: 50 (2): 247 – 254

- Banerjee A, Harries AD, Mphasa N et al. Evaluation of a unified treatment regimen for all new cases of tuberculosis using guardian-based supervision. International Journal of Tuberculosis and Lung Disease. 2000;4:333-339.
- Banerjee D, Anderson S. A sociological study of awareness of symptoms among person with pulmonary tuberculosis bull WHO, 1963; 29: 665.
- Banerjee D. Behaviour of TB patients towards a treatment organization offering limited supervision. Ind J Tuberc, 1967; 14 (3): 156.
- Banerji D. A Social Science Approach to Strengthening India's National Tuberculosis Programme. Indian Journal of Tuberculosis. 1993;40:61-82.
- Banerji D; Debabar Banerji A social science approach to strengthening India's national tuberculosis programme. Indian Journal of Tuberculosis. 1993, 40(2): 61-82
- Barnhoorn F, Adriaanse H. In search of factors responsible for noncompliance among tuberculosis patients in Wardha District, India. Social Science and Medicine. 1992;34 (3):291-306
- 8. Barnhoorn, F. & Van der Geest, S. . Letter to the editor. Social Science & Medicine (1997)45(10): 1597–1599.
- Begum V, Colombani de P, Das Gupta S, Hussain H et al., Tuberculosis and patient gender in Bangladesh: sex differences in diagnosis and treatment outcome, International Journal of Tubercle and Lung Disease, 2001, 5(7): 604-610
- 10. Betty Susan Ninan, Determinants of treatment noncompliance among pulmonary TB patients in RNTCP-DOTS, Trivandrum, India, Dissertation submitted for the award of MPH degree (Unpublished), Achutha Menon Centre for Health Science Studies, Sree Chitra Thirunal Institute of Medical Sciences and Technology, Trivandrum, India, 2001
- Dinesh M Nair, Annie George, and K T Chacko. Tuberculosis in Bombay: New insights from poor urban patients, Health Policy and Planning, 1997; 12(1): 77-85
- 12. Fair E, Islam A.M & Chowdhury A.S. Tuberculosis and Gender: Treatment Seeking Behaviour and Social Beliefs of Women with Tuberculosis in Rural Bangladesh, Working paper number 1, BRAC, Bangladesh, 1997
- **13.** Fox W; Wallace Fox Tuberculosis in India, past, present and future. Ind J of TB. 1990; 37(4): 175-213
- Fox, W. Complains of patients and physicians: Experiences and lessons from tuberculosis I. Br Med J, 1983; 287: 1

