

Supporting community action on AIDS in developing countries

Understanding and challenging TB stigma Toolkit for action

- **Introduction to TB and stigma**
- **More understanding and less fear about TB**

About the organisations involved

ZAMBART Project

Established in 1989, ZAMBART Project is a research NGO with a special focus on the overlap between TB and HIV and a commitment to improve the quality of life of people affected by the dual epidemic. ZAMBART aims to conduct operational, evidence-based, interdisciplinary and high quality research, addressing relevant and priority questions whilst building technical and scientific research capacity in Zambia. ZAMBART started conducting research on TB and HIV-related stigma in 2001, and has been involved in anti-stigma education since 2004.

International HIV/AIDS Alliance

Established in 1993, the International HIV/AIDS Alliance (the Alliance) is a global partnership of nationally-based organisations working to support community action on AIDS in developing countries. These national partners help local community groups and other non-governmental organisations (NGOs) to take action on AIDS, and are supported by technical expertise, policy work and fundraising carried out across the Alliance. In addition, the Alliance has extensive regional programmes, representative offices in the USA and Brussels, and works on a range of international activities such as support for South–South cooperation, operations research, training and good practice development, as well as policy analysis and advocacy.

Our mission is to support communities to reduce the spread of HIV and meet the challenges of AIDS. To date we have provided support to organisations from more than 40 developing countries for over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to treatment.

Registered charity number 1038860

For more information about Alliance publications, please go to www.aidsalliance.org

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Consortium to Respond Effectively to the AIDS TB Epidemic

 **Sida**

 **DFID** Department for
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Development

Understanding and challenging TB stigma: Toolkit for action

About the TB stigma module

The TB stigma module was developed through a partnership between the ZAMBART Project and International HIV/AIDS Alliance. It has been designed to be both a part of the bigger HIV stigma toolkit: *Understanding and Challenging HIV Stigma: Toolkit for Action* and to be a stand alone tool for specifically tackling TB stigma.

The exercises in the module were developed with TB patients, health workers and community TB support staff and can be used with a variety of audiences to help tackle TB stigma

The module was written by and for trainers. It has been designed to help trainers plan and organise participatory educational sessions with community leaders or organised groups to raise awareness and promote practical action to challenge HIV and TB stigma and discrimination.

This module, developed and written by

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The toolkit *Understanding and Challenging HIV Stigma: Toolkit for Action* is also available from the Alliance and includes the following modules:

Introduction

Using the toolkit

Module A

Naming the problem

Module B

More understanding, less fear

Module C

Sex, morality, shame and blame

Module D

The family and stigma

Module E

Home-based care and stigma

Module F

Coping with stigma

Module G

Treatment and stigma

Module H

MSM and stigma

Module I

Children and stigma

Module J

Young people and stigma

Moving to action module

Thinking about change

Moving to action

Developing skills for advocacy

Picture booklet

General stigma pictures

Rights pictures

Additional booklets will be published as new modules are developed.

Introduction

Introduction to the module

Tuberculosis (TB) has been associated with physical frailty, death, excessive social behaviour (e.g. smoking, high sexual libido) and certain groups (e.g. migrants, miners) for over a hundred years. It is also associated with urban poverty – particularly overcrowded housing conditions. And in addition it is an infectious and contagious disease spread through the air, which until the 1940s, could not be cured. Public health authorities have consistently aimed to isolate people who have TB, particularly those who have a high load of micro bacteria TB in their sputum (i.e. who are ‘sputum positive’) and to whom a large amount of transmission in communities is linked. In the past, this isolation included sanatoriums or special hospitals for those with TB. Currently, health workers commonly recommend a list of preventive measures for TB patient households – which often includes some unnecessary sanctions for the entire period of treatment, such as TB patients having separate utensils and being separated from children. And TB patients are often required to be observed taking their treatment on a daily basis – either at the clinic or at home. It is little wonder that TB is a stigmatised disease!

In some areas of the world this stigma will be a more temporary taint – that fades away once a person is cured – but in other areas of the world, such as Pakistan, TB is a more permanent stigma that can even affect marriage prospects and sever relationships.

In areas with high HIV prevalence, TB has become hard to control. People living with HIV are much more vulnerable to developing TB due to their compromised immunity. In Sub-Saharan Africa, countries are faced with the dual epidemics of TB and HIV, with high rates of people co-infected with TB and HIV. The HIV epidemic has therefore deepened TB stigma, since a TB diagnosis is assumed to signal underlying HIV infection. More recently with the roll-out of anti-retroviral therapy (ART) and the subsequent reduction of AIDS, there is some evidence that people with TB are even more targets of prejudice because of their physical degeneration.

This module was developed in the context of the dual epidemics of TB and HIV, but is also aimed at TB stigma in countries where HIV prevalence rates are much lower.

The exercises in this module were developed with TB patients, health workers and community TB support staff and can be used with a variety of audiences to help to tackle TB stigma, including community leaders, medical staff, TB patients and family members, TB programme volunteers, support groups and so on.

During the testing of the exercises, trainers agreed that using them in a mixed group, for example health workers alongside TB patients, resulted in higher levels of understanding and experience sharing.

In countries where prevalence rates of HIV are high, all stigma workshops should include exercises from this module since much of the HIV stigma will be related to TB.

Overview of the module

No.	Exercise	Brief description of exercise
	General/introduction	
1	Naming TB stigma through pictures	Pairs discuss pictures showing different forms of TB stigma as an introduction to the forms and effects of stigma
2	How has TB affected my life? (reflection)	Individual reflection – think about how your life, or your family's life, has been affected by TB. Sharing of stories
3	Naming TB stigma in different contexts	Groups identify forms of stigma in different contexts, e.g. home, workplace, clinic, etc. followed by problem solving
4	Forms, effects and causes of TB stigma	Problem tree exercise – participants cardstorm points on the forms, effects and causes of TB stigma
	Knowledge about TB	
5	Assessing baseline knowledge	Optional methods to assess baseline knowledge about TB: A. Rotational brainstorm B. Cardstorm C. Quiz D. Game
6	Fears about getting TB (risk continuum)	Listing fears about getting TB, discussing rationale behind the fears, then providing correct information to counter fears
7	Fears about getting TB at home	Making a diagram of a house to show fears of getting TB in different rooms and why, then responding to each fear
8	Countering myths and misconceptions	Brainstorming TB-related myths and misconceptions, then providing information to challenge the myths
	TB stigma and health facilities	
9	TB diagnosis and stigma	Groups document and discuss stigma and other problems faced by TB patients during the diagnosis process in a clinic
10	Do's, Don'ts and DOTS	Cardstorm on good and bad points about the DOTS system, then discussion on how to make DOTS more user-friendly
11	Challenging TB stigma in health facilities	Clarifying assertiveness, then role playing how to challenge stigma in a work context, using assertiveness
	Impact of stigma and how to respond	
12	TB-HIV link	Discussing the differences between HIV and TB, and how the two diseases are closely linked in people's perceptions
13	The burden of secrecy	Story about a TB patient hiding his status from colleagues and family, plus discussion on its impact on the TB patient
14	Sharing the burden of care	Role playing family and community meetings to discuss how they can support TB patients and primary caregivers
15	TB and human rights	Brainstorm rights, then each group analyses a scenario describing how rights are violated and works on solutions
16	How men and women experience TB stigma	Men's and women's groups discuss what happens when a man/ woman returns home with TB, then talk about the differences
17	Children and the wall of silence	Role playing and discussing different approaches used by families to inform children that they have TB
18	To tell or not to tell (children and information)	Decision-making game looking at when to tell children about TB and paired role play to practice how to inform children
19	Empowerment and action planning	Cardstorm what 'empowerment' and 'patients' rights' are. Case studies on effective action. Groups read case studies and draw out strategies, then develop their own strategies

Exercise 1 Naming TB stigma through pictures



Facilitator's notes

This exercise is the same as Exercise A1 in the Module A booklet, but uses pictures developed specifically to relate to TB stigma.

It is a useful opening exercise which helps participants to 'name' TB stigma and think about the different forms and causes of stigma.



Objectives

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

- identify different forms of TB stigma in different contexts
- identify how TB stigma affects individuals, families and communities
- begin to understand why TB stigma happens
- discuss examples of TB stigma from their own communities.



Time

1 hour



Materials

Selection of *TB stigma pictures* on pages 56–67.



Preparation

Display the pictures on a wall or table.

Step-by-step activity

Picture discussion

1. Divide into groups of two or three people. Ask each group to walk around and look at as many pictures as possible. Then, when the groups have viewed the pictures, ask each group to select one or two pictures.
2. Ask the group to discuss:
 - *What do you think is happening in the picture in relation to TB stigma?*
 - *Why do you think it is happening?*
 - *Does this happen in your community? If so, talk about some examples.*

Report back

3. Ask each group to present their analysis.
4. Record key points on flipchart sheets.

Examples from workshop in Zambia

Taking sputum to lab technician

Lab technician does not look at him, greet him or tell him what to do; just points to the table, indicating where to deposit the sample. Very cold and impersonal response – lab technician keeps himself at a distance, reflecting fear of infection. Makes TB patient feel bad.

TB patient carried in a wheelbarrow to clinic

Patient looks very sick, close to death; being carried in a wheelbarrow; no dignity; people pointing; people at the clinic are talking about him.

Man staying in a chicken run

Patient is not allowed in the house; forced to sleep in the chicken run. Man looks very lonely, isolated and depressed.

Bar scene – one man left drinking alone

Man coughing and assumed by the others to have TB; he is drinking all alone. Others are leaving; looking disgusted; Isolation and fear-based stigma.

Man sitting alone on a bed

Thin, sick man seated alone on a bed. He may have TB. Looks very lonely and worried – he seems to have lost all hope. No one is caring for him. Maybe his wife has run away. Sense of rejection by the family. People are scared to have physical contact with him.

Nurse running past TB corner

Nurse is racing past; she is trying to avoid contact; showing her fear of TB infection. Even professional health workers stigmatise.



Exercise 1 Naming TB stigma through pictures



! Action ideas

Show the pictures to family members or colleagues and use them to generate discussion. Help others to see what TB (or HIV) stigma means in our lives.

One health worker in Uganda used the pictures to challenge a colleague who was stigmatising patients. Instead of criticising him directly, she showed him the pictures and opened a discussion using them on how to treat patients.

Processing

5. Ask: 'What did we learn from this exercise?'

Summary

Draw out the main points from the participants' discussion. Make use of some of the points below to add key things which may be missing:

- Sometimes we treat people badly just because of a disease they have. We isolate or reject them, for example refusing to sit beside someone we think has TB; or we gossip about them and call them names because of the way they look when ill. This is called **stigma** because it makes the person who is ill feel disgraced, even dirty and ashamed.
- Stigma means 'spoiled identity' – an identity of an individual or a group that is 'spoilt' because it possess a sign (be it a disease or some other distinguishing trait) which carries with it negative meanings and can be considered to be a reflection of poor moral status. These negative meanings can be stronger and weaker in different societies and groups.
- To stigmatise is thus to believe that people are inferior; have done something bad or wrong (sinful or immoral behaviour). When we stigmatise we judge people, saying they have broken social norms and should be shamed/condemned; or we isolate people, saying they are a danger/threat to us, for example because of their TB.
- We have been socialised to stigmatise others – to judge or devalue them. We are often not aware that we are stigmatising.
- Stigma is a belief or attitude. The action resulting from stigma is discrimination – the unfair treatment of people with TB, for example firing an employee or chasing a family out of the house because of TB.
- Stigma can be viewed as something normal. It is seen as something natural, a part of life. People are not always aware of how it affects people with TB (or HIV) and how it affects the TB and HIV epidemics.



Exercise 2 How has TB affected my life? (reflection)



Objectives

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

- describe how they have been affected by TB
- recognise some of the different ways in which we are affected by TB.



Time

1 hour



Facilitator's notes

- In many Asian countries, in parts of Eastern Europe and in many high HIV prevalence countries in Sub-Saharan Africa, people will be familiar with TB and will have been affected by TB.
- This exercise helps us to think about and share our personal experiences of TB – of how TB has affected our lives, as individuals, families and communities. Often we talk about TB as a problem external to ourselves – something out there, and we don't have a chance to share our experiences.
- Some participants may be reluctant to do the reflection, or even to sit on their own. It can help to acknowledge that it is difficult exercise.
- The exercise requires a lot of trust and openness within the group. One way to get participants started is by the facilitators sharing their own experiences and feelings first.
- Sharing one's experience is voluntary. No one should be forced to give their stories. Encourage group members to listen carefully to each other's stories.
- The exercise can trigger strong feelings for some participants. You should be ready to deal with the emotions raised.

Step-by-step activity

Reflection

1. Explain the reflection. Spend a few minutes alone and think about how your life has been affected by TB. How has your life changed as a result of you or someone close to you getting TB? Think about what happened. How did it feel?
2. Ask participants to find some space and sit on their own to do the reflection.

Sharing in pairs or in plenary

3. In pairs: Tell participants that when they are ready they should find a partner and share with them any thoughts from the reflection.
4. In plenary: Invite participants to share their stories in the large group. This is voluntary – no one should be forced to give his/her story. People will share if they feel comfortable. If it helps, give your own story to get things started. As the stories are presented, ask: *'How did you feel? How did this affect your life?'*

Processing

5. Ask: *'What major things did we learn from these stories?'*

Summary

Possible points to mention, depending on the stories:

- These stories help us understand how it feels to be stigmatised. The feelings of being stigmatised are very painful. People get badly hurt.
- Some people judge or condemn people with TB – blaming them for being careless, or in some cases for 'bad behaviour' (e.g. 'immoral' sex).
- Stigma makes us feel like outcasts – as if we are no longer human – and this has a serious effect on our health.

Exercise 2 How has TB affected my life? (reflection)

Stories from the tool development workshop

I was diagnosed with TB and as a result lost my job because I had to ask for two months sick leave. Then, because of not working, things got difficult at home and eventually my wife left me. I was renting a house and had to leave because I couldn't manage the rentals. I became very depressed.

Luckily the church helped me and offered me a room in one of the church buildings. With their support I have come through the bad times and I now try to sensitise others about TB and stigma.

Last year I stayed with my sister for a while before starting my studies. Her 14 year old daughter was sick with TB and she used to cough. She was very sick and often coughed all night. It was difficult but I felt bad for her because her aunt and cousins used to mock her and make fun of her coughing. They even told her to control herself and that they never wanted to hear her cough again. I felt bad for her.

As a person who has been working with TB patients, when I get upset with my nephews and nieces, they laugh at me and say that the TB drugs and patients I look after have confused me. They even call my money 'TB money'. It feels bad.



Exercise 3 Naming TB stigma in different contexts



Facilitator's notes

You may want to organise this exercise as two separate sessions – the first dealing with the analysis of stigma in different contexts (steps 1–5), and a separate session focusing on problem solving (step 6).



Objectives

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

- forms of TB stigma in different contexts
- how stigma affects people with TB
- ideas for solutions and actions to change stigma.



Time

1–2 hours



Preparation

Put up flipchart sheets for different contexts (e.g. family, neighbours, clinic, workplace, church/mosque, school, market, bar) on different walls of the room. You can either write the names of the contexts, draw them yourselves or use the pictures starting on page 56 of this toolkit.

Step-by-step activities

Rotational brainstorm

1. Explain the instructions for the rotational brainstorm. Divide into as many groups as there are contexts. Each group will spend a few minutes at each flipchart, recording the types of TB stigma found in that context. At the sound of the drum (or song) groups will move to the next flipchart in a clockwise direction.

Role play

2. When groups have written on each of the flipcharts, ask them to return to the flipchart where they started and prepare a role play showing an example of stigma in that context. Then ask the groups to present their role plays.
3. Display all the flipcharts together.

Processing

4. Bring the whole group back together. Ask them to discuss:
 - *What are some of the common forms across the different contexts?*
 - *What are the attitudes/feelings in all contexts towards people with TB?*
 - *What are the effects on people who have been stigmatised?*

Finding solutions and action planning

5. Divide into groups and assign each group to work on causes and solutions to TB stigma in one of the contexts. Emphasise that we are looking for concrete actions, which can be implemented by participants themselves – not recommendations for government.
 - Make a list of solutions – things you can commit to doing yourself or help organise in your community.
 - Prioritise two or three actions you will work on.
 - For each of the priority actions decide: *Who will do it? How? To whom? With what? Specific messages?*

Gallery report back

6. Move around the flipcharts, hearing a brief presentation by each group.

Summary

- People with TB face stigma in many different places. Even a place where we are used to feeling comfortable, can become a place where we face stigma and hostility.
- The same forms of TB stigma may be experienced in completely different settings.
- When we are fighting against stigma, we need to consider the different contexts in which it occurs.

Adaptation for health workers

If you are working with health workers, you can do the same exercise, but include contexts from around the health facility, as a way of exploring stigma in clinics or hospitals. The contexts might include: out-patients department, screening room, laboratory, TB ward, other wards, VCT, pharmacy.

You could also do the exercise as a 'stigma walk' – walking staff through the clinic asking them to think about the different types of stigma that might occur in the different contexts.

