Tuberculosis Stigma Reduction
for Health Care Institutions

INTERVENTION PACKAGE

Allies Approach
The KNCV Stigma Reduction Tool Box

KNCV TUBERCULOSIS FOUNDATION
To eliminate TB

www.kncvtbc.org

Tuberculosis Stigma Reduction
for Health Care Institutions

INTERVENTION PACKAGE

Allies Approach
The KNCV Stigma Reduction Tool Box

Authors:
Ieva Leimane | Ellen M.H. Mitchell | Sarah van de Berg | Veriko Mirtskhulava

KNCV
August 2018

ACKNOWLEDGEMENTS

The authors would like to express their gratitude to everyone who provided support and guidance in the development and review of this document. We are grateful for the technical reviews by Kathy Fiekert, Rajita Bhavaraju, Mirjam Musch, Esther Buregyeya, D'Arcy Richardson, Tomas Chang Pico, Mayra Arias, Veriko Mirtskhulava, Ineke Huitema, Max Meis, Virginie Oddoux, Marcela Tommasi, Erik Post, Susan Bergson, and Ingrid Schoeman.

We are appreciative of the feedback and technical leadership provided by Michael Kimerling and Susan van den Hof.

The authors would like to express their appreciation to the training team who field tested these materials and provided feedback, including Ineke Huitema, Maria Idrissova, Marleen Heus, Marcela Tomasi, and Niesje Jansen. We appreciate the feedback from the Dutch TB nurses and medical technicians who participated in pilot tests and gave suggestions for improvement.

Copy editing
Colleen Mazin, MS/MPH

Layout design
Marcel R. Claxton

ATTRIBUTION

Some of the exercises in this package were adapted from original materials created by other authors. Some exercises in this package combine ideas from multiple sources. Each original source is listed in the exercise itself. These pioneering works are included in the original sources:

1. Abortion attitude transformation: Values clarification activities for global audience, Ipas. http://www.ipas.org/en/Resources/Ipas%20Publications/Abortion-attitude-transformation-A-values-clarification-toolkit-for-global-audiences.aspx.
2. A guide to Creating and Evaluating Patient Material, Guidelines for effective Print communication, Maine health. How to choose and develop written educational Materials. Rehabilitation Nursing, Vol. 35, No.3. May/June 2012. Canadian Council on Learning, 2007a, 2007b and 2008; Rootman & Gordon-El-Bihbety, 2008.
3. Doak CC, Doak LG, Root JH. 1996. Teaching Patients with Low Literacy Skills. JB Lippincott Company: Philadelphia, PA.
4. Generic Training Package Trainer Manual, Module 5 Stigma and Discrimination related to MTCT, Measurement guide. ICRW, PMTCT. https://www.cdc.gov/globalaids/resources/pmtct-care/docs/tm/module_5tm.pdf
5. Health Care Workers for Change, Women's Health Project, United Nations Institute Training and Research, for www.unitar.org.
6. Interpersonal communication and counselling, PATH. http://www.path.org/publications/files/CP_ukraine_tb_hiv_ipcc_fm.pdf
7. Non-violent communication, Connecting2life. http://www.connecting2life.net/nonviolent-communication-nvc/
8. Patient privacy and confidentiality, PATH. http://www.path.org/publications/files/RH_ensuring_privacy.pdf.
9. Patients' rights and confidentiality in tuberculosis control, U.S. Department of Health and Human Services Centers for Disease Control and Prevention. Elimination. https://www.cdc.gov/tb/education/ssmodules/pdfs/module7.pdf.
10. Reducing HIV Stigma and Gender-Based Violence. Toolkit for Health Care Providers in India. ICRW, www.icrw.org.
11. Understanding and challenging TB Stigma, Toolkit for action, HIV Alliance. http://www.aidsalliance.org/assets/000/000/831/4_Stigma_F_and_G_original.pdf?1407244500.
12. We are the change: Dealing with HIV-related self-stigma. Facilitators Guide Using the Work of Byron Katie: Inquiry-based stress reduction: www.theworkforchange.org.

Dedication

This document is dedicated to the frontline health care workers around the world and the patients, families, and communities that work to end TB.

TABLE OF CONTENTS

TABLE OF CONTENTS

INTRODUCTION

INTRODUCTION

Goal

The Allies Approach Intervention Package aims to change the attitudes and workplace conditions of health care workers to enable them to provide empathic, non-stigmatizing care to all (DR-) TB patients.

This package is called 'the Allies Approach' because it fosters a dynamic mutually-supportive alliance between patients and providers. The lack of attention to health workers' wellbeing may facilitate stigmatizing attitudes and behaviors of health workers towards (DR-) TB patients.

Overall Strategy

The intervention package provides a comprehensive approach.

1. **VALUES:** a module on the importance, ideals, and ethos of health care workers.
2. **HEART:** a module to explore self-compassion and compassion for patients.
3. **HEAD:** a module to reduce the impulse to judge.
4. **FACE:** a module on interpersonal communication.
5. **HANDS:** a module with practical tools to create an enabling environment for compassionate care work.

The theoretical change theories that inform the strategy include:

- Organizational Change.
- Diffusion of Innovation Theory.
- The Transtheoretical Model of Behavior Change.

Application of the Allies Approach Intervention Package

The Allies Approach Intervention Package consists of a self-learning module and a modular interactive learning approach.

The self-learning module aims to create awareness of (DR-) TB stigma and to provide the basic knowledge needed to reduce stigma. The interactive learning aims to reinforce and reflect on the lessons and insights acquired during the self-learning process, and allows participants to explore, question, clarify, and affirm their values and beliefs about (DR-) TB stigma.