- **15.** Fox, W. Complains of patients and physicians: Experiences and lessons from tuberculosis II Br Med J, 1983; 287: 101.
- 16. Fox, W. Short course chemotherapy for pulmonary tuberculosis and some problems of its programme application with particular reference to India; Lung India; 1984, 2, 161
- 17. Gaude G, Bagga AS, Pinto MJW, Lawande D & Naik A Compliance in alcoholic pulmonary tubercular patients - Role of motivation. LUNG INDIA 1994, 12, 111-116.
- 18. Geetakrishnan K; Pappu KP; Roychowdhury K. A study on knowledge and attitude towards tuberculosis in a rural area of West Bengal. Indian Journal of Tuberculosis. .(1988) 35(2): 83-9
- 19. Gehtakrishnan K, Pappu KP, Roychowdeury K. A Study on Knowledge and Attitude towards Tuberculosis in a Rural Area of West Bengal. Indian Journal of Tuberculosis. 1988;35:83-90.
- 20. Gill Walt, Jassica Ogden, Louisiana Lush The politics of 'branding' in policy transfer: the case of DOTS for tuberculosis control. Soc Science and Medicine 2003; 57: 179 – 188.
- Grange JM. DOTS and beyond: towards a holistic approach to the conquest of tuberculosis. Int J Tuberc Lung Dis (1997). 1 (4), 293-296.
- 22. Jagota P; Balasangameshwara VH; Jayalakshmi MJ; Islam MM; Mehter M Islam An alternative method of providing supervised short course chemotherapy in district tuberculosis programme. Indian Journal of Tuberculosis. 1997 Apr; 44(2): 73-7
- Jaiswal .A, V. Singh, J.A.Ogden, J.D.H. Porter, P.P.Sharma, R. sarin, V.K.Arora and R.C. Jain Adherence to tuberculosis treatment: lessons form the urban setting of Delhi, India. Tropical Medicine and International Health, 2003; 8 (7) 625 – 633.
- 24. John DH Porter, Krina Kielmann, TB Control in India: The need for Research in policy and decision making Health Administrator Vol: XV, number : 1-2 pg. 143- 148.
- 25. Joseph Marina Rajan, Orath Sunny P, Eapen C K . Integrating Private Health Care in National Tuberculosis Program: Experience from Ernakulam- Kerala, Indian Journal of Tuberculosis, 2001; 48: 17-19
- 26. Juvekar S K, Morankar S N, Dalal D B, Rangan S G, et al., Social and operational determinants of patient behaviour in lung tuberculosis, Indian Journal of Tuberculosis, 1995; 42: 87-94
- 27. Juvekar SK; Morankar SN; Dalal DB; Rangan SG; Khanvilkar SS; Vadair AS; Uplekar MW Deshpande A Social and operational determinants of patient

behaviour in lung tuberculosis. Indian Journal of Tuberculosis. (1995) 42(2): 87-94

- 28. Juvekar, S.K., Morankar, S.N., Dalal, D.B., et al. . Social and operational determinants of patient behaviour in lung tuberculosis. Indian Journal of Tuberculosis, (1995)42: 87–94
- **29**. Kant, S. Tuberculosis in India: question of compliance. (1993)Lancet 341: 1662.
- Kironde S. Meintjies M. Tuberculosis treatment delivery in high burden settings: does patient choice of supervision matter? Intl J of Tuberc and Lung Dis, 2002, 6(7), 599-608(10)
- 31. Krishnaswami KV, Abdhul Rahim, Parthasarathy R. A sociological study of awareness of symptoms and action taken by the patients to seek relif. Ind J tuberc, 1977; 24 (1):15
- **32.** Liefooghe, R, N. Michiels, S. Habib, M. B. Moran and A. De Muynck. Perception and social consequences of tuberculosis: A focus group study of tuberculosis patients in Sialkot, Pakistan Science & Medicine 1995 Jan: 41: 1685-1692
- 33. Liefooghe R, Suetens C, Meulemans H, Moran MB & De Muynck A. A randomised trial of impact of counseling on treatment adherence of tuberculosis patient in Sialkot, Pakistan. Int J Tuberc Lung Dis 1999; 3: 1073–1080.
- 34. Macq J. C. M. Theobald S. Dick J. Dembele M. An exploration of the concept of directly observed treatment (DOT) for tuberculosis patients: from a uniform to a customised approach. Intl J of Tuberc and Lung Dis, 2003, 7(2), 103-109(7)
- **35.** Manoharam E; John KR; Joseph A; Jacob KS. Psychiatric morbidity patients perspectives of illness and factors associated with poor medication compliance among the tuberculosis in Vellore, South India. Indian Journal of Tuberculosis. 2001 Apr; 48(2): 77-80
- 36. Morankar Sudhakar, Sociocultural Aspects of TB Among Women- Implications for Delivery of Services, Foundation for Research in Community Health, Pune, India, 2000
- Mudur, G. Private doctors in India prescribe wrong tuberculosis drugs. BMJ (1998) 317: 904.
- 38. Murthy K J R, Frieden T R, Yazdani A, Hreshikesh P, Public Private Partnership in Tuberculosis Control: Experience in Hyderabad, India, International Journal of Tuberculosis and Lung Disease, 2001; 5(4): 354-359
- 39. Nagpaul DR Sociological aspect of tuberculosis for programme assessment. Ind J of TB .1987 Apr; 34(2): 101-3
- 40. Narayan R, Prabhakar S, Thomas S et al. A Sociological Study of Awareness of Symptoms and Action Taking

of Persons With Pulmonary Tuberculosis (A Resurvey). Indian Journal of Tuberculosis. 1979;26(3):136-146.