Exercise 3 Naming TB stigma in different contexts



Examples of possible solutions

Clinic

- Challenge stigma among ourselves when we see a colleague stigmatising.
- Ensure staff have correct information on how TB is transmitted and how it is not transmitted.
- Hold regular meetings and presentations from different people on TB at the clinic.
- Have health education every morning when patients are waiting to be attended to.
- Have health education by people cured of TB.
- Identify influential people and educate them to dispel the misconceptions.
- Agree on anti-stigma guidelines to be adopted by all clinic health workers.

Family

- Talk with the family to support disclosure and teach TB patients about the advantages of disclosure.
- Allay fears of family members by giving enough information on how TB is and is **not** transmitted.
- Encourage the TB patient to join support groups and refer for emotional support.
- Bring neighbouring families together to provide mutual support and advice.

Forms of stigma in different contexts – sample responses

Home

Given separate room, separate plates, and eating alone so that others do not get TB. Not visited by friends or relations. Sent back to the village to avoid shame in town. Women with TB chased by their husband and told to “go to your mother”.

Neighbours

Isolation. Gossip. Teasing. Mocking. Finger pointing. Talking behind their backs. Neighbours say that the family cannot manage things properly – careless, no discipline.

Clinic

Patients holding sputum containers or X-rays are the focus for gossip. Health workers put on masks and gloves, and open windows. Patients fear that health workers will disclose their status to their families or relatives. Patients, before going to the TB ward, first check to see if there are people who know them.

Workplace

Finger pointing. Gossip. Separating cups. Avoiding contact. Given light duties or sent to do work outside the office to minimise contact. Viewed as unreliable and waste of resources. Labelled as a ‘non-performer’.

Church

Church leaders condemn TB patients for “promiscuity, adultery, breaking moral laws”. “You are being punished for not following God’s laws.” “TB is a demon – you need deliverance.” TB patients are not elected to positions of leadership. Not visited at home by church members.

School

If a child is known to have TB or is coughing a lot they are forced to sit near an open window. Isolated or separated from others. Teasing – “Your parents died because of their bad behaviour.” Teachers excluded from meetings and school events once they are diagnosed with TB.

Market

People stop buying from a market seller who is suspected to have TB or HIV. “Don’t buy from her, she coughs a lot – all her vegetables are contaminated.” Gossip about their health status. Finger pointing. Name calling. Judging.

Bar

Gossip/teasing. Avoid using the same beer container. Minimise contact.

Exercise 4 Forms, effects and causes of TB stigma

Facilitator's notes

It can be helpful to prepare sample cards for each category to show participants how the problem tree works.

Objectives

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

- identify different forms of stigma and how stigma affects people
- identify some of the root causes of stigma.

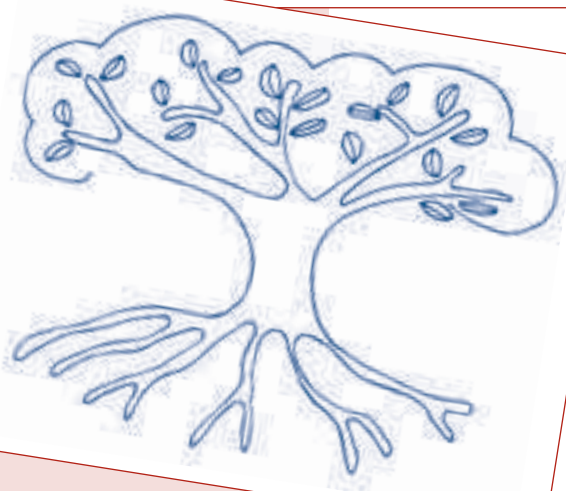
Time

1 hour

Preparation

Using flipcharts and cards, set up the structure for the tree on the wall (or use a picture of a tree).

Location	Feature	Question
Middle (trunk)	Forms	In what ways do people stigmatise? (e.g. name calling, gossiping)
Bottom (roots)	Causes	Why do people stigmatise? (e.g. moral judgements, lack of knowledge)
Top (branches)	Effects	What happens as a result of stigma (e.g. depression, unemployment, less productive)



Step-by-step activity

Cardstorming

1. Ask participants to work in pairs. Hand out cards and ask pairs to write points on each of the three topics – **effects**, **forms**, and **causes** of TB stigma. Write one point per card and stick them on the stigma problem tree drawing or wall diagram.

Clustering

2. Ask a few participants to come up to the wall diagram and organise the cards – eliminate repetition and cluster similar points together. Then ask these participants to summarise the cards they have organised.

Examples from a tool development workshop

Effects of stigma

- Personal: Shame. Self-blame. Isolation. Loneliness. Loss of status. Loss of self-esteem. Loss of hope. Depression. Stress. Denial. Anger. Violence. Alcoholism. Suicide. Death.
- Family: Family quarrels, mutual blame and conflicts. Chased from home. Divorce or separation. Property grabbing. Orphans and street children. Abuse of orphans.
- Avoid getting tested and disclosing status to partners and family. Avoid using TB services, or defaulting on treatment. Spread of TB.

Forms of stigma

- Blaming. Shaming. Name calling. Finger pointing. Judging. Teasing. Gossip. Isolation. Rejection. Neglect. Separating cups/utensils. Separate room. Keeping at distance.
- Self-stigma. Giving up on oneself. Withdrawal from activities.
- Stigma by association: Family affected by TB and TB health workers are stigmatised.

Causes of stigma

- Moral judgements: "TB patients are sinners." Promiscuous. Breaking social norms. Careless with hygiene and ventilation.
- Fear and ignorance: Lack of knowledge. Misconceptions about TB transmission. Fear about getting TB through casual contact.
- Gender and poverty. Women and poor people more stigmatised than men and rich people. Poor people in overcrowded rooms – more exposure to TB, blamed for being 'careless' about their health.
- Abhorrence of sputum and coughing. Physical reaction or disgust of sputum.
- Layers of stigma: Women, sex workers, and poor people are already stigmatised.

Exercise 4 Forms, effects and causes of TB stigma



Summary

Draw out the main points from the participants' discussion. Make use of some of the points below to add key things which may be missing.

Causes of stigma

- **Moral judgements** about how people with TB became infected – sometimes we 'shame and blame' people with TB for being 'careless', for example for poorly ventilated rooms or for going to places where they are exposed to TB germs, assuming they are responsible for their infection by smoking or drinking too much or through excessive sexual behaviour. In high HIV prevalence settings, these moral judgements about TB infection are even more likely.
- **Fears about casual transmission of TB** – fears about being infected with TB can be both legitimate and not legitimate, and can often lead to rejection or isolating experiences, for example forcing a TB patient to use separate utensils.
- **Public health prevention** – some public health prevention measures can cause TB stigma, for example separate TB wards, health education that prescribes that TB patients should have separate utensils or should not stay with their children. Some of these measures are genuine infection control strategies, but some are unnecessary and all can be experienced as stigmatising.
- **Poverty** – the financial burden of caring for TB patients can cripple poor households. The financial (and workload) burden increases bitterness and resentment towards people with TB.

Forms of stigma

- Shamed and blamed for having TB, for example called names, accused of being careless and irresponsible, told that TB is a punishment from God.
- Self-stigma – people living with TB blaming and isolating themselves as a reaction to stigmatisation from society. They accept the 'shame and blame' of society.
- Secondary stigma by association – family members of TB patients or health workers are stigmatised and their status affected.

Effects of stigma

- Discrimination – chased from the family, accommodation, work, etc.
- Embarrassment, shame, loss of social status and self-esteem.
- Sadness, loneliness, worry, stress, depression, suicide, alcoholism.
- Secrecy/hiding – stops people disclosing their situation and accessing services. People who think they have TB (or HIV) do not get tested, do not tell others and do not get support/love/help from others.
- Creates denial and this leads to harm (infection) to others and blocks TB treatment.



2 More understanding and less fear about TB

“ One day I went to visit a family with my sister. While we were there, I asked for water. The father gave me a glass of water, but my sister stopped me from drinking it. This confused me and really upset the man. We said nothing about it, but when we left my sister told me that people suspected he had TB, and touching the glass might have given me TB. ”

This story is an example of fear-based stigma. The man offered some water, but it was rejected out of fear of getting TB. This rejection was a form of stigma.

This section addresses the fear of getting TB. People fear becoming infected through sharing the same room, shaking hands, touching utensils, having sex, etc. with people who have TB. Whilst some forms of contact are potentially risky, for example living with someone who is sputum positive in an unventilated house, other forms of contact, for example shaking hands or sharing utensils with TB patients, are of no risk. People need to know the difference – how TB is transmitted and how it is not transmitted so they will stop stigmatising TB patients out of unrealistic fears.

There is a need for more public education on TB. People have some knowledge about TB, but it is incomplete, and influenced by myths and misconceptions such as:

- All people who are ‘coughing’ are infectious and can spread TB to others.
- You get TB through sex or it is caused by sleeping with a woman who has aborted or miscarried.
- There is no difference between TB and HIV and there is a ‘new’ TB (HIV-related) and an ‘old’ TB, and the new TB is not curable.

Some people don’t recognise that we have all been exposed to TB and have an inactive form of TB. It is only when our immune system becomes weak (especially if we are living with HIV) that our ‘TB infection’ is more likely to develop into active TB. But we should remember that TB can be successfully cured, even if we are living with HIV.

This section will help teach the basics on TB and counter the myths and misconceptions so that people have the right information and full understanding needed to overcome fears about getting TB.

This section involves three parts:

1. Exercise 5 is used to assess participants’ understanding on TB as a baseline. Once the gaps in understanding are identified, the facilitator can address them through:
2. Exercises 6–9 are optional exercises to help provide key information on how TB is transmitted and how TB is not transmitted.
3. A fact sheet is provided in Annex 1 to support this process.

This chapter should be used along with the *TB fact sheet* given in Annex 1. Photocopy the fact sheet and give it to participants.

Exercise 5 Assessing baseline knowledge



Facilitator's notes

This exercise will assess participants' knowledge about TB and gaps in their understanding. This will help to establish a baseline to build on and identify points of misunderstanding or fear that underpin stigma. It is important that one facilitator is well informed about TB – you could either invite a TB specialist (e.g. a TB treatment supporter, or TB health worker) to join you for this session or one facilitator could be familiar with the basic fact sheet in this module, and be able to take note of questions that participants find hard to answer.



Objective

By the end of this session, participants will be able to identify what they know and don't know about TB.



Time

1 hour



Materials

If you are going to do step C – copies of the *True or false quiz* on pages 50 and 51.

Step-by-step activities

The following are four optional methods to assess knowledge. Choose **one** of these exercises only. Use the fact sheet as a resource for answering questions or areas of confusion.

A. What do you already know about TB? (brainstorm)

1. Put up flipchart sheets on different walls of the room and put a question at the top of each sheet, for example:
 - *What is TB?*
 - *How is TB transmitted?*
 - *What are the signs of TB?*
 - *How are TB and HIV different?*
 - *How are people tested for TB?*
 - *How is TB treated?*
 - *How can people living with HIV prevent themselves getting TB?*
2. Ask participants to walk around in pairs and write down what they know about the topic and any questions, concerns or fears.
3. Then review each sheet with the big group and respond to questions, concerns or misinformation.

B. What do you want to know about TB? (cardstorm)

Divide into pairs. Hand out five blank cards to each pair. Ask pairs to write on each card things they want to know about TB and tape the cards on the wall. Eliminate repetition. Then discuss each question, with participants contributing their ideas. Help to sort out fact from misinformation.

Examples of questions raised by participants at a workshop

- What is the difference between TB and HIV?
- How long can you be exposed to a person with infectious TB before you get it?
- In what parts of the body is TB found?
- What precautions can people living with HIV take to prevent getting TB?
- What is TB treatment?
- What are the side effects of TB treatment?
- What is Isoniazid Preventive Therapy?
- What food is needed by people living with TB?
- Can you get TB by drinking milk?

C. True or false quiz – what do I know about TB?

Hand out a copy of the quiz to each person. Then discuss those questions where most participants are confused about the responses.



Exercise 5 Assessing baseline knowledge



Materials

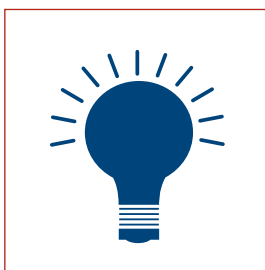
- A dice, which can be made from foam or a cardboard box wrapped in flipchart paper with symbols drawn using markers.
- A set of cards made from the quiz questions that correspond with the dice symbols.

D. Dice game – questions at random

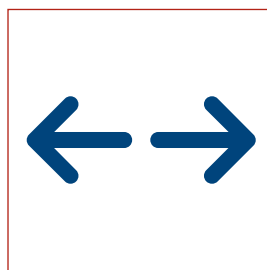
The dice game consists of a dice with six different symbols, which determine the set of questions regarding different topics related to TB and HIV.

1. Explain to participants that they should throw the dice and pick a card that corresponds to the symbol on the top of the dice.
2. Invite the participant to pick one question card from the respective symbol pile and hand it over to the facilitator who reads the question.
3. Encourage the group to discuss the question.

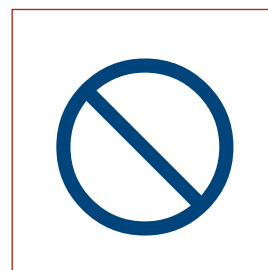
The following are the symbols and related categories:



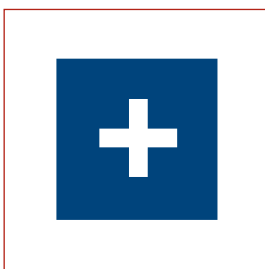
General



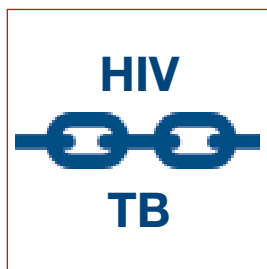
Transmission



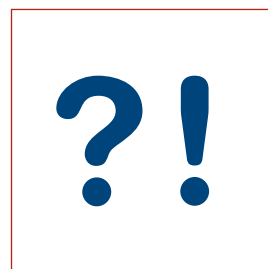
Prevention



TB testing and treatment



TB-HIV link



Myths and misconceptions

Exercise 6 Fears about getting TB (risk continuum)



Objectives

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

- name their fears in relation to specific forms of contact with people with TB
- explain how TB is transmitted and how TB is **not** transmitted.



Time

2–3 hours



Materials

Cards (half sheets of A4 paper), markers, masking tape.



Preparation

Put the risk continuum on the wall or on the floor – cards with the headings 'high risk', 'medium risk', 'low risk' and 'no risk'.



Facilitator's notes

In this exercise people identify forms of contact with people with TB which they fear may expose them to TB. Then they explain the reasons behind their fears and the trainer provides information to counter these fears.

This exercise takes a long time so we suggest you organise it as two separate sessions – the first dealing with risk analysis (steps 1–4) and the second to practice the new information (the Margolis Wheel).

In case you do not have a medical person to respond to people's fears, the *TB fact sheet* on pages 48 and 49 and the information provided at the end of this exercise should cover most issues raised. It is important to provide clear and consistent information to participants.

Step-by-step activities

A. Risk analysis (cardstorm)

1. Divide into pairs and hand out cards and markers. Ask: 'What are some of the fears in the community about TB transmission?' Ask pairs to write single points on cards and stick on the wall.

Sample responses

- Shaking hands, hugging, touching or kissing someone who has TB.
- Having sex with a woman who has aborted or miscarried.
- Sharing food, dishes, utensils, cups, etc. with a TB patient.
- Sitting in crowded waiting rooms, at a funeral or in a bar.
- Working in a TB ward or as a TB treatment supporter.
- Handling sputum bottles or containers without gloves.
- Having a father or grandfather who had TB.

Risk continuum

2. Ask participants to put each card under one of the categories – high risk, medium risk, low risk or no risk.

Analysing the fear

3. Take each of the high and medium risk activities and ask the pair who raised the fear to explain the reasons behind the fear.

Clarification

4. Then take each of the forms of contact and explain what the risks involved are. Invite a medical specialist to help as a resource person and hand out the TB fact sheet. See example on next three pages.

B. Practising the new information (Margolis Wheel)

1. When participants have learned the basic facts on TB transmission, allow them to practice this information by trying to convince someone that they should not fear certain forms of contact with someone who has TB.
2. Arrange the Margolis Wheel – two concentric circles of chairs – an inner circle and an outer circle.

Exercise 6 Fears about getting TB (risk continuum)



3. Ask the more confident participants to sit in the inner circle. Give the first question sheet to those in the outer circle. Ask them to ask the first question to their partner in the inner circle. Those in the inner circle should try to give clear information and reasons to explain the transmission question.
4. Then ring a bell (or beat a drum) and ask the outer circle to rotate and ask the second question and so on.
5. After four questions ask the two circles to change places and continue with the second question sheet so that both sets of participants have a chance to practice using this information.