Justification

Tuberculosis (TB) remains a major global health issue, despite the availability of curative treatment for many decades. Several factors cause and exacerbate the persistence of TB, including stigma. TB-related stigma has negative consequences on persons seeking medical help, community support, and even treatment adherence. Stigmatizing

attitudes and behaviors undercut the trust necessary for addressing the epidemic.

TB stigmatization of people with TB, their friends and family, and anyone who cares for them can occur in health care facilities. Stigmatizing behavior and attitudes are observed at health facilities among health workers of different professional levels. Stigmatizing attitudes of health care workers (HCW) during TB treatment can lead to treatment interruptions, with increased risk for the acquisition or spread of TB.

TB stigma not only affects patients, but it can also affect the health care workers who care for them. Health workers who offer TB services are frequently discredited or devalued in workplace hierarchies. (DR-) TB care providers in particular can be marginalized and made to feel that they are performing "dirty work" instead of saving lives.

Health workers who believe (DR-) TB will stigmatize them are often less likely to use on-site occupational health services, present for TB screening, disclose their TB status if they develop TB, and follow TB transmission prevention and control measures, such as wearing a N-95 respirator.

There are five main building blocks of stigma, i.e., processes that may result in stigmatizing behavior and attitudes:

- Emphasizing differences and exceptionalism instead of universality in TB care (e.g., by special terminology, extra scrutiny of drug consumption, or unnecessary masking.)
- Implying negative traits, such as untrustworthiness and selfishness.
- Blaming TB patients and their families for developing (DR-) TB.
- Emphasizing peril, causing fear of infection, and distancing.
- Linking TB to other disparaging traits or behaviors.

Health workers may lack safe and decent working conditions[1–4], or may be working in facilities that do not have adequate environmental and administrative infection control measures required to protect them.[3,4] They may care for (DR-) TB patients in public sector facilities where salaries are paid irregularly and commodities are insufficient.[5–8]

Health workers also experience a higher prevalence of workplace violence.[9–13] Poorly designed policies, guidelines, and educational messages may reinforce stigmatizing language and ideas among health workers. Irregular or absent supportive supervision is associated with stigmatizing behavior. Health workers' basic needs must be met in order for them to properly address the medical needs of patients.

Health workers who practice under decent working conditions and have self-compassion are, in turn, able to render respectful and compassionate care to patients. Health workers' well-being are influenced by protection of their rights through a safe working environment, job security for workers who become infected or develop (DR-) TB, alleviation of high work-loads, which may lead to high staff turn-over rates, and 'dirty work stigma'.

Conceptual Framework of TB Stigma

In order to effectively design and implement (DR-) TB stigma reduction interventions, one must understand how (DR-) TB stigma in health care facilities is created. The conceptual framework of TB stigma depicts possible drivers, facilitators, modifiers and manifestations of (DR-) TB stigma in health care facilities and how these may be interlinked.

Facilitators are policies and structural conditions of the health care facility that may reinforce stigmatization. They may include:

1. Lack of promotion and professional development for health care workers
2. Lack of effective transmission control policies and infra-structure.
3. Lack of policies to protect privacy of patients and health care workers.
4. Lack of visual and auditory privacy for patients.
5. Use of value-laden terminology in official documents.
6. Authoritarian treatment supervision policy.
7. Use of coercion, punishment, and threats.
8. Hierarchy among health care workers.

The organizational structure of a workplace (employee hierarchy) may enforce unofficial hierarchies that result from "dirty work stigma." This is when health care providers stigmatize themselves for caring for a stigmatized group, which may increase stigmatizing behavior towards TB patients.

Drivers are defined as health care workers individual characteristics that promote stigmatization:

1. *fear-based stigma* (fear from infection), and
2. *value-based stigma* (association of TB with disvalued characteristics). [2,3]

Drivers of fear-based TB stigma include lack of knowledge regarding TB transmission [2], infectiousness [2], appropriate transmission control measures, and the curability of the disease. [4] The main driver of value-based stigma is linking TB to disvalued characteristics, such as malnutrition, poverty and low social class, and HIV infection, leading to the transfer of HIV-associated stigma onto TB patients. A further TB-related driver may be the perception that the TB patient is responsible for contracting the disease. [2,5]

Modifiers are as health care workers individual factors that in combination with drivers, may enforce stigma. They may include lack of awareness of stigma and its effects and the denial of health care workers' rights to safe working conditions and lack of recognition of health care workers risk and need for support.

Manifestations of stigma are immediate, and mostly negative, results of stigma. [1] This includes the behavior attitudes that result from value- or fear-based stigma that lead to the patient feeling stigmatized. Transmission control measures, including wearing a mask and gloves and separating the patient from others may be isolating. These