- **41.** Narayan R; Thomas S; Srikantaramu N; Srikantan K; Radha Narayan; Susy Thomas Illness perception and medical relief in rural communities. Ind J of TB. 1982 Apr; 29(2): 98-103
- 42. Narayan, R., Prabhakar, S., Thomas, S., Kumari, S.P., Suresh, T. & Srikantaramu, N. A sociological study of awareness of symptoms and action taking of persons with pulmonary tuberculosis (A resurvey). Indian Journal of Tuberculosis (1979) 26(3): 136–146.
- **43**. Ngodup, Patient-provider interaction in the community based case management of tuberculosis in the urban district of Bangalore city, south India. A thesis submitted by Dr Ngodup, Postgraduate student, as a part of his PG course on "Community health and health management in developing countries" of the University of Heidelberg, Germany (1998)
- Nguyen Hoang Long, Eva Johansson, Vinod K. Diwan and Anna Winkvist. Different tuberculosis in men and women: beliefs from focus groups in Vietnam Science & Medicine 1999 Sep: 49: 815-822
- **45.** Nichter, Mark Illness semantics and International Health: The weak lungs/TB complex in the Phillipines; Soc.Sci Med,1994, 38 (5)649 663
- **46**. Nichter, Mark TB in India: Local perceptions that affect tuberculosis management; Society for applied anthropology, Sante Fe, New Mexico. 1990
- **47**. Nichter, Mark , TB in India Have Perceptions of the disease Changed in the last 20 years.? Society for applied anthropology, Atlanta, Georgia.. 2002
- 48. Ogden, J., Rangan, S., Uplekar, M., Porter, J., Brugha, R., Zwi, A., & Nyheim, D. Shifting the paradigm in tuberculosis control: illustrations from India. International Journal of Tuberculosis & Lung Disease (1999)3(10): 855–861.
- 49. Pathania V, Almeida & Kochi A, TB patients and private for profit health care providers in India. WHO/TB/97. 233.
- Pathania, V, Almeida, J. & Kochi, A. . TB patients and private for-profit health care providers in India. WHO, Global TB Programme. (1997)
- Pathania, V., Almeida, J. & Kochi, A. . The behaviour and interaction of TB patients and private for-profit health care providers in India: A review. WHO Executive Summary Online http://www.who.ch/programmes/ gtb/reviews/execsum.htm. (1997)
- 52 . Paul Farmer. Social scientists and the new tuberculosis Science & Medicine 1997 Feb: 44: 347-358