Questions for the Margolis Wheel

- Can you explain why shaking hands or hugging someone with TB is not risky?
- Can you explain why sharing utensils with someone with TB is not risky?
- Can you explain why handling sputum without gloves does not pose a risk of getting TB?
- Can you explain why there may be a risk of TB transmission if you are in a choir?
- Can you explain how someone working in a hospital or clinic might get TB, and how to minimise this risk?
- Can you explain why sharing beer is not a risk, but going to a bar might be a high risk activity?
- Can you explain how a mini bus driver might be at risk of getting TB?
- Can you explain why sleeping with a woman who has had an abortion would not put you at risk of getting TB?

Which activities might be risky? (risk continuum)

Activity	Reasoning behind fear	Correct information	Correct rating
Breathing in droplets from someone with positive sputum	TB is airborne and transmitted by breathing in TB-infected droplets.	The only way to get TB is from droplets floating in air: big droplets fall quickly, but small ones hang in the air if there is no ventilation to blow them away. If someone coughs in an enclosed space, the person entering comes into contact with these droplets in the air. The more prolonged the contact, the higher the risk of being infected. For TB to be transmitted, there must be someone who is infected with TB and who is not yet on TB treatment.	High
Breathing in droplets from someone with negative sputum	TB is airborne and transmitted by breathing in droplets.	There is some risk but it is much lower than in a smear-positive person.	Low
Breathing in droplets from someone who is taking TB treatment	Someone is known to have TB.	After you have taken medicine for 2–3 weeks you are less likely to spread TB bacteria to others.	Low
Being in a confined space with someone with TB who is coughing	Breathing in TB.	If someone has TB and is not on treatment (or has only just started treatment), coughing results in TB bacteria (bacilli) getting into the air where other people can breathe them in – so it is high risk. But 2–3 weeks after someone is on TB treatment, the risk becomes much lower.	High

Exercise 6 Fears about getting TB (risk continuum)

Activity	Reasoning behind fear	Correct information	Correct rating
Handling sputum samples	Handling sputum without gloves. Sputum bottles may not be closed tightly, contents may spill into the air and we could breathe in the bacteria.	<p>TB is airborne. One can only get TB when germs are in the air. The only way to spread TB germs is by coughing, sneezing, talking, singing – these activities generate many TB droplets.</p> <p>If sputum in a cup spills, it does not get into the air. Gloves are used for hygiene reasons. Gloves will not protect you because you don't get TB through physical contact.</p> <p>The only time a lab technician could be at risk (low) is when making a smear. Lots of people in the community handle TB sputum without getting TB.</p>	Low/No
Stepping on sputum	Sputum may splash onto skin and get into the body.	TB is transmitted through the air, not through touch or physical contact.	No
Working in a clinic or hospital	Lots of contact with people who are sputum positive.	<p>High risk with undiagnosed patients or with newly-diagnosed patients. Health workers have to get close to do diagnosis and to care for patients. Also, they are often spending prolonged periods in wards and clinics. Health workers living with HIV are especially at risk and should be on TB preventive therapy (IPT or isoniazid).</p> <p>To emphasise this important point – ventilation reduces risk significantly. Windows on both sides means air comes in one side and out the other and blows droplets out of the room where sunlight destroys them.</p> <p>Sunlight – TB germs do not survive sunlight or normal light outside. If someone coughs droplets are they are exposed to sunlight, within minutes the droplets will die.</p> <p>Standard masks are useless for health care workers. High quality masks might reduce risk, but are expensive. However if a person who is coughing covers their mouth and nose with a tissue or mask it reduces the droplets that get into the air.</p>	High
Working in a TB ward	Being close to people with TB in the same space.	TB wards are likely to have newly-diagnosed patients, very sick patients and even drug-resistant TB patients. So the risk of transmission for health workers is high. Infection control measures are very important, particularly ventilation, sunlight and TB preventive therapy for health workers living with HIV.	High
Treatment supporter	Exposure to TB when encouraging patients.	Period of contact is only 20–30 minutes per visit so risk is low. But care must be taken if patients are sputum positive.	Low
Sharing an office with a TB patient who is coughing	Breathing in TB droplets.	When someone is diagnosed 'first smear positive' they are usually given two months sick leave then may come back to work (once on treatment they are quickly no longer infectious). Before they are diagnosed there is a risk if ventilation is very poor.	Low

Exercise 6 Fears about getting TB (risk continuum)

Activity	Reasoning behind fear	Correct information	Correct rating
Shaking hands	Touching sputum droplets or saliva which might contain TB.	No risk. TB transmission does not occur through touching, but through breathing in TB germs.	No
Sharing a bedroom	Catching TB from bedding or breathing the same air.	TB transmission does not occur through touching but through breathing in TB germs. Sharing unventilated air space with someone is a risk.	High
Having sex	Being so close to someone, breathing in droplets.	TB is not transmitted through sex (unlike STIs or HIV). There is no risk. But if a person is coughing this is close contact and puts one at risk of infection.	No
Kissing	Getting TB through contact with saliva whilst kissing.	No risk. TB bacilli are produced deep in the lungs, not in saliva, so there is no risk of getting TB through kissing. But if a person is coughing this is close contact and puts one at risk of infection.	No
Sharing utensils	May eat the bacteria on utensils or food.	TB is transmitted through the air so there is no risk involved in sharing food or utensils. Health workers should not tell people to separate utensils as it creates isolation and stigma and is not necessary.	No
Sharing beer (drinking from the same beer can or tin)	Getting TB from exchange of saliva when sharing beer containers.	You don't get TB from sharing beer, but some research has shown that bars can be places where TB is contracted if they are small, crowded and unventilated. Some people in bars may have TB but not realise it or have started treatment and defaulted.	No risk
Funerals	Being in an enclosed space with lots of people.	Large numbers of people in a small space, especially where a room is unventilated and people stay for several days. Research has shown that funerals can be places where TB is contracted.	High risk
Drinking milk	Linking to the idea that cattle get TB and it may be passed through the milk.	If milk is not pasteurised, there is a possible risk of transmission of another type of mycobacterium similar to TB. Pasteurised milk is safe and good for TB patients.	Low risk
Being a minibus driver	Coming into close contact with many people, some are coughing.	There is a risk of exposure over time, especially if the bus is poorly ventilated.	Medium risk
Being HIV positive	If our immunity is low, we can get TB very easily from contact with TB patients.	This is true. When immunity is low, a person with HIV has more chance of getting TB. The majority of TB patients in Sub-Saharan Africa are HIV positive, i.e. co-infected with TB and HIV.	High
TB passed on through the family	The TB germ is inherited by children of those with TB.	TB is transmitted through the air, and is not in our genes. If your grandparents had TB, it does not mean you automatically will get TB unless you are exposed to TB.	No risk
Abortion/ miscarriage	Getting TB from sleeping with a woman who had an abortion or miscarriage.	Transmission only happens when the bacteria is in the air, not through blood exchange or sex, or through contact with someone who is considered unclean or polluted.	No risk

Exercise 7 Fears about getting TB at home



Facilitator's notes

This is an optional exercise, since all of these fears are addressed in Exercise 6. Exercise 6 is important because many people lack information about TB transmission and different forms of contact in the home.

What makes this exercise interesting is the drawing of the house, so be sure to include this step.

Use the *TB fact sheet* on pages 48 and 49 to help explain how TB is transmitted and not transmitted.



Objectives

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

- identify places in the home where family members fear getting TB from a family member who has TB – and understand which of these fears are realistic
- provide practical advice and information that people need to protect the family in a positive and non-medical language.



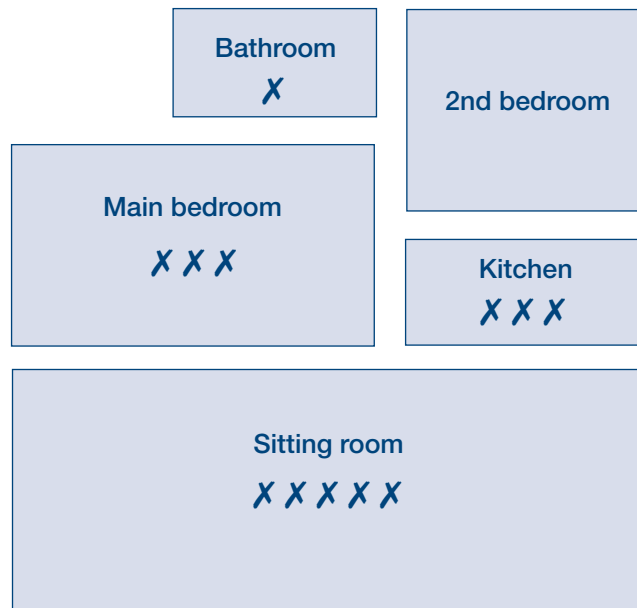
Time

1 hour

Step-by-step activity

Household mapping

1. Divide into small groups. Ask each group to:
 - make a drawing on a flipchart sheet of a typical house with a bedroom, kitchen, bathroom and sitting room
 - mark the rooms in the house where people might be scared of getting TB from contact with a family member who has TB which leads them to stigmatise or isolate the family member.



Report back

2. Ask each group to present their drawing and explain why each room that they have marked makes them scared and whether this results in stigma. After each group presentation, explore in the large group whether there is any risk of getting TB and how you can explain it to others.

Optional methods for organising this activity

- A. Each group analyses TB fears in the whole house, but reports back on just one room.
- B. Each group is assigned to do the task (analysing TB fears) for a single room.
- C. Put a big map/diagram of house on the wall and do a cardstorm of fears in each room.
- D. Create a house diagram on the floor using chalk – divide into groups and ask each group to go to one room, discuss the fears in the room and do a role play to show those fears.

Exercise 7 Fears about getting TB at home

Possible points of fear and stigma in the household

Room	Forms of contact feared	Misconception behind fear
Bedroom	Having sex. Kissing	Close contact with sputum during kissing and sex – TB germs may get into body
Sitting room	Sitting together. Sharing food and utensils	Person with TB coughs, covers mouth with hand, sputum on hand comes into contact with other hands, or clothing
Kitchen	Eating food cooked by person with TB	TB germs get into food while person with TB is cooking
Bathroom	Sharing the same washcloth	TB spreads through spit or mouth fluids



Processing in large group

3. Ask the group to discuss:

- *What did we learn from these diagrams?*
- *How can we help to counter these fears?*
- *What advice can we give households on caring for and supporting TB patients? Use the list below to add to useful points.*

Advice on caring for and supporting TB patients

- Don't segregate TB patients unnecessarily – explain any steps that you are taking so the patient knows it is not to stigmatise them.
- Open the windows to encourage lots of ventilation.
- Encourage people with TB to cover their mouth when coughing.
- Avoid serving food which is dry and triggers coughing.
- Discuss with all family members how TB is and is **not** transmitted.



Exercise 8 Countering myths and misconceptions



Facilitator's notes

Create an atmosphere where people feel free to discuss and explore different myths and misconceptions.



Objective

By the end of this session, participants will be able to assess a number of beliefs which affect people's attitudes towards TB and people with TB.



Time

1 hour



Materials

Copies of the *TB fact sheet* on pages 48 and 49.

Step-by-step activities

Whispering game – warm-up

1. Ask participants to form a line. Whisper a message to the person at one end of the line. The message is then passed through whispers to the other end of the line. The person who receives the message at the end of the line writes it on the flipchart. Then write the original message.
2. Ask the group to discuss:
 - *What happened as the message got passed along?*
 - *Why did the message change?*
 - *What does this game tell us about communication?*

Summarise

3. The game shows how information is distorted as it is passed from one person to another. The same is true of beliefs about TB. These ideas are also distorted as they are communicated from one person to the next.

Myths and misconceptions (cardstorm)

4. Divide into pairs and ask them to brainstorm common beliefs about TB. Write each belief on a card and stick them on the wall.
5. Ask participants to help cluster similar points and summarise.

Examples of myths and misconceptions

- Men can get TB by having sex with a woman who has aborted or miscarried.
- Men can get TB from a woman who is menstruating.
- Men can get TB by having sex with a widow.
- You can get TB if you step on a place where a stillborn baby was buried.
- You can get TB through sharing food and utensils with someone with TB.
- TB can be easily transmitted even after someone has started TB treatment.
- Women have more TB germs. Women are the ones who give men TB.
- Women with TB are more infectious because they sleep around with many men.
- TB is HIV. The new TB cannot be cured.
- The new TB cannot be called TB – it is worse than the old/normal TB.
- The new TB can re-occur after one completes medication.
- TB medication can actually kill you.
- All people who are coughing are infectious and can spread TB to others.
- Using masks is the best form of prevention.



Exercise 8 Countering myths and misconceptions

Topic groups

6. Divide into topic groups. Ask each group to select one of the beliefs and try to analyse it. Ask:

- *Where does this belief come from?*
- *What are some of the reasons or thinking behind the belief?*
- *How does this belief lead to TB stigma?*

Report back and processing

7. Ask each group to report on their belief. Then in a large group ask: *'What are some of the strategies we can use to challenge these beliefs?'*

8. Distribute copies of the *TB fact sheet* on pages 48 and 49.

Example of analysing a myth

Myth: TB = HIV. The new TB cannot be cured. New TB is worse than the old TB.

Where does this come from?

This view – that there is a new form of (HIV-related) TB – is linked to the stigma faced by people living with HIV.

What are the reasons behind this belief?

This is related to the fact that HIV cannot be cured. It is true that there is more TB because of HIV and that people living with HIV are more likely to get TB.

How does this belief lead to stigma?

People with TB face the same stigma as people living with HIV, including judgements about their behaviour and morality. People with TB are viewed as worthless or hopeless because of the belief that they cannot be cured.



Exercise 9 TB diagnosis and stigma



Objectives

By the end of this session participants will have:

- identified some of the stigma barriers which discourage people who have TB symptoms from completing their diagnosis at a clinic
- developed strategies for improving things in the clinic.



Time

1 hour

“The first time I went to the TB corner after being diagnosed, I went with my wife. The TB nurse didn't look at me, but shouted I should be careful how I coughed even though I had covered my mouth with my sweater. It was humiliating!”

Ex-TB patient, Zambia

“I went to the hospital to find out about a cough I had. I waited a long time and finally got to see the doctor. He was very impatient, and after a few minutes told me to go to the lab and get tested. He opened the door, and looking down the hall, in front of a line of waiting patients, shouted to someone at the lab, “Give this lady a sputum test”. People in the line were staring at me. This behaviour shocked me, but I continued with the test and found that it was nothing – no TB. But I will never go back to that hospital!”

Community worker, Zambia



Facilitator's notes

This exercise looks at the process involved in going to a clinic to be diagnosed for TB and some of the stigma barriers at each step.

A suitable alternative to the method described in step 1 would be a rotational brainstorm – put up flipchart sheets on different walls of the room, each representing one step in the process; then ask groups to move around the room recording what the barriers are at each step. To add some interest, ask groups to do short role plays to show interactions between health workers and patients.

Step-by-step activity

Steps in the TB diagnosis process

1. Divide into four groups – two groups working on what happens at the clinic and two groups on what happens at home and in the community in relation to the process of being diagnosed with TB (e.g. when a family member returns home from the clinic carrying a sputum bottle).

Stigma barriers at each step

2. In the same groups, participants draw a diagram showing some of the steps involved in diagnosis and the stigma barriers at each step (see examples of experiences in Zambia below).

Report back and processing

3. Ask each group to present its diagram, then discuss:
 - What are the major stigma barriers that arise when being diagnosed?
 - What are the effects of these stigma barriers?
 - Why are these stigma experiences happening?
 - What can we do to reduce the stigma faced by TB patients?

Examples based on experiences in Zambia

Stigma barriers in the clinic

- Bureaucratic and unfriendly treatment. Harsh and scolding language.
- Delays in providing services – “We're on tea break! Come back tomorrow!”
- Clinic staff keep their distance (out of fear) and show their disapproval/judgemental attitude.
- Clinic staff gossip about patients. Break confidentiality – tell families.
- No time to explain things carefully to patients – everything done in a rush.
- Many steps in the process – no clear information on what to do to complete the process.
- Ping pong/bounce from one department to another – this is confusing.
- If sputum samples are brought too late, the person is told to go home and come back the following day.

Exercise 9 TB diagnosis and stigma



Examples based on experiences in Zambia (cont.)

- Just carrying the sputum bottles makes the patient a target for stigma/gossip – it's humiliating.
- Bombarded with information at the end of the diagnosis – at this stage tired and sick with no interest in this information – just want to go home.
- Forced to be weighed on scale without any support when weak.

Stigma barriers at home and in the community

- Stigma in the family – isolation, questioned about behaviour, finger pointing and blame.
- Carrying sputum bottle is stigmatising – many questions, for example *"Why are you going to the clinic every day?"*
- Women blamed and victimised – kicked out of the house and sent to mother.
- Family forces the person to see a traditional healer – looking for someone to blame TB on.
- Neighbours – watching, gossip, come to check on you (voyeurism), no real sympathy.
- Communal tap – isolation, told to take the water first and leave, so others can gossip.
- Church – isolation, finger pointing, no support if you have not paid your tithe. Some churches tell family to get water from hot springs for special treatment.