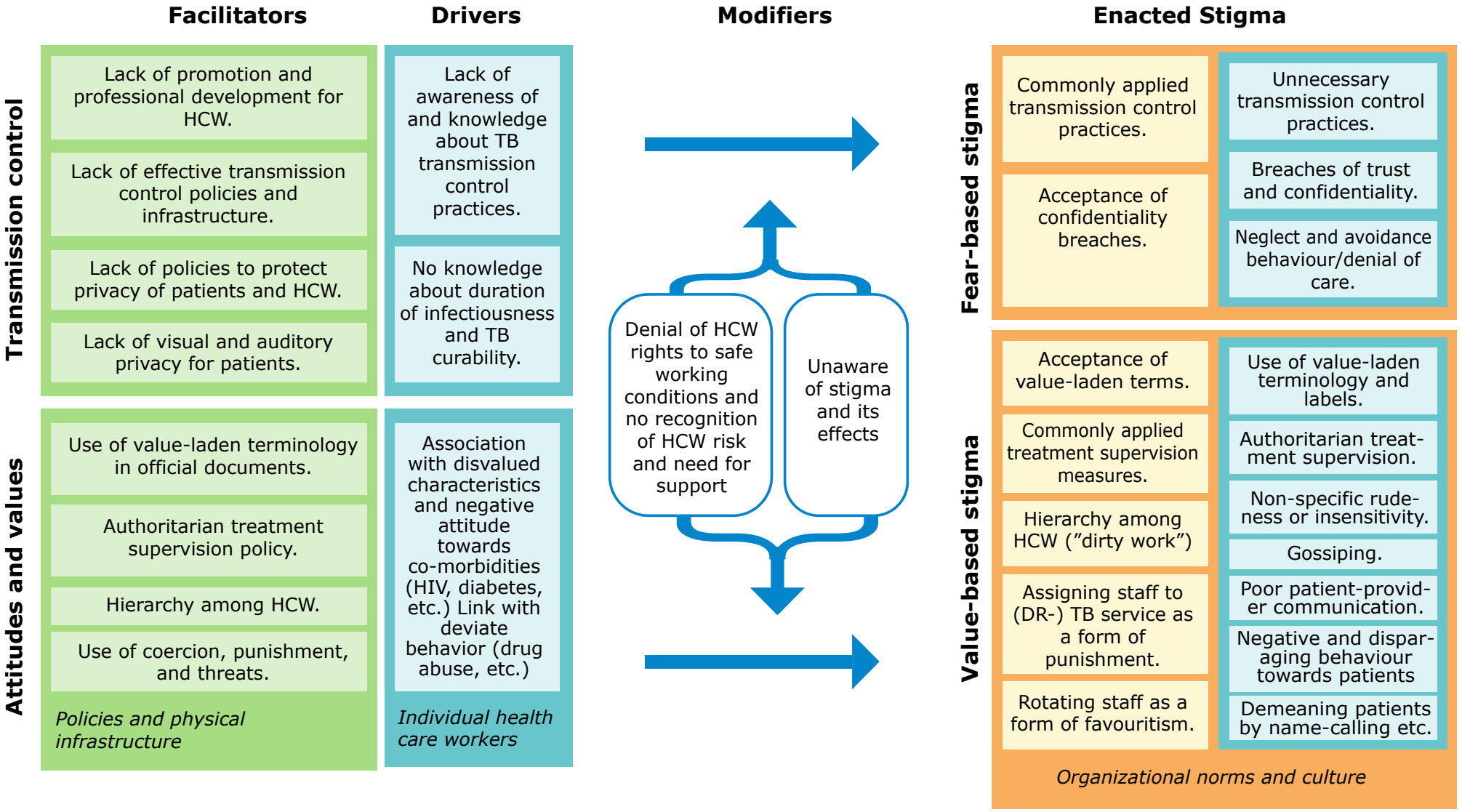


Figure 1. Conceptual Framework of TB Stigma.

measures enhance fear and make patients feel ashamed. [6,7] Patients may lose confidence when the health care workers fear of getting infected causes neglect and avoidance behaviors. [6] It is essential to distinguish between legitimate precautions and stigmatizing or discriminatory measures. [6] Negative attitudes towards TB patients may manifest in microaggression including negative and disparaging behavior towards patients, name-calling, rudeness, or insensitivity. [8]

Specific Behaviors and Conditions the Intervention Will Reduce

Management systems

- Denial of health care workers' access to effective infection transmission commodities and screening.
- Recognition of health care workers' risk and need for support.
- Denial of professional development opportunities for health workers with TB.

Organizational structures and strategies

- Lack of visual and auditory privacy.
- Lack of adequate administrative and environmental measures to reduce TB transmission.
- Lack of safe working conditions, both architectural and structural.

Transmission Control measures*

- Masking.
- Separation.
- Hospitalization and isolation.

Providers' behaviors and attitudes

- Negative and disparaging attitudes and behavior towards TB patients.
- Use of value-laden terminology.
- Gossiping and breaches of trust and confidentiality.
- Demeaning patients.
- Demeaning health care workers for providing (DR-) TB care.
- Rudeness, insensitivity, and name-calling (microaggressions).
- Use of pressure, punishment, and threats.

TB policies and practices

- Authoritarian treatment supervision.
- Task-shifting, over-referral, and denial of services.
- Use of value-laden terminology in policies.
- Obligatory disclosure of personal information (breech of privacy).

**Note: Before applying these measures, review if and when they are necessary.*

Effective Organization Change

There are multiple ways to implement the package, but organizational change is most likely to be embraced and sustained if the management welcomes the intervention and health workers, and the staff identifies the need for stigma reduction. Effective interventions at the organizational level (including those that focus on stigma reduction) have the following characteristics:

Perception of Benefits

1.	Observability	The degree to which the results of an innovation are visible to potential adopters.
2.	Relative Advantage	The degree to which the innovation is perceived to be superior to current practice.
3.	Compatibility	The degree to which the innovation is perceived to be consistent with socio-cultural values, previous ideas, and/or perceived needs.
4.	Trialability	The degree to which the innovation can be experienced on a limited basis.
5.	Complexity	The degree to which an innovation is difficult to use or understand. This reflects its simplicity.

What is necessary for sustainable and lasting change in health care institutions?

- The right audience and supporters.
- Perception of benefits.
- A good intervention.