- Fope D.S. Chaisson R.E. TB treatment: as simple as DOT? [Counterpoint], Intl J of Tuberc and Lung Dis, 2003, 7(7), 611-615(5).
- 54. Purohit SD; Gupta ML; Madan A; Gupta PR; Mathur BB; Sharma TN; Arun Madan Awareness about tuberculosis among general population : a pilot study. Indian Journal of Tuberculosis. (1988)35(4): 183-7
- 55. Rajeswari, R., Balasubramanian, R., Muniyandi, M., Geetharamani, S., Thresa, X., & Venkatesan, P. Socioeconomic impact of tuberculosis on patients and family in India. International Journal of Tuberculosis & Lung Disease (1999). 3(10): 869–877.
- 56. Ravindran, TK.S., Alex, S.C., & Ninan, B.S. .Gender and poverty issues in Tuberculosis: a summary and overview of selected studies from the WHO South East Asia Region. Trivandrum, Kerala, India: Achutha Menon Centre for Health Science Studies. (2002)
- 57. Reed Joanna B, McCausland Rachel, Elwood J Mark. Default in the outpatient treatment of tuberculosis in two hospitals in Northern India, Journal of Epidemiology and Community Health, 1990; 44: 20-23
- 58. Reed, J.B., McCausland, R. & Elwood, J.M. Default in the outpatient treatment of tuberculosis in two hospitals in Northern India. Journal of Epidemiology and Community Health (1990) 44: 20–23.
- 59. Seetha MA, Patients' compliance towards different drug regimens under District Tuberculosis Programme. NTI NL 1988, 24, 46-51.
- **60**. Sexana P, Mathur G P, Singh MM. Treatment taken before reporting at a tuberculosis clinic. Indian Journal of Tuberculosis. (1987) 34(2): 104-7
- Singh, V., A. Jaiswal, J.A.Ogden, J.D.H. Porter, P.P.Sharma, R. sarin, V.K.Arora and R.C. Jain TB Control, poverty, and vulnerability in Delhi, India. Tropical Medicine and International Health, 2002; 7 (8) 693 – 700.
- 62. Suhadev, Ganapathy.S et al A retrospective study of non complaint patients in controlled clinical trial of short course chemotherapy Indian Journal of Tuberculosis 1995; 42: 221 223.
- 63. Syabbalo, N. Tuberculosis infection in a rural population of South India: 23-year trend. Respiratory Medicine (1987) 86: 173.
- **64**. Uplekar M, Rangan S, The search for solutions, social and operational constraints in TB control in Maharashtra, India, FRCH, Pune.
- **65**. Uplekar M; Rangan S; Mukund Uplekar; Sheela Rangan Alternative approaches to improve treatment adherence in tuberculosis control programme. Indian Journal of Tuberculosis. 1995 Apr; 42(2): 67-74

- 66. Uplekar MW, Rangan S. Private doctors and tuberculosis control in India. Tuberc Lung Dis1993;74:332-337.
- **67**. Uplekar MW, Shepard DS.Treatment of tuberculosis by private general practitioners in India. Tubercle 1991;72:284-290.
- **68.** Uplekar, M., Pathania, V., & Raviglione, M.. Private practitioners and Public health: weak links in tuberculosis control. The Lancet (2001)358: 912–916.
- **69**. Uplekar, M.W., & Rangan, S.. Tackling TB: The Search for Solutions. Bombay: FRCH. (1996)
- 70. Uplekar, M.W., & Shepard, D.S.. Treatment of tuberculosis by private general practitioners in India. Tubercle, (1991)72(4): 284–290.
- 71. Uplekar, M.W., Rangan, S., Weiss, M., Ogden, J.A., Borgdorff, M.W., & Hudelson, P. . Attention to gender issues in tuberculosis control. Int J Tuberc Lung Dis (2001)5(3): 220–224.
- Van der Veen, K.W. Private practitioners and the national tuberculosis programme in India. Journal of Research and Education in Indian Medicine (1987) 6(3–4): 59–66.

- 73. Vasan, R.S. Selected Summaries. Community health workers and tuberculosis control. The National Medical Journal of India (1997)10(6): 283–284.
- 74. Vijay S; Balasangameshwara VH; Srikantaramu N Treatment dynamics and profile of tuberculosis patients under the district tuberculosis programme (DTP): a prospective cohort study. Indian Journal of Tuberculosis. (1999) 46(4): 239-49
- 75. Vijay Sophia, Balasangameshwara V H, Srikantaramu N. Treatment Dynamics and Profile of Tuberculosis Patients Under the District Tuberculosis Programme (DTP)- A Prospective Cohort Study, Indian Journal of Tuberculosis, 1999; 46: 239-249
- 76. Vijaya Raman A, Chadha V K, Shashidara A N, Jayagopal M V et al., A Study of Knowledge, attitude and practices of patients currently under treatment for tuberculosis and defaulters in a backward area of South India, NTI Bulletin 1997, 33/1 and 2, pp 3-8.