Effects, causes and solutions from Zambia workshop

Effects

- People with TB drop out of diagnosis and don't get treated.
- People resort to other forms of treatment – traditional healer or church.

Why are these problems happening?

- Nurses have large workloads and experience burnout. Not trained on how to interact with patients. They have fears about getting TB through interaction with TB patients.
- Lack of confidentiality is related to nurses' fears about getting TB on the job. They see it as their right to know which patients have TB so they can keep their distance and inform each other about who has TB.

Solutions

- Educate the family and community on TB and how to support TB patients.
- Encourage patient to complete the diagnosis – accompany her/him all the way through the process.
- Change health worker attitudes to be more caring and less stigmatising. Train all clinic staff on how to treat patients and show them how poor treatment leads to dropout.
- Provide clear, written directions about the diagnostic steps – what you do first, second, etc.
- Operate the lab 24 hours a day and train community volunteers to help with basic tests.
- Help health workers deal with their own stress, worries and frustrations.

Summary

A TB diagnosis is hard enough without having to face or anticipate stigmatising experiences at the different steps.

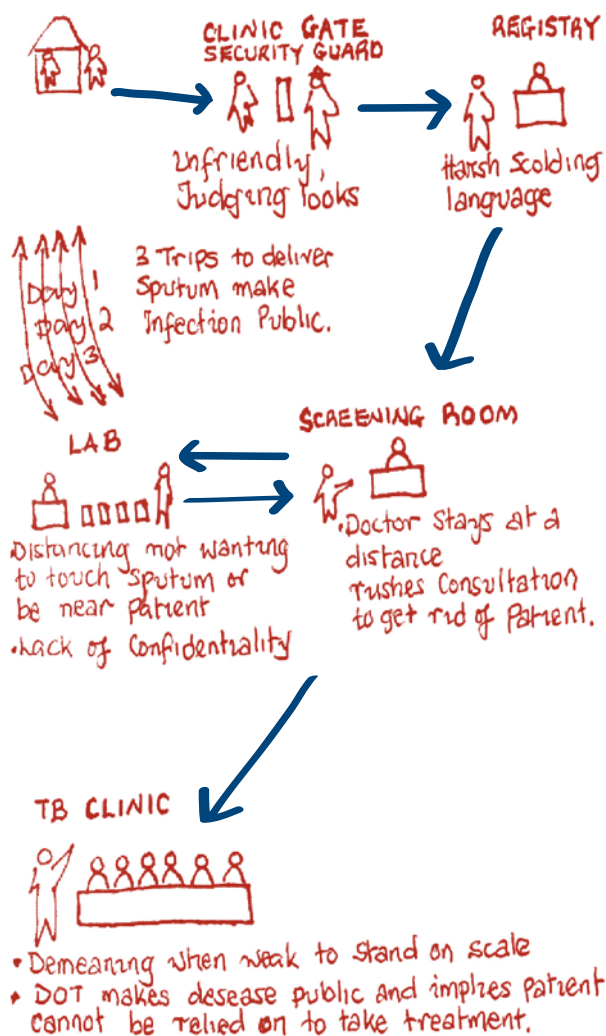
Health workers need to find ways to reduce the stress and frustration for potential patients so that they do not get lost. This will involve:

- making our clinics more friendly and stigma free
- getting all clinic staff to be supportive and welcoming to patients
- recognising how it feels to be a potential TB patient, feeling sick and trying to find out what is wrong with you, and fearing being made fun of, gossiped about, seen by others in the community in a very frail state.

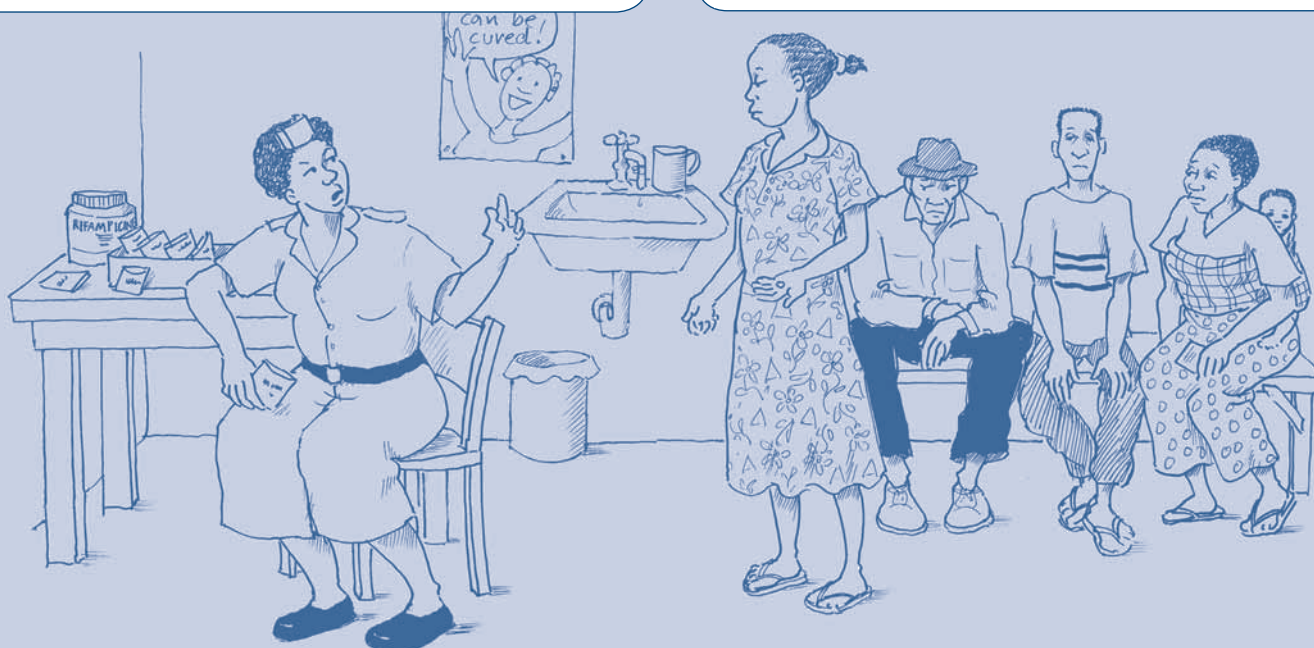
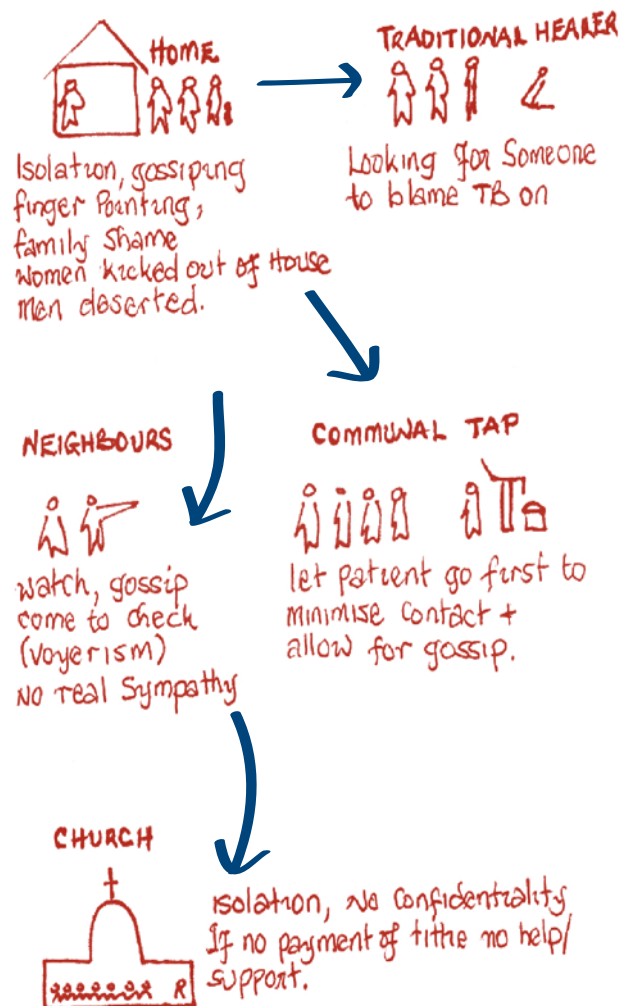
Exercise 9 TB diagnosis and stigma

Example of diagrams from Zambia

Stigma barriers at the clinic



Stigma barriers at home and in the community



Exercise 10 Do's, Don'ts and DOTS

Objectives

By the end of this session participants will have:

- explored the positive and negative aspects of DOT
- discussed ideas for creating user-friendly DOT services
- produced guidelines to use with health workers and health committees on more effective DOT services.

 **Time**
1 hour



Facilitator's notes

It is important to be clear when using this exercise that the aim is not to undermine the DOTS system, but to look at how sometimes it can be used as a way of stigmatising people with TB.

DOTS is a strategy advocated by the World Health Organisation (WHO) since the early 1990s. DOTS is a recognised and effective way of controlling TB infection – it has five clear and solid aims which are:

1. Clear and sustained political commitment by governments.
2. Detecting TB cases through examining sputum and, if necessary, doing culture and drug-resistance testing. This requires good laboratory work.
3. Providing standard treatment, with supervision and patient support. This may include Directly Observed Therapy (DOT) which involves either the clinic or the community or people at home directly observing patients taking their treatment on a daily basis.
4. An effective drug supply and management system.
5. Monitoring and evaluating the TB programme – and measuring its impact.

DOTS – the five point strategy – and DOT are often confused, but DOT (Directly Observed Therapy) is actually just one component of one of the five aims! DOT is the act of observing TB patients taking their TB treatment and the justification for it is to avoid drug resistance and to improve adherence – both laudable reasons.

But TB patients have reported that being diagnosed with TB and undergoing the DOTS programme can result in feelings of humiliation and shame. Some patients say they don't feel trusted to take their own medicine and feel they are being treated like children.

It may be worth reminding participants that similar programmes to DOTS have developed over the years since they were first introduced, in response to actions, complaints and demands by people with TB.

In this exercise health workers write their own guidelines for a stigma-free, user-friendly clinic, which they then use on the job. Applying the new guidelines on a daily basis helps to reinforce what was learned during the workshop. Staff begin to internalise the new, non-stigmatising ways of working, which will become standard practice. This will ensure that the rights of TB patients are supported and that they receive high-quality care – and this in turn ensures that everyone completes their treatment.

This exercise works really well if you have a group of health workers and patients together – sharing experiences and coming up with ideas on how to improve things.

Step-by-step activity

Understanding of DOTS and DOT

1. Start a short discussion to clarify the difference between DOTS and DOT. This doesn't need to be a lecture – just a round robin with some definitions on a flipchart or agreed with the group. Then it is a question of getting the group to focus on DOT – directly observed therapy!

Exercise 10 Do's, Don'ts and DOTS



Example of a charter

Building a stigma-free, user-friendly TB service

- All TB patients will be treated with respect, dignity and privacy.
- Access to treatment will not be denied or delayed to any TB patients. TB patients will receive the same standard of quality care provided to other patients.
- All staff will be trained in patients' rights and the right of TB patients to equal care and confidentiality.
- All staff and service users will be encouraged to challenge stigmatising words and actions.
- Everyone is encouraged to talk openly about their fears and concerns about TB and clear information will be made available at all times.
- We believe that TB is a manageable and curable disease.

As a clinic we are committed to act against stigma at all times.

Positive and negative aspects of DOTS (cardstorm)

2. Divide into pairs and hand out two different coloured cards to each pair. Ask pairs to write down positive aspects of DOTS on one coloured card, and negative aspects on the other. Give each pair several cards to get as many points as possible and remind participants, one point per card. Stick the cards on the wall.
3. Ask a few participants to cluster similar points together and to then give a summary of the positive and negative aspects.
4. Prioritise the aspects by asking the group to discuss: *'Which aspects cause the most stigma to people with TB?'*

Finding solutions (small groups)

5. Divide into groups and ask each group to take one of the negative aspects. Brainstorm together:
 - *What would make things better?*
 - *What needs to change to make DOT more user-friendly?*

Implementing change

6. Ask groups to join together to form bigger groups. Share ideas. Then discuss and draw up guidelines for a user-friendly DOT service, which could be used in clinics and with health workers to promote better services. These could be written in the form of a poster or a charter.

Report back

7. Stick up the charters and listen to each group's ideas.

Examples from a Zambia workshop

Negative things about how DOT is implemented

- When a health worker sees a patient with a green card, he/she doesn't even greet the patient. Quickly rushes to get another health worker to see the patient.
- The DOT system makes you feel like you are the worst patient – you need to be 'watched'.
- It seems to assume that if a person is sick, he/she can no longer take any responsibility.
- DOT exposes TB patients to stigma – everyone sees that they go to the clinic every day for treatment (if DOT is administered by the clinic).
- If DOT is administered through a home-based community (HBC) worker, the visits are stigmatising – the HBC worker arrives with a hat and a bag and everyone knows who they are.
- Language is stigmatising – HBC worker says, *"I'm going to see my patient"*. Family adopts the same language – *"Come in, your patient is waiting!"*

Positive things about DOT implementation

- Supports patients through treatment difficulties.
- Helps adherence and prevents drug-resistant TB – MDR.
- Helps to avoid patients dropping out after they begin to feel better.
- It can be supportive.
- You can meet others in the same situation.
- Your progress is monitored.

Exercise 11 Challenging TB stigma in health facilities



Facilitator's notes

This exercise looks at how to challenge TB stigma. Participants learn how to be assertive and then practice this skill in a series of paired role plays. In countries with high co-infection rates (high prevalence rates of TB and HIV), this will also help tackle the combined 'TB/HIV' stigma.

“ I never knew I could be the one to challenge stigma in the clinic. This exercise has given me the confidence to speak out about stigma and make a difference. ”

Nurse from Uganda



Objectives

By the end of the session participants will have:

- shared experiences and analysed how TB stigma takes place in the health setting
- discussed how TB stigma affects the quality of care provided
- practised how to challenge TB stigma and change the situation using assertiveness.



Time

1 hour

Step-by-step activities

What is assertiveness? (buzz groups)

1. Divide into pairs and ask: 'What is the meaning of assertiveness?' Use round robin reporting and record points on a flipchart. Summarise using the definition below:

Assertiveness is saying what you think, feel, and want in a clear and honest way that is good for yourself and others. It is not being aggressive or showing anger.

Practising assertiveness (paired role plays)

2. Divide into pairs and ask the pairs to act out the following scenarios. In each role play the person being stigmatised should use assertiveness to challenge the stigmatiser. The role plays are performed at the same time, but after all pairs have tried it out, ask a few pairs to show their play in the centre of the circle. After each role play, ask:
 - What happened?
 - Was it realistic?
 - What behaviours are stigmatising and what are not?
 - Which assertiveness approach worked best?

Role play 1: Read the scenario and ask pairs to role play:

- One of you is a health worker and you overhear a patient complaining about another patient, saying that she is contagious, always coughing and delaying the queue, and always at the clinic.

Role play 2: Change pairs, read the scenario and ask pairs to role play:

- You hear a colleague complaining about another colleague, saying that he is going to die after his wife passed away recently. He has been heard coughing so he must have TB and AIDS.

Role plays 3–5: Combine pairs to form three groups and continue with the following scenarios:

- Two colleagues approach you and begin to gossip about another nurse who has been on sick leave, saying that she has been on leave for a long time with TB and that she has not improved. They continue to gossip.
- You hear two patients gossiping about a health worker, saying that they could not be attended by someone who looks like they have TB.
- As a health worker you see people avoiding joining a queue, upon approaching them they say that they don't want to stand next to a TB patient.

Processing

3. At the end of the role plays, discuss (in pairs or as a large group): *What changes on the part of health workers are needed to ensure that people with TB are not discriminated against?*

Exercise 11 Challenging TB stigma in health facilities

Summary

4. Draw out the main points from the participants' discussion. Make use of some of the points below to add key things which may be missing:
 - Health workers and patients can work together to challenge stigma.
 - Assertiveness can be used to challenge stigma, especially on an individual level. You can challenge stigma even though it is not directed towards you.
 - However, when stigma leads to discrimination you may need to refer to, or develop, policies to protect health workers and patients. Involve senior managers in this process.

Assertiveness techniques

- Tell people what you think, feel and want clearly and forcefully
- Say 'I'... feel, think, or would like
- Don't apologise for saying what you think, or put yourself down
- Stand or sit straight in a relaxed way
- Hold your head up and look the other person in the eye
- Speak so that people can hear you clearly
- Stick with your own ideas and stand up for yourself
- Don't be afraid to disagree with people
- Accept other people's right to say 'No' and learn how to say 'No' yourself.

Option: stop-start drama

You can use stop-start drama instead of the paired role plays to explore issues in more depth. Ask for volunteers from the group to role play the following scenarios and then analyse them together.

Scenario A

A clinical officer comes to the clinic with a relative who is coughing and needs attention. Some patients start complaining that the health worker is contaminated and they don't want to be attended by a health worker who has sick relatives, putting them at risk of getting TB. A nurse overhears and tries to talk to them.