Selecting Health Care Facilities

A health care facility is most likely to make organizational changes as a result of the intervention if:

- Knowledge sharing happens at all levels.
- Changes are routine.
- Teams are cross-functional.
- Prudent risk taking is rewarded.
- Sources of change are trustworthy.
- Motivating and communicating with implementers of change (change agents) occurs
- The purpose, benefits, and anticipated results of the change are clear.
- There is ongoing technical support.
- The health care institution staff are willing to implement the change (buy-in)
- There is clearly assigned and accepted responsibility for implementing the change (buy-in).

If a health care institution does not enable organizational change, it does not mean that the Allies approach will not work there. It is still very important to work in challenging settings, but one should adjust the intensity (dosage) of the intervention and/or lower expectations of uptake accordingly. An intervention is more likely to change organizational culture if it is implemented in a setting that is open to change and has a change culture.

Participants should support each other, as a team approach facilitates the application of new competencies. Service providers need to allow post-training follow-up visits for stigma reduction measurement and performance evaluation.

Selecting the Implementation Team

To successfully carry out the intervention, select a team at each facility who will coordinate the interactive learning sessions, catalyze policy review, support the monitoring and evaluation, and liaise with interested parties (e.g., TB survivor groups, union leaders, management, and TB patients.) The team should embody the principles of the intervention and help to role model new attitudes and behaviors to help change norms and inspire staff to apply new competencies on their job (Diffusion of Innovation Theory).[14-15] For more information on identifying effective team members, refer to the section *Selection of Facilitators (Key opinion leaders)* below.

Target Audience for the Allies Approach Intervention

The intervention is appropriate for all levels of the health care institution . There is no need to screen or choose workers to participate. Indeed, it is important for broad participation and generous coverage to change organizational culture.

Part I. Self-learning

The primary audiences for Part I of the Allies Approach Intervention Package are health care workers, including nurses, auxiliary staff, laboratory staff, social workers, community health care workers, registrars, cleaners, and those who provide supportive services, such as patient registration, food, and laundry services. There is no need to screen or select workers in the health care facilities for participation. The intervention is appropriate for all literate staff.

Part II. Interactive Learning

Part II is designed to be adapted to a variety of stakeholders, including policymakers, health care workers, managers, students and faculty of universities and medical schools, advocates, community members, and the media.

Monitoring and Evaluation

To monitor and evaluate (M&E) interventions, it is necessary to undertake baseline measurements to map the "stigma situation" at a specific health care institution . Additional guidance and training materials can be found in the "TB Stigma Measurement Guidance." www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf

The facility baseline and additional tools referenced in this section can be found in the annex "Baseline/ Endline Evaluation," including:

1. Facility baseline, measuring structural- and self-stigma (HCWs and patients).
2. Feedback on usability/acceptability/curriculum performance.
3. End-line facility assessment measuring structural- and self-stigma (HCWs and patients).

Facility Baseline

Assess how favorable the environment is before selecting a health care facility for an intervention. A comprehensive baseline for evaluating the impact of a stigma reduction intervention in health facilities should explore structural-level stigma, such as norms and policies that may mandate masking, triage, and physical separation of TB patients. It should also evaluate how things actually occur, which may differ from official policies. Secondary stigmatization of health care workers by their peers should also be measured.

Figure 2 shows where stigma can be embedded. The baseline should include these levels:

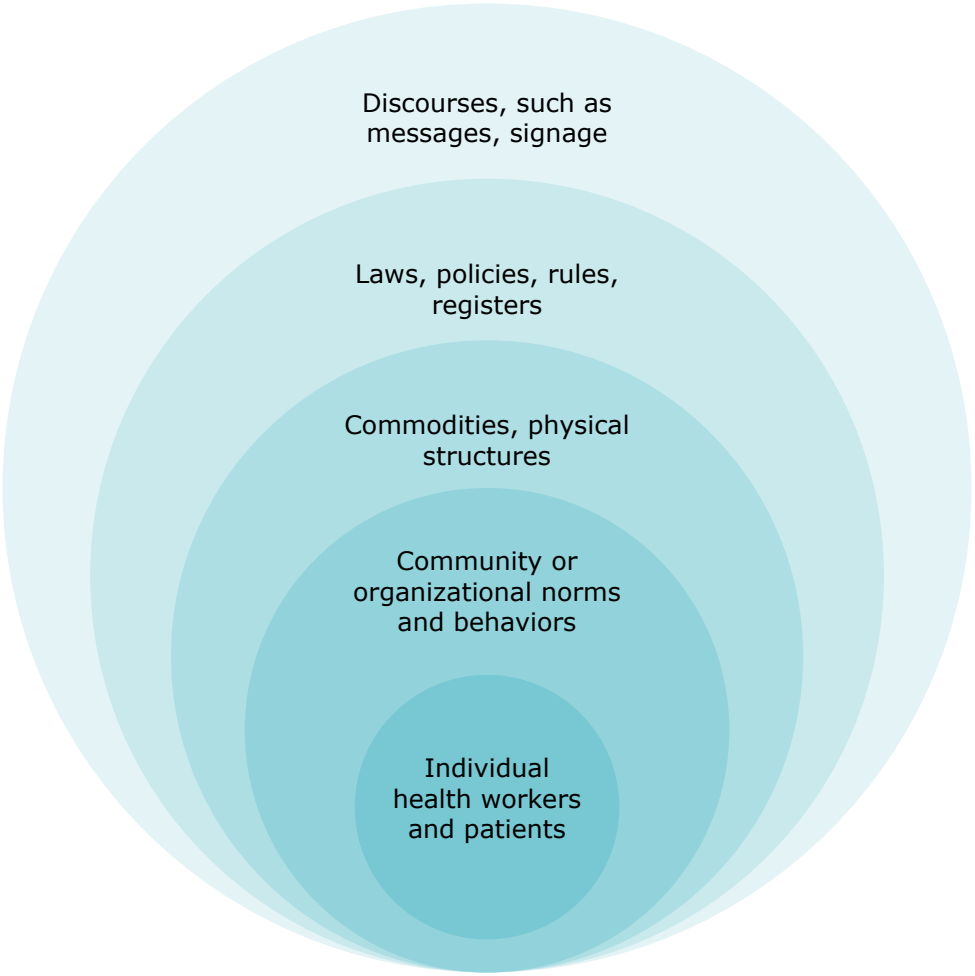


Figure 2. Potential sources of stigma in a health care facility

The baseline should include a content analysis of health care facility policies, infrastructures, organizational norms and culture, and structure. We hypothesize that structures related to the drivers and manifestations of TB stigma are facilitators of stigma. These structures include:

1. **Policies:** on infection control, confidentiality, treatment supervision use of value-laden terminology, and HCW training/education.
2. **Infrastructure:** distinct TB rooms/buildings that may reveal TB patients and messaging (signs, posters).
3. **Organizational norms and culture:** learning culture and acceptance of stigmatizing attitudes and behavior

The baseline data will be used to choose and prioritize modules, workshops, and exercises to address the gaps identified in the baseline. For example, if there is a lack of stigma knowledge, then interventions in the HEAD and VALUES modules could be prioritized. Similarly, if policy is a priority, exercises to catalyze changes in policy and the enabling environment for compassionate care, such as those found in the HEART and HANDS modules, can be prioritized. In addition, having a sense of the staff culture at any facility through the baseline can help prioritize workshops or exercises. For example, if staff burnout is an issue, exercises in the HANDS module could be prioritized.

Methods for policy, behavior, and cultural stigma measurement are explained in the TB Stigma Measurement Guidance. www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf

Measuring Change Individual Health Care Worker's Behavior and Attitudes

Part I includes an assessment of participants' knowledge, attitudes, and practices via self-learning to aid in participant selection and to tailor the initial exercises to the group.

Tracking changes in attitudes and behavioral intention of individual staff is also important. There are a variety of generic scales for measuring discriminatory attitudes that can be adapted to TB. These are discussed in the TB Stigma Measurement Guidance: www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf

Policies, Infrastructure, and Organizational Norms and Culture

Changes in health care institution policies, infrastructure, and organizational norms and culture should result from changes in health workers' behavior and attitudes. There should be deferred measurement of changes in these structures following the assessment of individual health workers' behavior and attitudes change.

In addition, measuring change can also help identify additional modules, workshops, or exercises that can be reinforced or repeated to address any future gaps in behavior and attitudes.

PART 1

SELF-LEARNING

Authors:
Sarah van de Berg
Ieva Leimane
Ellen M.H. Mitchell

INTRODUCTION

This self-learning module is developed for health care workers who work with tuberculosis (TB) patients and provide people-centered care. This module aims to raise awareness about the stigmatization of TB patients and health care workers providing TB services in health care institutions. It will enable non-stigmatizing care.

Objectives

After you have completed this self-learning module, you will know:

1. What is TB stigma, what are the causes of stigma, and why it is important to address stigma?
2. How do people stigmatize and how are they stigmatized in the health care setting, and how can you mitigate this stigmatization?
3. How can you strengthen a health care worker's position?

Before starting this module, we would like you to answer following questions.

Current profession/position

1. What is your current profession and level of involvement in (DR-)TB patient care?

- ☐ Administrator
- ☐ Cashier
- ☐ Manager
- ☐ Medical Record staff
- ☐ Receptionist
- ☐ Translator/interpreter
- ☐ Medical doctor, TB physician
- ☐ Medical Laboratory Technician
- ☐ Nurse
- ☐ Pharmacists
- ☐ Specialist, please specify: _____
- ☐ Counselor
- ☐ Food server
- ☐ Health education staff
- ☐ Janitor
- ☐ Social worker
- ☐ Support staff
- ☐ Volunteer
- ☐ Other, please specify: _____

Level of involvement in (DR-)TB patient care

2. What is your level of involvement in DR-TB service provision (tick all that apply)?

- ☐ Prevention
- ☐ Diagnosis
- ☐ Treatment
- ☐ Support
- ☐ Other, please specify: _____
- ☐ None

What are my attitudes and behaviors surrounding transmission control?

3. How worried would you be about TB infection if you did the following things?

Situation	Not worried	A little worried	Worried	Very Worried	N/A
Touch bedding or belongings of a TB patient	0	1	2	3	99
Collect a sputum sample from a coughing person	0	1	2	3	99
Dress the wound of a TB patient	0	1	2	3	99
Provide counseling to a coughing person	0	1	2	3	99
Handle sputum in the laboratory	0	1	2	3	99

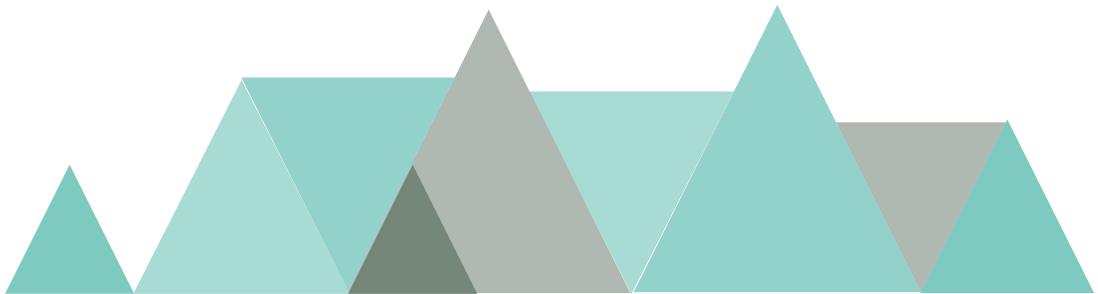
4. Do you typically do any of the following when providing care or services to people who are coughing?