Scenario B

A nurse is attending to a client who tells her he has been suffering from a bad cough for six weeks, having night sweats and is coughing up blood. Instead of showing compassion and speaking kindly and respectfully to the client, the nurse quickly covers her face with a mask and asks the client to move his chair to the other side of the consulting room. The client's relatives are upset by this reaction. The client feels afraid and humiliated.

Exercise 12 TB-HIV link



Facilitator's notes

In this exercise participants explore the relationship between TB and HIV – what the two diseases have in common, what are the differences and how community perceptions about HIV affect people with TB.



Objectives

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

- understand the commonalities and differences between TB and HIV
- share experiences on how HIV-related stigma affects people with TB
- analyse how perceptions of the TB-HIV link affect how people perceive TB patients.



Time

1 hour

Step-by-step activities

Comparison between TB and HIV (small groups)

1. Break into groups and ask: 'What do you know about TB? HIV? What are the differences? What are the links?'

Organise a round robin report back (i.e. one new point from each group) and record in a table, comparing the two diseases.

	TB	HIV
What is it?	TB is a bacteria	HIV is a virus
Where it is found in the body	Lungs and other body parts	Body fluids – blood, semen, vaginal fluid, breast milk
Effect	Attacks lungs and other body parts	Attacks and destroys immune system. May lead to AIDS
Route of transmission	Air – TB is airborne. TB sputum positive person coughs TB droplets into the air, and someone breathes in the droplets	Unprotected sex or infected needle injections or mother-to-child transmission
Curable?	Yes – TB is curable, even in a person who has HIV	No – ARV treatment improves immunity, but HIV is not curable
Prevention messages	<ul style="list-style-type: none"> • If you are coughing for more than three weeks go to the clinic and give a sputum sample • The most important thing is to take your medicine • Always cover your mouth with a tissue when you cough or sneeze. Put tissue in closed bag and dispose safely • Open windows and air out your room often (if it is not too cold outside). TB spreads in small closed spaces where air does not move • Allow a lot of sunlight into your room 	<ul style="list-style-type: none"> • Use condoms correctly and consistently • Abstain from or delay sex • Remain faithful to one (uninfected) partner • Seek medical advice on preventing HIV infection to your unborn or breastfeeding child if you are HIV positive
Signs and symptoms	<ul style="list-style-type: none"> • A prolonged (more than three weeks) cough with sputum and sometimes blood • Excessive night sweats and persistent fever • Loss of appetite and weight 	<ul style="list-style-type: none"> • A person with HIV can be asymptomatic (no symptoms) if their immune system is still strong (CD4 count is still high) • Symptoms of HIV are body rashes, cough and persistent flu

Exercise 12 TB-HIV link

	TB	HIV
Signs and symptoms (cont.)	<ul style="list-style-type: none"> • Tiredness and weakness • Chest pain • Symptoms can vary depending on how TB spreads in the body 	
Testing	Most commonly used is a sputum test	Most commonly used is a blood test for antibodies to HIV
Treatment	It varies: <ul style="list-style-type: none"> • Treatment length depends on the strain, or specific variety, of TB a person has, and their age • If the strain is not drug resistant, the treatment course may be as short as 6–8 months • A person with drug-resistant TB may require treatment every day for up to two years to be cured 	Anti-retroviral (ARV) treatment is life-long

Why is the TB-HIV link important?

2. Divide into small groups and give each group two or three of the stories below to read together. Ask the groups to discuss:

- *What is the link between HIV and TB in each story?*
- *How does this link affect how people with TB are perceived?*
- *What is our own experience of how people react to TB and HIV?*

Story 1

My health was good, but I took an HIV test and found out I was HIV positive. I felt really upset and worried about what people would say about me. I did not tell anyone. I managed to start taking ARVs without anyone knowing. Then one day I began to cough and the cough wouldn't go away. I tried all kinds of cough medicine, but nothing worked. I knew it was TB, but now I felt my life had ended – everyone would find out about the HIV.

Story 2

Mr Sakwiba recently went to the clinic for a TB test and was diagnosed TB sputum positive. The nurse told him he should go for an HIV test, but he refused and said he did not want to know his status, he feared that it would only bring more stigma and judgements. He did not go for the test.

Story 3

When my uncle got TB and began to cough continuously, we all tried to ignore it. We came up with lots of excuses to explain the coughing – *“He ate this kind of food; he slept outside at a funeral; there's too much dust and so on. No one wanted to mention the words ‘TB’ or even worse ‘HIV’. We all just prayed that he would get better.”*



Exercise 12 TB-HIV link



Summary

Build on participants' points and include the following if they are not mentioned:

- Many people think that HIV and TB are the same, that there is no difference. This is wrong – TB and HIV are different diseases.
- **But** there is a link – people living with HIV can have low immunity so they are more vulnerable to getting TB. Therefore, large numbers of people who have HIV get TB (e.g. in Zambia 70% of TB patients also have HIV).
- When people get TB, it is often assumed that they also have HIV and they get stigmatised – often blamed for living a promiscuous life.
- People also assume that because of TB the person living with HIV will die quickly.
- Because of these attitudes, some people living with HIV who get TB symptoms are reluctant to go for testing and treatment – and they can get sick and die.
- It is important to counter these attitudes with more effective public education and information on a) the differences and b) the links between HIV and TB; and the importance of people living with HIV seeking TB testing and prevention services, and people with TB getting tested for HIV.

Story 4

When my sister found out I had started TB treatment she was very angry. She started saying things about how I had lived my life, that I was too promiscuous and that it was my own fault. She said, *“We used to tell you what would happen”*. I felt very bad when she left the house, saying she needed to protect herself and could no longer stay with me.

Story 5

My elder brother was diagnosed with TB and called me to tell me his landlord had evicted him and he had nowhere to stay. He came to stay with me. I felt angry and I said I felt that he was putting my children at risk of getting TB and HIV. I made sure I gave him separate eating utensils and bedding.

Story 6

Pastor Mwembe was diagnosed with TB at a local hospital. He refused to accept the results, saying it was impossible for him to have TB because he had lead a good and honest life. He went to another hospital and took another test, where he received the same result. He refused to take TB treatment, even though he had seen the counsellor. After a few weeks he became very sick, and it was only then that he started treatment.

Examples of the TB-HIV link and how it affects people

- A person living with HIV has no visible symptoms, so she/he can hide it and not get stigmatised. A person who gets TB has visible symptoms, and so is a target for stigma.
- *“The minute I got TB, I started to worry that I may also have HIV. When people got to know I had TB, I started to worry that people would give me funny looks and judge or stigmatise me because they assumed I also have HIV.”*
- In people's minds, TB is the quickest indicator that someone has HIV.
- In people's minds, TB is the same thing as HIV – they don't see any difference.
- Because of this association, if a person gets TB symptoms they will be reluctant to go for testing and treatment.
- HIV is stigmatised and so is TB, so if a person gets both, then they have a double stigma and more pressure to hide and not disclose, making it more difficult to access testing and treatment.
- Because of ARVs, a person who is HIV positive can live a long time. But once she/he gets TB, people assume she/he will get very sick and die quickly.
- You can live well with HIV, but once you get TB too, people write you off as ‘finished’.
- People with HIV often are or become poor and are forced to stay in crowded rooms where they are more exposed to TB germs.

Exercise 13 The burden of secrecy



Facilitator's notes

This exercise uses a dramatised story – someone reads out the story, scene by scene, and participants act it out – to make the issues real.

This exercise works well when the lead actor uses a monologue, i.e. talking to himself about what he is thinking, e.g. *“If they find out, what will they say about me? How will they treat me?”* This helps everyone see how the situation affects the lead character emotionally. Another way of doing this is to have the facilitator stop the action at points and ask the actor: *“What are you thinking or feeling?”*



Objectives

By the end of this session, participants will have:

- explored the tension between confidentiality, disclosure and stigma
- explored how secrecy can become a barrier to adherence to TB treatment.



Time

1 hour



Materials

Copies of the story, one for each participant.



Preparation

Select a few participants beforehand to act out the drama, assign them roles (Adam, workmates, boss, nurse) and get them to practice.

Step-by-step activity

1. Hand out copies of the story. Ask one participant to read the story, stopping at the end of each scene so the acting group can perform it. At the end of each scene ask the lead actor (Adam): *‘How are you feeling?’*

Story – The burden of secrecy

Scene 1

Adam is 37 years old. His wife passed away six months ago and he has started to have a prolonged cough and lose weight. One of his workmates has noticed he is not well and advises him to go to the clinic. Adam decides to go but he is worried he may have TB and maybe even be HIV positive. What will his family and friends say?

Scene 2

Adam goes to the clinic where a nurse does a TB test. The nurse tells him he has TB. This news upsets him – all he can think about is what people will say about him. The nurse tells him he must start treatment and gives him a number of instructions, but he hardly hears what she is saying. He takes the medicine she gives him and leaves the clinic in a confused state

Scene 3

After a few days, Adam returns to work. His colleague asks him, *“What happened?”* He says, *“Nothing, I’m okay”* and changes the topic of conversation. He feels like everyone is watching him and tries not to cough. When he is alone, he asks himself, *“Who knows? How can I take treatment without people finding out? Will I lose my job?”*

Scene 4

Adam has an appointment to go back to the clinic. He is afraid to ask permission from his boss for more time off. He doesn’t know what to do. Finally he phones a friend and asks him if he will go to the clinic to collect his medicine. He asks him not to tell anyone.

Processing

2. After the whole story has been dramatised, discuss the following questions:
 - *Why is Adam hiding his TB treatment?*
 - *How will his worries about secrecy affect him?*
 - *Why is it important to break the secrecy and tell someone?*
 - *Do situations like this happen in our communities? Share examples.*
 - *What can we do to support people on treatment to break through the secrecy?*

Examples of how support can help break the secrecy

- Emphasise that TB is curable and the person should focus on getting treated, not worrying about what people will say about her/him.
- Help them to learn more about TB so they are confident in talking about it.
- Help them to plan and manage the time between getting diagnosed and treated, e.g. taking a two weeks break from work.
- Discuss with the person how to disclose to others, starting with people she/he is close to.

Exercise 14 Sharing the burden of care



Facilitator's notes

This exercise looks at what is involved in caring for people who have TB. The burden often falls on women as the primary care-givers. They are often expected to do this job on their own, with limited resources and without support. Men often have the burden of finding money and resources for the patient. This exercise will look at how families and communities can provide support to care-givers.



Objectives

By the end of this session participants will have:

- explored the different challenges that families face when a member falls sick with TB
- identified some of the roles that members of a family or community can play in helping to care for a patient
- developed strategies to engage communities in sharing responsibilities for care and support.



Time

1 hour



Materials

Copies of the *Scenarios* on page 36.

Step-by-step activity

Group work

1. Divide into groups. Give each group a scenario to discuss. Ask each group to imagine they are the family and friends in the scenario. Their task is to:
 - Decide who they are – for example, they might choose some of the following roles: patient, care-giver, father, mother, uncle, etc. – and then play these roles for the remaining two tasks.
 - In role, identify some of the challenges faced by those caring for the TB patient.
 - Decide how you can support the TB patient and primary care-giver.

Examples of support from different family members

Family member	Roles in caring for TB patient and primary care-giver
Care-giver (mother)	Cooking, washing, cleaning, accompany to clinic, sourcing money
Father	Helping to collect the medicine from the clinic, sourcing money
Teenage daughter	Drawing water every morning, collecting medicine from the clinic
Teenage son	Doing piece work to help buy special food
Grandfather	Listening to the patient and giving encouragement
Neighbour	Cooking some of the family meals

Brief the groups

2. Ask the groups to select two members of the family to represent them in a community meeting. In the meeting they will report on the challenges of caring for a TB patient and the forms of support provided by different family members.

Report back – community meeting

3. Group representatives sit in the middle – sharing points from their discussions – and the rest of the participants sit in a circle around them, watching the meeting. The meeting is chaired by one of the facilitators who plays the headman/woman. The agenda for the meeting is:
 - *What are some of the challenges/hardships in caring for a TB patient?*
 - *What forms of support are provided at the family level?*
 - *What can the community do to support families?*

Processing

4. Come together as a big group. Ask participants:
 - *What did we learn from the meeting?*
 - *Did any group send the TB patient as a representative? If not, why not?*
 - *What forms of support helped to lessen the burden of care?*
 - *What other things can we do to support families caring for TB patients?*

Exercise 14 Sharing the burden of care



In Misisi township, Zambia there was a project which helped to bring families together who were caring for people with TB. The families used to share ideas and sometimes resources, in order to lighten the burden of care which often fell heavily onto one or two family members.

Summary

Bring together some of the key points of the discussion. Add the following points if they have not come up:

- Any contributions, however small, can help – everyone can play a role.
- There will usually be a primary care-giver who will do most of the caring – helping to support him/her will help to lighten the load.
- Knowledge about referral networks for support are important (e.g. food and nutrition support from the home-based care team).
- Psychosocial support is also an important part of caring – talking to the patient and the care-giver can help and support the family.
- Look for ways of involving the patient in the decision-making. This helps to build up his/her morale.

Scenarios for small groups

1. My sister, who was staying in the village, fell sick for a long time. I went to visit her and found her coughing. I took her back to the city and my wife took her to a clinic, where she was diagnosed as TB sputum positive. She started taking the TB pills, and although it was difficult at first with all the visits to the clinic, we managed to support her to get better. My wife was the main care-giver, but everyone in the family helped in different ways and even some of the neighbours helped out.

2. A few years ago I received a call from my brother-in-law, who said he was coming to my place because he had been diagnosed with TB. He said that since I am a nurse and know about TB, I should look after him. He had left his own home and wife to come and stay with me. Other members of my family pledged to help but in the end the burden fell on me and I fed and cared for him. After four months he started to improve and he was called home. His health worsened.

3. I am a pastor's wife and last year my husband fell sick with TB. We had recently moved to a community where we have very few relatives and our children are grown up. The clinic is far away and when he was diagnosed, I worried about how we would manage to get to there every day for his medicine. That was when members of the church and some of our neighbours came to our aid and helped us in different ways.

4. I live in a township near the city centre and two years ago I got sick with TB. I was the main breadwinner and so my family was worried when I had to stop work. My wife took on the role of caring for me and at the same time was trying to provide for the family. My children helped with different tasks and other family members gave support where they could. I got worried because we ran short of money and two of our children returned to school late because we could not pay their school fees.

Exercise 15 TB and human rights



Facilitator's notes

This exercise looks at how the rights of people with TB are violated and what we can do to try and protect our rights.

During the initial brainstorm, as participants are naming the rights, you should probe further on how those rights may be violated.

During the second activity where groups are discussing solutions, push them to come up with realistic solutions.



Objectives

By the end of the session participants will have:

- identified and explored different rights which could be violated if we are TB patients
- developed realistic strategies for protecting our rights.



Time

1 hour



Materials

Copies of Case studies on page 38.

Step-by-step activity

Which rights are violated? (buzz groups)

1. Divide into pairs and ask them to discuss:

- *What rights may be violated if we have TB?*
- *How are they violated?*

Then ask the pairs to report back and after each response ask: 'How is this right violated?' Ask pairs to give an example of how the right may be violated.

Examples of violated rights

Right to information: TB patients not given enough/correct information about TB, treatment, how TB is transmitted. When you go to the clinic the nurse doesn't take time to really explain everything, she/he just wants to see you leave.

Right to health care: Health staff may ignore other diseases which a patient may have and focus solely on HIV or TB. Family may refuse to finance medical costs. Family may stop the patient from being treated at the clinic and take the patient to a traditional doctor.

Right to shelter/accommodation: Sometimes you are chased from your house or taken back to the village. May be put in poor and unhygienic accommodation. If landlord discovers you have TB, he may chase you away.

Right to work: Fired for having TB. Forced into 'early retirement' on 'medical grounds'. Told you are a 'threat to your workmates'.

Right to be loved: Separated from family, children and partners. Forced to terminate a relationship because your spouse's family chases you away.

Finding solutions (case studies)

2. Divide into small groups and give each group one of the case studies on page 38. Ask them to read the case study and discuss:

- *Which right has been violated?*
- *What could you do if you were the person whose rights were violated?*
- *What examples do you have from your own experience?*

Report back and processing

3. Ask groups to present the key points from their discussions, giving the main strategies to challenge the violation.

Examples of strategies

Dismissal from work: Get help from a trade union or human rights organisation. Try to get support from the health authorities or clinic to say whether fit to work.

Eviction from rental accommodation: Find out where to go for legal information. Get community leaders to talk to the landlord. Ask the community health worker to explain to landlord about TB treatment and transmission.

Blocked from having a relationship: Ask a family member or friend to help explain things to grandmother, i.e. that TB is no longer infectious after taking treatment for two months.

Stopped from taking TB medication: Get a health worker to meet with the family and explain the hazards of stopping TB treatment at this stage.

Stopped from helping organise the wedding: Ask an older family member to talk to the organiser and explain that your TB treatment means you are no longer infectious and that involving you will be good for your morale.

Exercise 15 TB and human rights

Summary

Bring together some of the key points of the discussion. Add the following if they have not come up:

- We need to recognise that people with TB have rights: the right to have work, right to have relationships, right to have health care, etc. and that they should be able to access those rights.
- Violation of someone's rights can result in depression, loss of health and financial loss.
- If we have TB, we need to ensure that we are still involved in making decisions about our lives, even if we get sick. We are still capable.

Case studies

1. Joshua works in a private company and was recently diagnosed with TB. He was put on two months leave and when he reported back for work, found he was being transferred to a new town. On arrival at the new place he was told there was no vacancy for him. He went back to the head office to find out what was happening and was told to wait at home for a while. After a month, he received a letter terminating his contract. The letter argued that because of his poor health he would be unable to contribute effectively to his work.
2. Robert is a married man with three children. He and his family were chased out of his house when his landlord discovered that he had TB. The landlord said he didn't want Robert to infect other people and that it would be bad for his business.
3. Thabo was prevented from travelling to another country on a peace-keeping mission, because he was found to have TB, even though he was not sick. Being turned down for this mission resulted in depression and a loss of confidence, and eventually Thabo was dismissed from the army.
4. Selina is a young woman who is living with her grandmother. She was diagnosed with TB a few months ago and has been responding well to treatment. Recently she met a young man whom she really likes and hopes to marry one day. However, her grandmother has told her that she cannot be in a relationship – she must wait until her TB treatment is finished and she is sure that she is well.
5. Natalie has been on TB treatment for two weeks and has not been responding well. She is very sick. Her family calls a meeting and decides that she should stop taking the drugs and go to her grandmother's house in the village where she can rest and recover.
6. Kenneth has had TB for the last three months and is responding to treatment well. He stays with his family and while he is there, the family starts planning the wedding for his youngest sister. Kenneth asks to help with the wedding arrangements, but his father tells him, *"People like you don't need to be involved in these things"*.

Exercise 16 How men and women experience TB stigma



Facilitator's notes

This exercise examines the differences between men and women's experiences of being stigmatised. Participants divide into a men's group and a women's group and analyse the experience of how men or women are treated when they get TB – and then the whole group compares the two.



Objective

By the end of this session, participants will have identified what the differences are in the way women and men are stigmatised for getting TB.



Time

1 hour



Step-by-step activities

What happens when TB enters the home (gender groups)

1. Divide into two groups – a men's group and a women's group. Discuss:
(Men's group) *What happens when a man returns home with a TB diagnosis? How is he treated by the family? How is he judged?*
(Women's group) *What happens when a woman returns home with a TB diagnosis? How is she treated by the family? How is she judged?*
2. Make a list of points on a flipchart.
3. Do a role play to show what happens.
4. Organise a report back by each group using the flipchart points and the role play.
5. Processing: Ask for comparisons: 'What are the similarities? What are the differences?'

Examples of women's and men's problems and concerns

Women's	Men's
<ul style="list-style-type: none"> • Looked upon with suspicion. Blamed • Husband will not accept situation – will reject wife and send her back to her mother • Marriage breakdown, separation or divorce • No care for the woman. No financial support • Forced to do housework (no time to rest/heal) • Forced to sleep separately, e.g. in kitchen • Sex denial or excessive sex as punishment 	<ul style="list-style-type: none"> • Fear of being judged by others • Fear of loss of social status (no longer breadwinner for the family) • Fear of being deserted by wife • Isolation. Shame. Divorce. Violence. Depression. Anger. Feeling suicidal. Guilt • Wife refuses to have sex with husband

Examples of similarities and differences

Wife	Husband
Loss of social status – loss of husband, income and social position.	Loss of social status – fear of being seen as having failed to provide for the family.
Shame and blame plus suspicion of infidelity.	Shame and blame – fear of being judged.
Her alleged behaviour is condemned and not excused. Used to justify harsh treatment.	His behaviour is excused – blame has less impact. He may even shift blame to his wife.
Gender violence – beaten and thrown out of the house and property grabbed. Rape – sex used as a form of punishment.	Wife angry but no violence towards husband.
Rejection. Divorce. Sent back to parents.	Desertion or fear of being deserted.
Sex denial.	Sex denial.
Still expected to do household chores.	Depression. Feel suicidal. Loss of role.
Economic pressure.	Economic pressure – man to supposed to be the provider.



Exercise 16 How men and women experience TB stigma

Problem solving (stop-start drama)

5. Ask the group to identify one key issue and to 'buzz' possible solutions. Then organise a stop-start drama and ask the group to play out some of the solutions to test their realism and explore alternative solutions. After each attempt, ask: *'What worked? What didn't work? What else can we do?'*

Example of a key issue – rejection by husband

Possible solutions

- Arrange for a mediator (husband's peer) to talk to him
- Reassure the husband that TB is curable
- Let him know that others have got TB and have taken treatment and recovered
- Let him know that his friends and church members support him
- Ask TB supporters to brief husband about TB, e.g. that TB is not HIV, how transmitted and not transmitted, form of treatment, etc.
- Encourage the husband to go for testing
- Encourage him to help his wife with her treatment

Summary

Bring together some of the key points which have been discussed. Include the following if they are not mentioned:

1. Men and women often experience different forms of stigma if they get TB.
2. In many communities, women are more heavily stigmatised than men in relation to HIV and TB:
 - They are blamed for getting sick and accused of being sexually promiscuous
 - They are often blamed for being the first one to bring TB home
 - Some are beaten and chased from the house
 - Some are subjected to sexual violence as a form of punishment
 - They are often expected to continue doing the housework, even when they are sick.



Exercise 17 Children and the wall of silence



Facilitator's notes

This exercise looks at how children with TB are treated. Often they are left totally in the dark about what is happening to them. This exercise explores how it affects them, and how we can empower children with information



Objectives

By the end of this session participants will have:

- explored some of the issues that children face if they have TB
- identified the impact of providing information on the treatment process
- discussed different ways that families can support children with TB.



Time

1 hour



Materials

Copies of *role plays*.



The worst thing was not knowing what was happening to me. I thought I might be dying. I thought my cough would never end. Nobody explained anything to me.

15 year old girl (ex-TB patient), Zambia

Step-by-step activities

Warm-up game

1. Ask for two or three volunteers to play the role of children. One facilitator takes the 'children' and briefs them. The children have TB and are desperate to find out what is happening to them. Their role is to move around inside the circle, asking different questions to the adults about their condition.

The other facilitator briefs the rest of the participants to play the role of 'adults'. They must stand in a tight circle, shoulder to shoulder, and avoid answering the children's questions, either by ignoring them or changing the subject.

Play the game and after a few minutes ask how people felt during the game. Debrief the 'adults' first, then the 'children'.

Role plays and discussion

2. Ask for eight volunteers to present two role plays – four volunteers to play Family A and four volunteers to play Family B. Give each group one of the family descriptions.

Role plays

Family A

Jameson is 10 years old and has been diagnosed with TB. His family has told him what they know about the disease and the importance of taking medicine every day. They are very supportive and Jameson knows he will get better soon.

Family B

Manuela is 11 years old and has been diagnosed with TB. Her family has not told her about her condition. Every day her aunt gives her pills from a bag without any label on it. Her aunt says, *"Don't tell anyone you are taking these pills. Take them in secret or people will laugh at you and you will be isolated."* Whenever the nurse comes, she is told to leave the room. She worries that she will never get better.

3. After the performances, ask the group to discuss:

- *What did you see happening in the role plays?*
- *What made a difference in the case of Family A?*
- *What can we do to improve the situation in Family B?*

Exercise 17 Children and the wall of silence



Examples of role play analysis

Family A

- The whole family are present when they talk to Jameson about TB – he feels part of the family.
- The family are patient, answer all his questions and help him understand TB.
- They reassure him that he will get better quickly and will be cured of TB.
- He is given clear information so he knows how to help himself to get better.
- They help to prepare him to deal with stigma in the community or at school.

Family B

- No one has given Manuela information about the disease (TB), the medicine she is taking and how long the treatment will last.
- All they told her was, “*Don’t tell anyone*”.
- When she tries to get information, everyone keeps putting her off.
- This response and the lack of information makes Manuela afraid and confused.
- She doesn’t understand why she has to take the pills, so feels it is a punishment.
- She feels alone and stigmatised – left in the dark and not knowing what is happening.
- No one gives her a chance to exercise responsibility – to look after her own health.

Summary

1. Children have the right to know what is happening to them. We may want to protect them from being hurt, but if we keep the TB a secret, we may be making things more difficult for them.
2. If children are told what is happening, they will have less fear about it, and will be able to feel more in control of what is happening to them.
3. Withholding the information may result in the child feeling isolated or stigmatised and this may have an adverse effect on their treatment.
4. It is important to think about how we inform children so that we help them understand their condition. Here are some tips:
 - Create a comfortable, informal atmosphere for this discussion
 - Involve the whole family – it is a good chance to inform and educate everyone
 - Keep the information as clear and simple as possible
 - Let the child ask as many questions as they want
 - Reassure them that they are going to get better
 - Talk about stigma and how the child might want to deal with it.

Exercise 18 To tell or not to tell (children and information)

Objectives

By the end of the session participants will have:

- decided whether it is appropriate to disclose someone's TB status
- explored advantages and disadvantages of disclosure
- explored different techniques on how to disclose about TB, especially to children.



Time

1 hour



Materials

Coloured cards, labelled 'Tell' and 'Don't tell'.



Facilitator's notes

This exercise focuses on how to disclose to children. The first game with the scenarios is an introduction to thinking about **when** to disclose to someone – so make it quite fast or it could become boring. The paired role plays then provide an opportunity to explore **how** to disclose, especially to children.

When talking about children's issues, it can be powerful if you can arrange for a child or young person to come and talk about their own experience of having TB or of a family member having TB, and how they found out about it. If this is possible, plan out how to do this in the most comfortable way for the child. Ensure that they know what is expected of them and that there is someone escorting them who can support them. If this is not possible, you may ask the group to begin by sharing some of their own experiences of disclosure.

Step-by-step activities

Tell or don't tell (game)

1. Divide participants into groups of three. Let each group sit in its own space away from the others. Each group has two different coloured cards, one labelled 'Tell' and the other labelled 'Don't tell'.

Read out one scenario at a time. Give groups a few minutes to discuss and decide whether they would 'tell' or 'not tell' about their TB status. Then give a signal and ask groups to hold cards up to show their decision. After sharing the results, ask one of the groups (a different group each time) how they came up with that answer.



Scenarios

- A. Your wife has had TB for the last six months and your last born child asks you, "Why is mummy coughing so much? What's wrong with her?"
- B. Your 11-year-old son has been taking TB medication for three months. He is in the sitting room and asks you, "Why am I the only one taking medicine in the family?"
- C. You are an aunt and have been on TB treatment for the last two months. Your 10-year-old niece sees you as you are taking some tablets and asks you what they are for.
- D. Your neighbour's child keeps coming to your house and asks a lot of questions. This time she tells you that she has heard that her friend, your child, has TB. What do you tell her?

How to disclose to children (paired role playing)

2. Explain that, as we have seen in some situations, we need to be able to disclose to children. This activity will give you practice in disclosing to children. Ask participants to divide into pairs and give the following instructions:



Exercise 18 To tell or not to tell (children and information)

Why disclose in some situations?

Ino kuti ndabaambila bantu abulwazi bwangu, inga bandjaila nkuku na.

If I disclose to my neighbours are they going to kill a chicken for me!

Role play A: Each pair decides who will play the parent and the child. The child comes home from school and tells you that some friends at school have been saying that he/she has TB. They ask the parent if it is true.

Ask to see a few of the role plays. Discuss which strategies worked and which did not.

Role play B (four people): Get two pairs to combine to make a family and decide who will play the child, the others are family members. As a family you have decided it is time to explain to your 13-year-old child that the medicine he is taking is for TB, so that he sees how important it is to take it properly.

Ask to see a few of the role plays. Discuss which strategies worked and which did not.

Processing

3. Ask the group to discuss:

- What have we learnt about disclosing to children?
- What are some of the reasons why we might disclose TB? What are some of the reasons why we may not disclose?
- What are some of the ways we can disclose to children?

Examples

- The whole family may need support from someone (e.g. a counsellor) to help them disclose to a child
- It is important to reassure children that their parents will be okay even if they have TB
- Be aware of the right environment for disclosure.

Stories from Zambia

When Annie found out that she had TB, she went to live with her daughter's family because their house was closer to the clinic, where Annie went daily to receive her TB medication. Annie's eight-year-old grandson and ten-year-old granddaughter came to her one day and asked her where she was going everyday. She said that she was going to the clinic to take TB medicine so that she would get better. Annie explained that she took the same medicine that their baby sister took when she was sick and that she would recover just like their sister did.

Janet is the single mother of three children. Her mother, the children's grandmother, moved to Janet's home to take care of her after Janet was diagnosed with TB. Janet's mother called the children into the bedroom with their mother and they all sat next to Janet as their grandmother explained that Janet was suffering from TB. She explained that Janet was taking medicine and would get better and then gave the children a chance to ask questions. Janet appreciated that her mother told the children about her illness because she did not feel free to talk to them about it at first. Having her mother explain that she was suffering from TB helped Janet talk to her children about TB.

Stories from PhD fieldwork on *Children's Role in Managing TB, Zambia*, Jean Hunleth 2008.



Exercise 19 Empowerment and action planning



Facilitator's notes

This exercise can be used to get participants to look at how to respond in a practical way to stigma – through individual action and lobbying for policy change.

It builds on the problem solving and action planning in earlier exercises, including 3, 9, 10, 11, 13, 14 and 15.



Objectives

By the end of this session participants will have:

- developed a clear understanding on 'empowerment' and 'patients' rights'
- reviewed examples of best practice on empowering action from a number of countries
- developed their own strategies to support positive change.



Time

2 hours



Materials

Copies of *Empowerment examples from around the world* on page 47.

Step-by-step activity

Empowerment and patients' rights (cardstorm)

1. Divide into pairs and hand out cards. Put up topic cards on the wall – 'Empowerment' and 'Patients' rights'. Ask participants to produce points on each topic and stick on the wall.

Examples from cardstorm

What is 'empowerment'?	What are 'patients' rights'?
Standing on your own two feet. Avoiding dependency – self-reliance. Standing up for your rights. Taking responsibility for one's life. Building self-confidence to challenge. Being equipped to do something. Training – knowledge empowers. Earning money and building up resources. People working together to change things.	Being involved in decisions about treatment. Having a say in how services are provided. Right to ask questions to doctors and nurses. Making changes to the way services are provided. Getting the information needed to contribute to decisions on one's health. Improved interactions between health workers and patients.

2. Then ask: *'What would empowerment look like for TB patients?'*

Empowerment examples

- TB patients deciding on how services for TB patients are designed
- TB patients organising together to make demands on the public health system
- TB patients working with health workers to overcome stigma
- TB patients and health workers coming up with their own guidelines for a stigma-free clinic
- TB patients educating the community about TB and TB-related stigma.

Examples of empowerment models

3. Divide participants into groups working in the same facility or location and hand out copies of the empowerment examples. Ask the groups to read the examples and then answer the following questions:
 - *What can you learn from the case studies?*
 - *Can you identify key strategies or approaches which are making a difference?*

Ask participants to develop their own strategies for their district or organisation, based on what they have learned and their experience of what approaches work best.

Exercise 19 Empowerment and action planning

Things you can do yourself

- Watch your own language and avoid stigmatising words
- Visit and support TB patients and their families in your neighbourhood
- Encourage TB patients to use available services, e.g. VCT, medical care, etc.

Things you can do to involve others

- Use informal conversations, pictures, and stories to get people talking about stigma
- Challenge stigmatising words when you hear them – get people to think about how their words can hurt
- Help normalise TB and HIV. Get people to regard TB patients as ‘people with an illness’, not ‘people with bad behaviour’
- Encourage people to talk openly about their fears and concerns about TB and correct myths and misconceptions about TB.

Things to get the community acting against stigma

1. Activities which get people to identify stigma in the community:
 - Testimonies by TB patients or their families about their experience of TB.
 - Language watch – get school children to do a ‘listening survey’ to identify stigmatising words used in the community.
 - Community mapping of stigma – display map at a community meeting place.
 - Stigma walk to identify points of stigma in the health centre.
 - Drama by a youth group based on real examples – trigger for discussion.
 - Pictures drawn by youth or children – focus or starting point for discussion.
2. Community meetings to make decisions about what the community wants to do, e.g. agreeing on a code of conduct, specific support to TB affected families, etc.
3. Training workshops on stigma for community and peer group leaders.