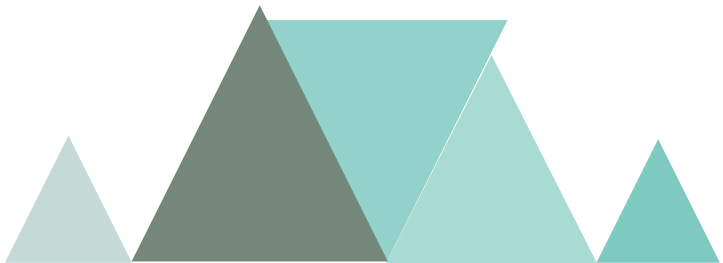
Action	Yes	No	N/A
Wear double gloves	1	0	99
Wear N95 respirator	1	0	99
Ask people who cough to wear a mask	1	0	99
Keep windows and doors open	1	0	99
Isolate all TB patients	1	0	99
Properly dispose sputum waste	1	0	99
Use and teach proper cough etiquette	1	0	99
Wear a respirator when talking to DR-TB patients in the continuation phase of treatment	1	0	99

5. Do you agree with any of the following statements about transmission control (attitudes)?
Response categories: 5 points Likert scale, ranging from 1 (Strongly Disagree) to 5 (Strongly Agree)

Response categories	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
Coughing into a cloth is courteous	1	2	3	4	5
Treating coughers before other patients benefits everyone	1	2	3	4	5
Everyone coughs	1	2	3	4	5
Wearing a respirator protects myself and my family	1	2	3	4	5
Wearing a mask tells people I have TB	1	2	3	4	5

Response categories	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
People look at me differently when I wear a respirator	1	2	3	4	5
People avoid me when I wear a mask	1	2	3	4	5
A mask is not needed after two months of effective TB treatment	1	2	3	4	5
Preventing TB transmission requires strength	1	2	3	4	5
I feel bad when I keep a distance from my patients	1	2	3	4	5
Wearing a mask makes me feel bad	1	2	3	4	5
A mask indicates risk of TB	1	2	3	4	5
A respirator reduces infection risk	1	2	3	4	5
It is disgusting when people clear their lungs by spitting	1	2	3	4	5
Opening doors and windows makes me safer	1	2	3	4	5





Content

During this self-learning module, the following topics will be covered: stigma theory, subconscious stereotypes of TB patients, health care workers' rights and well-being, stigma of transmission control, upholding patients' rights and creating a good patient-provider relationship, terminology, and champions/opinion leaders in TB care. Respective exercises can be found below.

Topics	Exercises	
Stigma theory	• What is Stigma? • Conceptual Framework of TB Stigma • What Causes Stigma?	• Why is it Important to Address Stigma? • How Can You Address Stigma in Health Care Institutions?
Health Care Workers' Rights and Well-being	• What are Health Care Workers' Rights?	• How are Health Care Workers Affected by Stigma? • What are Safe Working Conditions?
Stigma of Transmission Control	• Which Transmission Control Measures May be Stigmatizing, if Misinterpreted? • How to Avoid Being Stigmatizing in Stressful Situations?	• Can You See How People Feel? • Which Patients are Infectious? • Summary: Transmission Control Measures in Health Care Institutions.
Subconscious Stereotypes of TB Patients	• What are Subconscious Stereotypes?	
Upholding Patients' Rights and Creating a Good Patient-Provider Relationship	• Counselling Patients • Which Questions Should I Ask? • Which Questions are Appropriate? • What are Patients' Rights?	• What should be done? • The "Right" to Refuse or Enforce Treatment - an Ethical Dilemma • How to Protect Patients' Privacy?
Terminology	• What Terms Should I Use?	
Champions/Opinion Leaders in TB Care	• How to be a Change Agent/Opinion Leader	

Topics	Exercises	
Summary	• What is Stigma? • What Causes Stigma? • Why it is Important to Address Stigma?	• How do People Stigmatize, and How are People Stigmatized in the Health Care Settings? • How can You Mitigate Against Stigmatization?
Assessment	• Test	
Closing	• Closing Remarks	

Table 1. Self-learning module topics and exercises.

WHAT IS STIGMA?

Stigma is defined as the relationship between an attribute and a stereotype that assigns undesirable labels, qualities, and behaviors to a person. Labeled individuals are devalued socially, leading to inequality and discrimination.[1] For example, a TB patient is always assumed to be infectious, and therefore is labelled as dangerous, which justifies behaviors and policies that create social distance (e.g., triage, separation).