Summary

- We are all responsible for challenging stigma. We can all play a role in educating others and advocating new attitudes and practices.
- Be a role model. Apply what you have learned in your own life. If you have had TB, talk openly about your experiences. Think about the words you use when talking about people with TB and try to change how you think and act.
- Encourage community leaders to speak out – to talk to others about TB and HIV and condemn stigma.
- Encourage TB patients to speak out – to help people understand how it feels to be the object of stigma – and make sure that they are listened to.
- Share what you have learned. After the training tell others what you have learned and get others talking about stigma and how to change it.
- Talk openly about TB. Show you are not afraid to talk about TB. This will help people see that this is not a shameful thing that has to be hidden.
- Discuss stigma with family, neighbours and friends: *What are the most common forms of stigma in your community? What can be done to change things?*
- Challenge stigma when you see it in your home, workplace and community. Speak out, name the problem and let people know that stigma hurts.
- Act against stigma as a community. Each community can look at stigma in their own context and agree on practical things they can do to bring about change.
- Develop guidelines of what changes you want to see in your own health facilities.
- Saying ‘stigma is wrong’ is not enough. Help people move to action – agree on what needs to be done, develop a plan and then do it.
- Think big! Start small! Act now! Have a far-reaching vision but start with a seed. And don’t wait – act immediately!

Exercise 19 Empowerment and action planning

Empowerment examples from around the world



- In Mongolia, in a context of TB stigma and low case detection, TB clubs have been organised with cured patients, patients under treatment and community leaders (*He et al., 2005*).
- In Ndola, Zambia, former TB patients have created health education committees, which organise talks about TB, thereby reducing the stigma linked to the disease (*Harries, Kenyon, Maher, Floyd, Nyarko & Nkhoma, 2001*).
- In Peru, group therapy sessions have been established for patients with multi-drug-resistant TB. Former patients continue to participate by providing testimonies to others who are still under treatment (*Shin, Furin, Bayona, Mate, Kim & Farmer, 2004*) and providing psychological and financial support for TB patients and suspected patients (*Getahun & Maher, 2000*).
- In Orissa, India, the 'trialogue' approach has been identified as of particular importance in interpersonal communication among providers, patients and the community. Trialogue aims to change community attitudes and behaviour through active participation in caring for people affected by the disease and through open, honest discussions about fears, prejudices and problems associated with TB. It has an impact on the patient-provider interaction and allows action against stigmatisation (*Raye, Nayak & De Munynck, 2005*).
- In Nicaragua, a package of interventions was tested in five municipalities, with the aim of improving the interaction between health care providers and TB patients and eliciting a more positive image of TB patients from the care providers' point of view. It included discussions of patient problems, revision of patient flow and home visits by two providers to observe the patients' social context (*Macq et al., 2004*).
- In Cambodia, the main activity of Mith Chouy Mith or 'friends helping friends' is a monthly meeting to coordinate comprehensive care for people living with HIV and TB. These people are given the opportunity to share their experiences and receive capacity building for advocacy. The result (no data presented) has been less discrimination by hospital staff and better attendance of people living with HIV. A network has also been established (*Natpratan, 2005*).



Annex 1 TB fact sheet

What is TB?

TB is a disease caused by a germ called *mycobacterium tuberculosis*. TB can affect the lungs or other parts of the body. When the disease affects the lung it is called pulmonary TB and when it affects other parts of the body it is called extra-pulmonary TB.

Pulmonary TB is more common than extra-pulmonary TB. When TB is extra-pulmonary, it may cause serious illness, but this type of TB is not infectious unless the lungs are also affected.

How is TB transmitted?

TB germs are spread through the air. People who have TB carry the TB germs in their lungs or their throat, and can spread the TB germs to other people. TB spreads through droplets produced when the infected person coughs or sneezes in the air. If another person inhales these droplets containing the TB germs, they can become infected with TB.

Without treatment, a person who has TB will infect an average of 10 to 15 people every year. It is easy to pass germs to family members when many people are living closely together.

Anyone can get TB. However, not everyone who is infected with TB will become sick. If you are healthy and strong, you can fight the germs.

TB is **not** easy to catch. Remember:

- Only one in three people who stay in a home and very close to a person with sputum positive TB will develop TB. Most people have very minimal contact with infectious TB.
- The TB germ dies quickly with sunlight and ventilation – open the windows and let the sun in! If a room is dark and unventilated, TB germs can stay in the room for up to three days thus increasing the risk of infection.
- After two to three weeks of TB treatment, most diagnosed TB patients are **not** infectious.
- People living with HIV are **much** more at risk of developing TB and should be on TB-preventive therapy.

Myths about TB

TB **cannot** be transmitted:

- **By a woman who has aborted or miscarried**
A woman who has aborted or miscarried needs prompt medical attention and good care (conditions accompanied by bleeding), but she is not able to transmit TB.

- **Through sexual intercourse**

Once a person has been on TB treatment for two weeks he/she is most likely to be non-infectious and can continue normal relations, as long as he/she feels up to it.

- **Through sharing utensils with a TB patient**

TB is not passed from one person to another through saliva. Saliva that might get onto eating utensils does not contain TB bacteria – saliva is a substance that is made in the mouth, as opposed to sputum that comes from the lungs.

How do you know if you have TB?

Pulmonary TB

Signs and symptoms, which could be suggestive of pulmonary TB, are:

- A prolonged (more than three weeks) cough with sputum and sometimes blood
- Excessive night sweats and fever
- Loss of appetite and weight
- Tiredness and weakness
- Chest pain.

Extra-pulmonary

- TB may occur anywhere in the body outside of the lungs, for example, in the lymph nodes, bones, kidneys and the central nervous system. Disseminated (miliary) TB is caused by the spread of the bacteria through the bloodstream.
- Many people with extra-pulmonary TB also have pulmonary TB. Diagnosis of extra-pulmonary TB is difficult but the treatment is the same as the treatment of pulmonary TB.

If you suspect that you have TB, you should go to your nearest clinic for testing.

TB treatment

TB is treatable and curable. The treatment for TB involves taking tablets every day for between six months and one year. After the first two to three weeks from beginning the treatment, you are most likely to be no longer infectious.

It is very important that you remember to take your treatment everyday, otherwise the TB germs can get stronger and medicine becomes less effective.

Do TB patients need to be isolated?

No! Two to three weeks after you have started taking your treatment you are no longer infectious. This means

Annex 1 TB fact sheet

you can eat, sleep and work with others as normal. You do not need special utensils or separate bedding. Just remember to keep taking the treatment regularly.

How to prevent TB from spreading

- Seek health care early if you suspect you have TB
- Take regular treatment to cure TB
- Cover your mouth and nose when coughing or sneezing
- Open windows and doors to allow fresh air through the home.

TB and HIV

If you are infected with TB it **does not** mean you have HIV or AIDS. However, together HIV and TB are a deadly combination, each disease making the other progress faster. HIV makes the immune system weak, so that someone who is HIV positive and also infected with TB becomes much more likely to get sick with TB than someone infected with TB who is HIV negative.

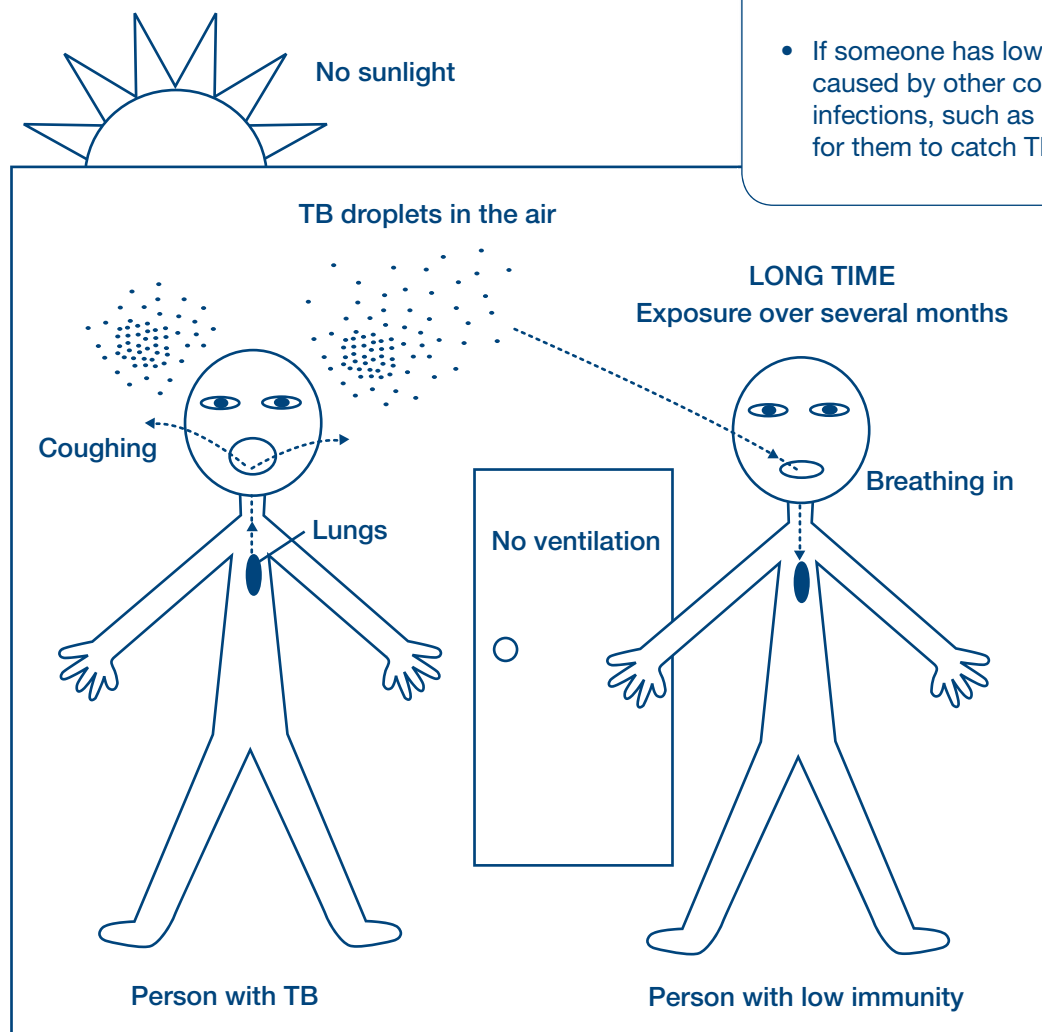
TB is the leading cause of death among people who have HIV. HIV is the single major reason why there has been such a large increase in cases of TB over the past decade.

Transmission tool

This is a simple tool that you can use to help explain TB transmission.

Sketch the diagram below on a flipchart to help explain the following points:

- TB bacteria are produced through coughing and sneezing. Droplets are then released into the air.
- These droplets only survive where there is no ventilation and no sunshine. TB droplets thrive in dark, poorly ventilated places which are not exposed to sunlight.
- Transmission takes place through breathing in the droplets over a period of time – not through a single, one-time contact.
- If someone has low immunity caused by other conditions or infections, such as HIV, it is easier for them to catch TB.



Annex 2 True or false quiz – questions

This questionnaire is used to assess the knowledge level of participants, and in particular, to identify gaps in knowledge. Once you have identified the gaps, provide information to fill the gaps and improve understanding.

Use the questionnaire as a quiz completed by individuals or in a game.

Answer the following questions by ticking either the true or false box	True	False
General		
1. TB is an infectious, airborne disease that mostly affects the lungs.		
2. TB is becoming harder to treat.		
3. TB can attack any part of the body, e.g. lungs, glands, brain, spine, hip, intestines.		
4. When the lungs are damaged by TB, a person coughs up sputum from the lungs and this produces TB droplets in the air.		
5. TB germs (droplets) can remain floating in the air for many hours.		
6. Everyone who gets TB infection will become sick with TB disease.		
7. Signs and symptoms of TB may include coughing, fever, sweating at night, loss of appetite, weight loss and feeling weak.		
8. There is no difference between TB infection and TB disease.		
Transmission		
9. You get TB by breathing in germs in the air from a person with TB who is coughing.		
10. You can get TB the first time someone who is infectious with TB coughs in your face.		
11. All people who are coughing are infectious – they can spread TB to others.		
12. You can get TB through shaking hands, touching or kissing someone who has TB.		
13. You can get TB through staying in the same house with someone who has TB.		
14. You can still transmit TB to other people when you are on TB treatment.		
15. You can get TB by going to bars or other crowded places like funerals.		
16. Health workers are at risk of getting TB because of frequent exposure to patients with infectious TB disease.		
Myths and misconceptions		
17. You can get TB from a man or woman who has many sexual partners.		
18. You can get TB through having sex with a woman who has aborted or miscarried.		
19. Having sex with a virgin cures TB.		
20. Women have more TB germs. They are the ones who give men TB.		
21. There are two types of TB – old TB and new (HIV-linked) TB.		
22. The new TB is dangerous and not curable.		
23. Stop working immediately if you have TB.		
24. People whose families have had TB (e.g. grandfather) are more at risk of getting TB.		

Annex 2 True or false quiz – questions

Answer the following questions by ticking either the true or false box	True	False
Prevention		
25. Wearing masks is the best form of protection against TB.		
26. Ventilation and sunlight are the most important methods for preventing TB.		
27. Putting TB patients in isolated rooms is a good method for preventing TB.		
28. Stopping the sharing of utensils is a good method for preventing TB.		
29. Sticking to only one sexual partner is a good method for preventing TB.		
30. It is important to get tested if you have a prolonged cough or cough up blood.		
31. If you are coughing or sneezing you should cover your nose and mouth.		
32. People living with HIV who don't have TB should take preventive therapy.		
TB testing and treatment		
33. TB is diagnosed by examining the patient's sputum.		
34. It is safe to take TB treatment during pregnancy.		
35. A person cannot take TB treatment at the same time as taking ARVs.		
36. The treatment used to treat adults for TB is the same treatment for children.		
37. You can be cured of TB if you take treatment consistently for six or eight months.		
38. The side effects of TB treatment are ...		
39. During TB treatment eat well, avoid alcohol and tobacco, and avoid stress.		
TB and HIV		
40. TB is the same thing as HIV. There is no difference.		
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44. A person living with HIV can progress rapidly from TB infection to TB disease over a few months rather than several years as is common for people who are HIV negative.		
45. A person living with HIV cannot be cured of TB.		
46. There is no interrelationship between HIV and TB.		
47. People who are HIV positive and not taking ARVs have a higher risk of getting TB than people who are HIV negative.		

Annex 2 True or false quiz – answers

Question	Answer
General	
1. TB is an infectious, airborne disease that mostly affects the lungs.	TRUE. TB is a disease caused by a germ called <i>mycobacterium tuberculosis</i> . TB can affect the lungs or other parts of the body. When the disease affects the lung it is called pulmonary TB and when it affects other parts of the body it is called extra-pulmonary TB. This form of TB may cause serious illness, but the disease is not infectious unless the lungs are also involved. Pulmonary TB is more common than extra-pulmonary TB.
2. TB is becoming harder to treat.	TRUE. Over time, the TB germ slowly works out how to resist being killed by the major TB drugs, especially when the drugs are not taken properly. Some strains or specific varieties of TB have become resistant to at least one of the major anti-TB drugs, meaning that fewer weapons are available to fight the infection. These strains are called drug-resistant TB.
3. TB can attack any part of the body, e.g. lungs, glands, brain, spine, hip, intestines.	TRUE. The most common part of the body to be affected by TB disease is the lungs, but TB can also attack other parts of the body.
4. When the lungs are damaged by TB, a person coughs up sputum from the lungs and this produces TB droplets in the air.	TRUE. The person coughs up sputum or mucus from the lungs and it produces TB droplets in the air
5. TB germs (droplets) can remain floating in the air for many hours.	TRUE. When a person with TB coughs, s/he produces droplets into the air. The droplets can hang in the air for long periods, if there is no ventilation to blow them away and sunlight, which often kills them.
6. Everyone who gets TB infection will become sick with TB disease.	FALSE. Not everybody who breathes in TB germs will get TB disease. If people are healthy and strong, they can fight the TB germs. The germ can become inactive, remaining alive in the body without causing any disease but can become active later. TB infection does not cause a person to feel sick, and there are no symptoms. TB disease develops when the immune system cannot keep the TB germ under control and the germs begin to multiply rapidly.
7. Signs and symptoms of TB may include coughing, fever, sweating at night, loss of appetite, weight loss and feeling weak.	TRUE. A person with TB may experience coughing, fever, sweating at night, loss of appetite, weight loss and feeling weak.
8. There is no difference between TB infection and TB disease.	FALSE. TB infection means that the TB germ can be found in your body, but it doesn't make you feel sick. A healthy immune system can't destroy the TB germ by itself if you get infected with TB, but it can keep the TB germs trapped in your lungs and unable to spread. But because the TB germ is strong and protects itself with a thick coating, it can remain in an inactive state in the body for many years. TB disease occurs when the immune system can't keep the TB germs trapped anymore. The TB germs can attack the lungs, or even go to the kidneys, brain or spine.
Transmission	
9. You get TB by breathing in germs in the air from a person with TB who is coughing.	TRUE. People with infectious TB, release TB droplets into the air through coughing. A person who is in the same room as the source who breathes in the droplets can become infected.