Video: "Stop the Stigma" https://www.youtube.com/watch?v=DWaOsPiv-gw

TB patient quotes

1 - "...A nurse, who seemed quite mature, looked like very much fearing that it [TB] could be transmitted to her. She suggested to me to put on the mask every time and not to put it off even for a fraction of time as if she was alarmed and saying to me "be careful."' (18 year old female patient) .[2]

2 - "I'll tell you what happened to me when I was suspected of TB. ... [At his first visit to a hospital while seeking diagnosis] I mentioned that I saw blood in my sputum last week and came here for treatment. Suddenly and surprisingly she asked me to stand far from the window and she covered her mouth, her behavior changed. I got surprised and worried I may have got a dangerous disease. I felt so scared and [went] to the room [i.e., home] without any checkup. ...Now I do not want to remember that time." (29 year old community member).[2]

3 - "…when you have TB and report to the hospital, you are isolated to a place where many people will not see you; that is why it is a shameful disease …" (Female community member, individual interview).[3]

---

*1 **Discrimination** - to enact stigma through illegal means or denying a person the equal treatment to which they are entitled.*

Stigmatization and discrimination
Stigmatization reflects an attitude, but discrimination is an act or behavior. Discrimination is a way of expressing, either on purpose or inadvertently, stigmatizing thoughts. Stigma and discrimination are linked. Stigmatized individuals may suffer discrimination and human rights violations. Stigmatizing thoughts can lead a person to act or behave in a way that denies services or entitlements to another person.

Source: Module 5. Stigma and Discrimination Related to MTCT. https://www.cdc.gov/globalaids/Resources/pmtct-care/docs/TM/Module_5TM.pdf

What is Stigma? (continued)

4 - ". . . if you are talking about the hospitals, even the doctor is afraid of TB, so by the time he gets to the patient he had already covered the nose and mouth. At times the relatives even pay the nurses to keep the patient at the hospital because the nurses wear gloves and mask before they attend to the patient. And when the family brings food for the patient, they just give it to the nurse with a message for the patient and go back home …" (Male community member, focus group).[3]

5 - "…when I went to Accra, I met a lady doctor; the woman has no patience at all! When you cough, she will shout at you saying "gentleman, go there, go there". The way she behaves means that when you have this disease, she does not want you to come near her; she hates you. When it happened like that, I decided to stop going there and came here instead … there are some people who wouldn't like to be treated like that, so they would not go to the hospital just because of the way she will treat them …" (Male patient with TB, focus group).[3]

6 - "…the doctors made us aware that the disease is infectious, so no one should use a cup used by the person; he should be isolated and his plates should be separated …" (Male community member, focus group).[3]

7 - "People are not willing to approach TB patients...Even I remember a multidrug resistant TB patient returned to his home due to the fact that the health care worker refused to treat him...TB is a fearful disease."[4]

8 - "I came to the clinic, because I was not feeling well […] the nurse did not respond well, because they suspected TB. When I came I was coughing and she was very rude. She shouted: "If you are coughing, this is not the right place to come. Go to the TB corner!" I felt stigmatized at that first day." (TB patient during Focus Group Discussion)[5]

9 - "They [TB patients] are not open. They don't want to share. Anything with TB, its' just that they don't' accept TB. […] I think they're having a problem with thinking that TB is only for HIV people. But a person that has a normal TB with no HIV, a normal person, just gets TB with no HIV. She doesn't accept that. […] (Community health worker)[6]

For more information see:

» *Women and Stigma – Conversations of Resilience in the War Against TB, http://gctacommunity.org/?p=6503&v=a7bdee32cb21*

WHAT CAUSES STIGMA?

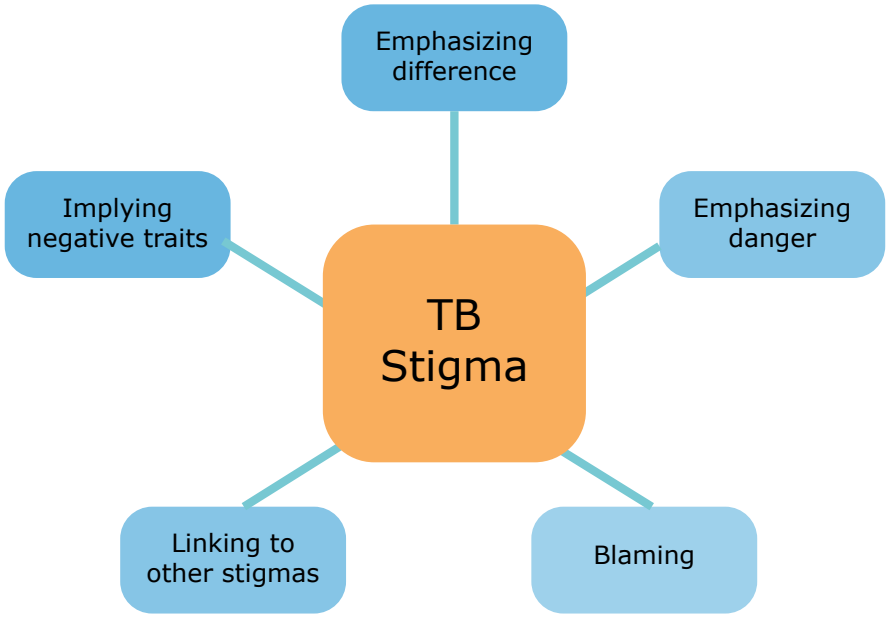


Figure 3. Causes of Stigma

TB stigma is created by emphasizing differences and danger, by blaming patients for getting TB, by linking TB with other stigmatized characteristics and by considering all TB patients to be bad.