Annex 2 True or false quiz – answers

Question	Answer
10. You can get TB the first time someone who is infectious with TB coughs in your face.	FALSE. TB is not usually spread by brief contact. There needs to be prolonged contact for there to be any transmission.
11. All people who are coughing are infectious – they can spread TB to others.	FALSE. Only people with TB who are sputum positive or ‘infectious’ can transmit the germs to other people through a cough.
12. You can get TB through shaking hands, touching, or kissing someone who has TB.	FALSE. TB is not transmitted through touch or physical contact. In the case of kissing, TB bacilli are produced deep in the lungs, not in saliva, so there is no risk of getting TB through kissing.
13. You can get TB through staying in the same house with someone who has TB.	TRUE. People who live in the same house with someone who has infectious TB are at risk of getting TB. TB spreads when an infected person coughs or sneezes, spraying germs into the air. Others may breathe in these germs and become infected. It is easy for germs to pass to other family members when people live closely together. There needs to be prolonged contact for there to be any transmission.
14. You can still transmit TB to other people when you are on TB treatment.	FALSE. There is a possibility of transmission of TB when one is on treatment, but the risk is reduced two to three weeks after starting treatment or when they become sputum negative.
15. You can get TB by going to bars or other crowded places like funerals.	TRUE. Some people in bars may have TB, but not realise it, or have started treatment but defaulted. A person with TB who has not yet been diagnosed or just started treatment has a high risk of infecting others. Setting or environment is the issue – you can get TB in bars or funerals or church.
16. Health workers are at risk of getting TB because of frequent exposure to patients with infectious TB disease.	TRUE. As part of their daily work health workers come into contact with patients who have unsuspected TB disease and who have not yet been diagnosed and started on treatment. This daily contact puts them at risk.
Myths and misconceptions	
17. You can get TB from a man or woman who has many sexual partners.	FALSE. TB is spread through the air, not through sex. But it is important that you stick to one sexual partner to reduce the risk of contracting sexually transmitted infections which include HIV.
18. You can get TB through having sex with a woman who has aborted or miscarried.	FALSE. This is a common myth, but it is not true. A woman who has aborted or miscarried needs prompt medical attention and good care for her condition which is not able to transmit TB.
19. Having sex with a virgin cures TB.	FALSE. Virgins do not have any power to heal TB-infected individuals, just as they cannot heal HIV-infected individuals. Having sex with a minor puts them at a lot of health risks.
20. Women have more TB germs. They are the ones who give men TB.	FALSE. TB does not discriminate by gender.
21. There are two types of TB – old TB and new (HIV-linked) TB.	FALSE. There is no old or new TB. It is true that people living with HIV are at increased risk of TB because of the weakened immune system.
22. The new TB is dangerous and not curable.	FALSE. There is no old or new TB. But TB can be classified as pulmonary (of the lung) and extra-pulmonary (affecting other body parts).

Annex 2 True or false quiz – answers

Question	Answer
23. Stop working immediately if you have TB.	FALSE. There is no need to stop work. After you take medicine for about two or three weeks, you are likely to no longer spread the TB germ to others. If your doctor or nurse agrees, you will be able to go back to your daily routine. People with TB should not be forced out of work. People are still strong enough to hold down a job and earn an income, and it is important for their morale and security.
24. People whose families have had TB (e.g. grandfather) are more at risk of getting TB.	FALSE. TB is transmitted through the air, not by our genes. If your grandparents had TB, and you did not meet them, then there is no risk you would get TB.
Prevention	
25. Wearing masks is the best form of protection against TB.	FALSE. Standard masks are of little value. High quality masks might reduce risk, but are very expensive.
26. Ventilation and sunlight are important methods for preventing TB.	TRUE. Ventilation reduces the risk of getting TB by 90%. Windows on both sides of a room – air comes in one side and out the other – allows for the TB droplets to be blown out of the space and into the air, where sunlight destroys them. TB germs do not survive sunlight – normal light outside. If someone coughs droplets and these droplets are exposed to sunlight, within minutes the germ will die. If a room is dark and unventilated, TB germs can stay trapped for up to three days.
27. Putting TB patients in isolated rooms is a good method for preventing TB.	FALSE. Isolating TB patients is not a good method for preventing TB; it also promotes stigma. However, patients have been isolated in some cases where they have resistant strains of TB.
28. Stopping the sharing of utensils is a good method for preventing TB.	FALSE. TB cannot be transmitted through sharing eating utensils. Everyone can use the same utensils. Stopping the sharing of utensils promotes stigma.
29. Sticking to only one sexual partner is a good method for preventing TB.	FALSE. It is generally important to stick to one sexual partner to avoid infections such as STIs including HIV. This does not include TB as it is not transmitted through sex.
30. It is important to get tested if you have a prolonged cough or cough up blood.	TRUE. Taking a test helps you know if you have TB so you can start treatment early.
31. If you are coughing or sneezing you should cover your nose and mouth.	TRUE. The recommended practice is to lift the arm up and cover the nose and mouth with the inner surface of the arm when coughing or sneezing. This is to keep germs away from the hands. The hands cannot spread TB, but other respiratory germs such as influenza can.
32. People living with HIV who don't have TB should take preventive therapy.	TRUE. People living with HIV who don't have TB should take a drug called isoniazid to prevent the risk of TB.
TB testing and treatment	
33. TB is diagnosed by examining the patient's sputum.	TRUE. One way to diagnose TB is by examining sputum.
34. It is safe to take TB treatment during pregnancy.	TRUE. A pregnant person can be on TB treatment.
35. A person cannot take TB treatment at the same time as taking ARVs.	FALSE. One can take TB treatment and ARVs. It is important that she/he seeks advice from qualified health workers at the health centre.
36. The treatment used to treat adults for TB is the same treatment for children.	TRUE. Children and adults take the same treatment; however, there are differences in the dosage and the period taken. Other drugs are not recommended for children such as streptomycin.

Annex 2 True or false quiz – answers

Question	Answer
37. You can be cured of TB if you take treatment consistently for six or eight months.	TRUE. It is important to take medication as prescribed to ensure success in treatment of TB.
38. The side effects of TB treatment are...	Some of the side effects of TB treatment include nausea, abdominal pains, pain in joints and burning sensation in the feet. Severe side effects include ringing in the ears, deafness, severe skin rash, dizziness, yellowness of the eyes, poor sight, loss of colour perception. If one presents any of the above they should seek medical attention from qualified medical personnel at the clinic.
39. During TB treatment eat well, avoid alcohol and tobacco, and avoid stress.	TRUE. The body needs nutritious foods to build it up, give it energy and make it stronger so that it can fight infections and sicknesses. Alcohol and cigarettes can damage the body's ability to fight off diseases, so stopping or reducing their consumption can help to keep the body strong.
TB and HIV	
40. TB is the same thing as HIV. There is no difference.	FALSE: TB and HIV are different. TB is a germ, which is transmitted through the air. HIV is a virus, which is transmitted through sex or contact with infected body fluids. HIV attacks and destroys the body's immune system over a period of time. Once the body is weak, the person begins to suffer from illnesses such as TB.
41. TB is the most common opportunistic infection and the leading cause of death in people living with HIV.	TRUE. Statistics show that TB is the major cause of death in people living with HIV.
42. Roughly one third of people living with HIV will develop TB in their lifetime, in the absence of isoniazid preventive therapy or anti-retroviral therapy.	TRUE. It is estimated that roughly one third of people living with HIV will develop TB in their lifetime, in the absence of isoniazid preventive therapy or anti-retroviral therapy.
43. People living with HIV are at high risk of getting TB because their immune system is weak.	TRUE. People living with HIV are at increased risk of getting sick from TB because their immune system is weak and their bodies cannot fight off germs very well. In Zambia 70–80% of TB patients are HIV positive.
44. A person living with HIV can progress rapidly from TB infection to TB disease over a few months rather than several years as is common for people who are HIV negative.	TRUE. This is because of the weakened immune system that a person living with HIV may have. TB also accelerates the pace at which they may progress to an AIDS diagnosis.
45. A person living with HIV cannot be cured of TB.	FALSE. TB can be cured, even in people living with HIV. The main thing is to continue the treatment on a regular and consistent basis.
46. There is no interrelationship between HIV and TB.	FALSE. Together, HIV and TB are a deadly combination, each disease making the other disease progress faster. HIV makes the immune system weak, so that someone who is HIV positive and also infected with TB becomes much more likely to get sick with TB than someone infected with TB who is HIV negative. In some countries, TB is the leading cause of death among people who have HIV. HIV is the single major reason why there has been such a large increase in cases of TB over the past decade.
47. People living with HIV who are not taking ARVs have a higher risk of getting TB than people who are HIV negative.	TRUE. A person living with HIV who is not on ARVs can progress more rapidly from TB infection to TB disease than one who is HIV negative and does not have a condition that lowers their immune system because they are able to fight the infection.

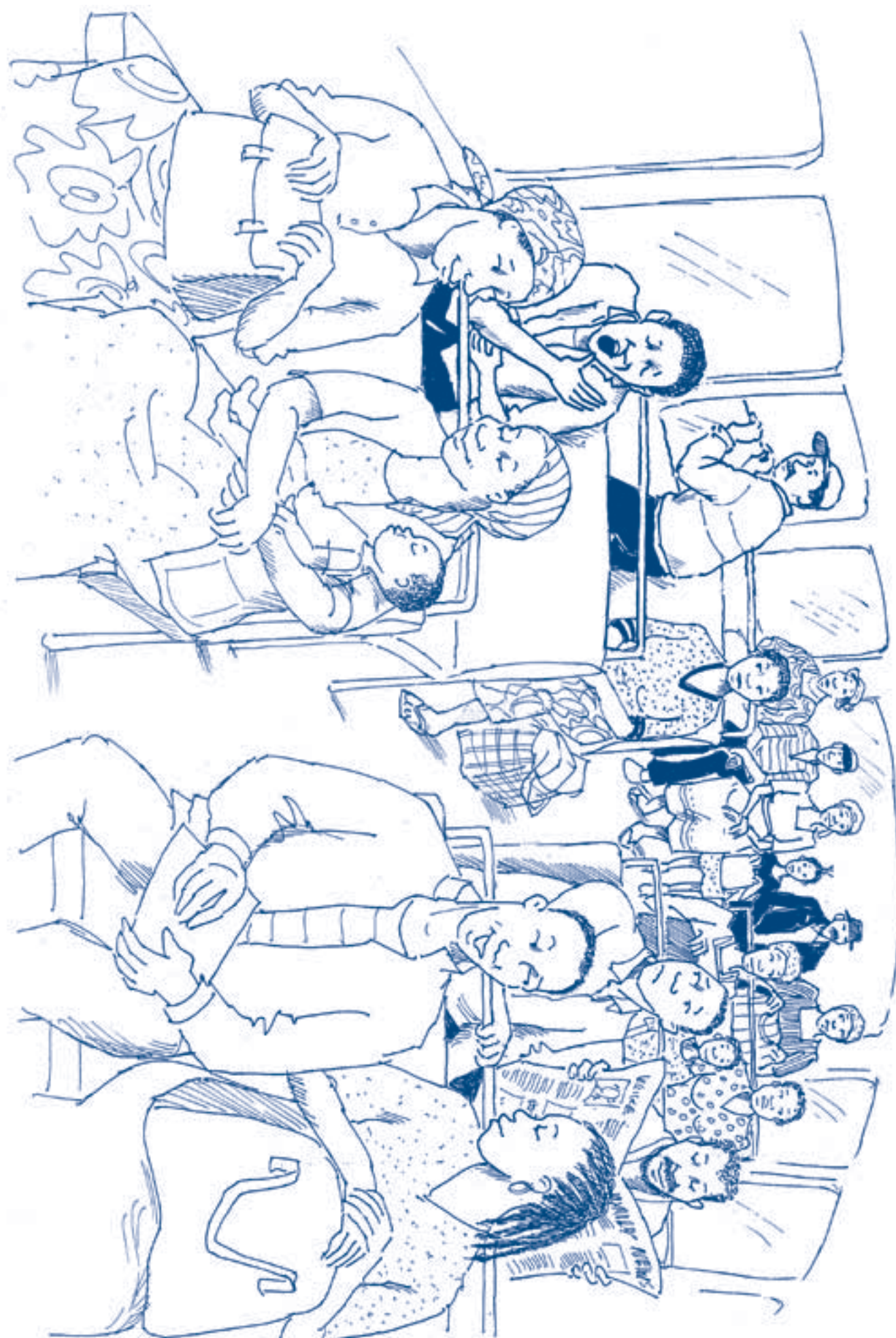
TB stigma picture 1

These pictures show examples of TB stigma and can be used with exercises in this module (such as Exercise 1) or in conjunction with the Alliance toolkit *Understanding and Challenging HIV Stigma: Toolkit for Action*. The pictures can also be used informally as a way of assisting a group discussion about TB stigma with clinic staff and even family members.





TB stigma picture 3

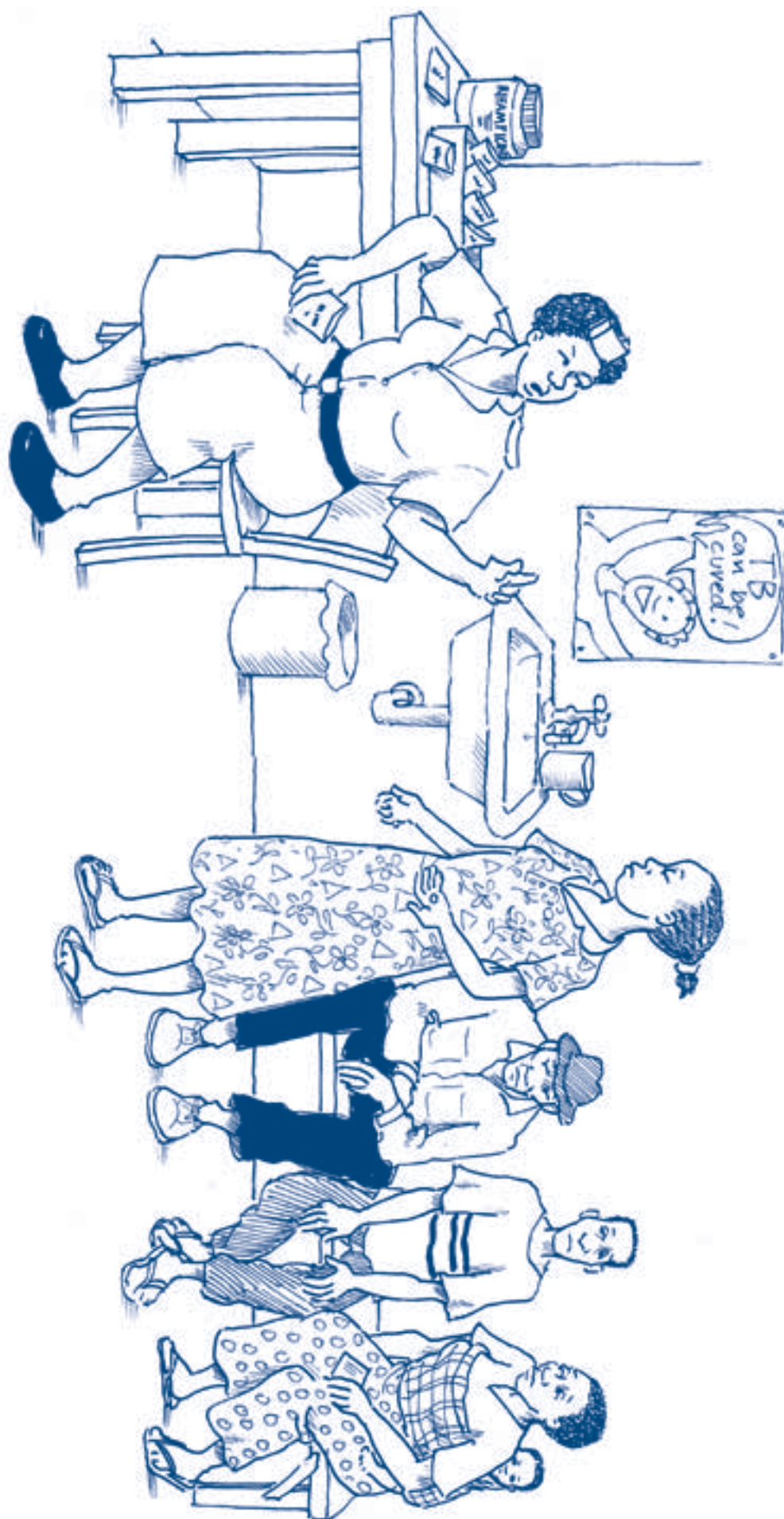


TB stigma picture 4



TB stigma picture 5





TB stigma picture 7





TB stigma picture 9





TB stigma picture 11







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Related resource

The toolkit *Understanding and Challenging HIV Stigma: Toolkit for Action* is also available from the Alliance and includes the following modules:

Introduction

Using the toolkit

Module A

Naming the problem

Module B

More understanding, less fear

Module C

Sex, morality, shame and blame

Module D

The family and stigma

Module E

Home-based care and stigma

Module F

Coping with stigma

Module G

Treatment and stigma

Module H

MSM and stigma

Module I

Children and stigma

Module J

Young people and stigma

Moving to action module

Thinking about change

Moving to action

Developing skills for advocacy

Picture booklet

General stigma pictures

Rights pictures

Additional booklets will be published as new modules are developed.