Emphasizing differences

TB stigma is created by emphasizing that TB patients are different. This can be done through labelling or masking. This happens especially to DR-TB patients. Side effects of DR-TB treatment, such as discoloration of the skin and neuropsychiatric effects, may make them appear not normal to others.[1]

Emphasizing danger

TB stigma is created by emphasizing the danger of TB patients. This includes being afraid of infection/transmission and keeping distance and isolating patients. DR-TB patients are considered more "dangerous".[1]

Blame

TB stigma is created by blaming patients for getting TB. This happens especially for DR-TB patients, as people may think they caused their resistant TB because they did not adhere to previous TB treatment.[1]

Link to other stigmas

TB stigma is created by linking TB with other stigmatized characteristics, such as social deviancy, being poor, and being a drug addict.[1]

Implying negative traits

TB stigma is from considering all TB patients to be bad, untrustworthy, ignorant, or selfish.[1]

What Causes Stigma? (continued)

Stigma is not generated in isolation but is influenced by surroundings. In Figure 4 you can learn how stigma may be reinforced in health facilities.

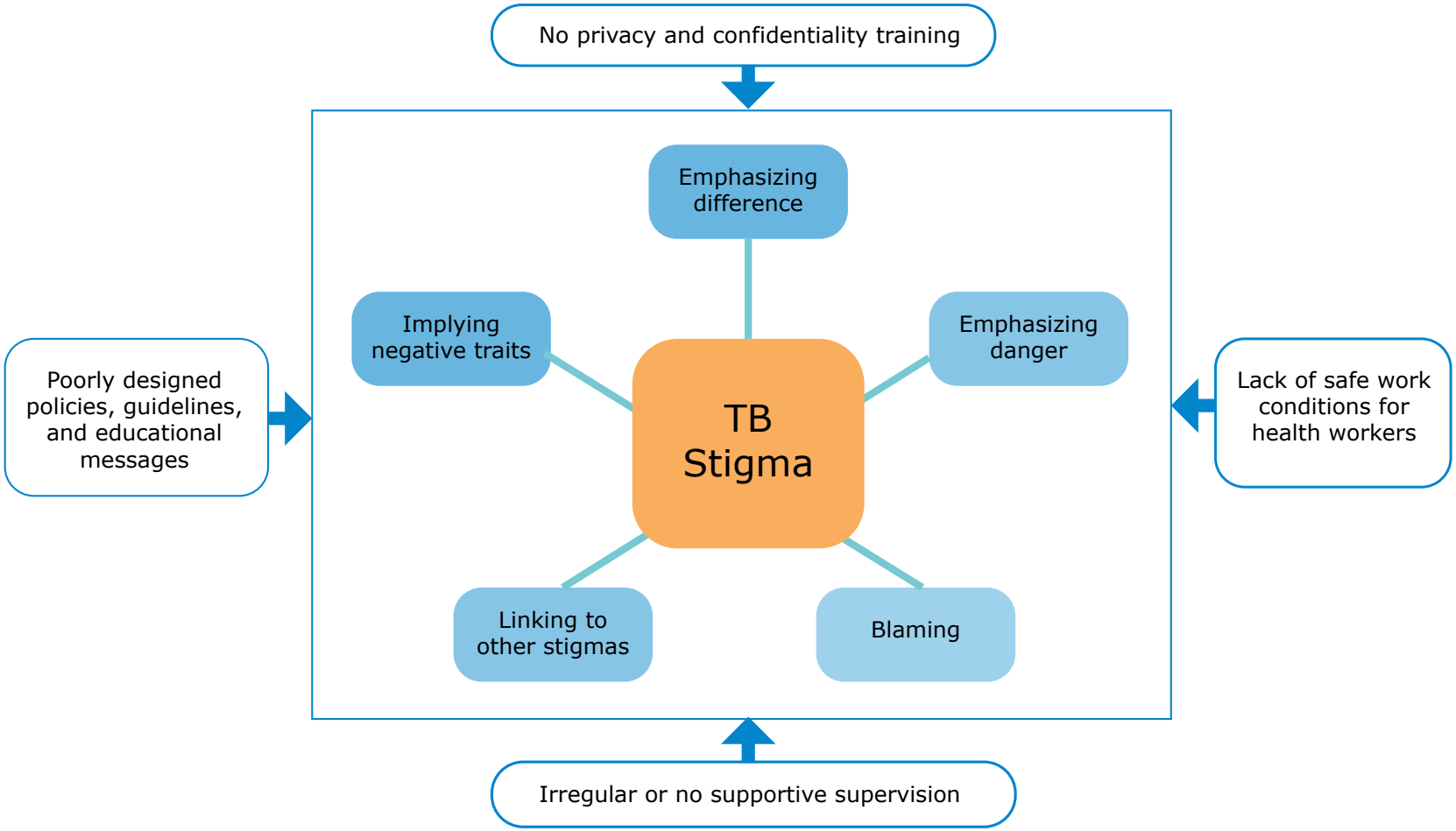


Figure 4. Stigma Reinforcement in Health Care Institutions.

What Causes Stigma? (continued)

Lack of safe work conditions for health care workers

Health care workers in some facilities may not have safe working conditions. They may be stigmatized for working with TB patients ("dirty work stigma"). Health care workers' basic needs must be met for them to properly address the medical needs of patients. Health care workers who practice under safe and decent working conditions are, in turn, able to render respectful and dignified care to patients.

Poorly designed policies, guidelines, and educational messages

Poorly designed policies, guidelines, and educational messages may reinforce stigmatizing language and ideas among health care workers.

Irregular or no supportive supervision

Irregular or no supportive supervision is associated with stigmatizing behavior.

Lack of privacy and confidentiality training

Not having privacy and confidentiality training is associated with stigmatizing behavior.

WHY IS IT IMPORTANT TO ADDRESS STIGMA?

The picture below shows the effects of stigma in health care institutions.

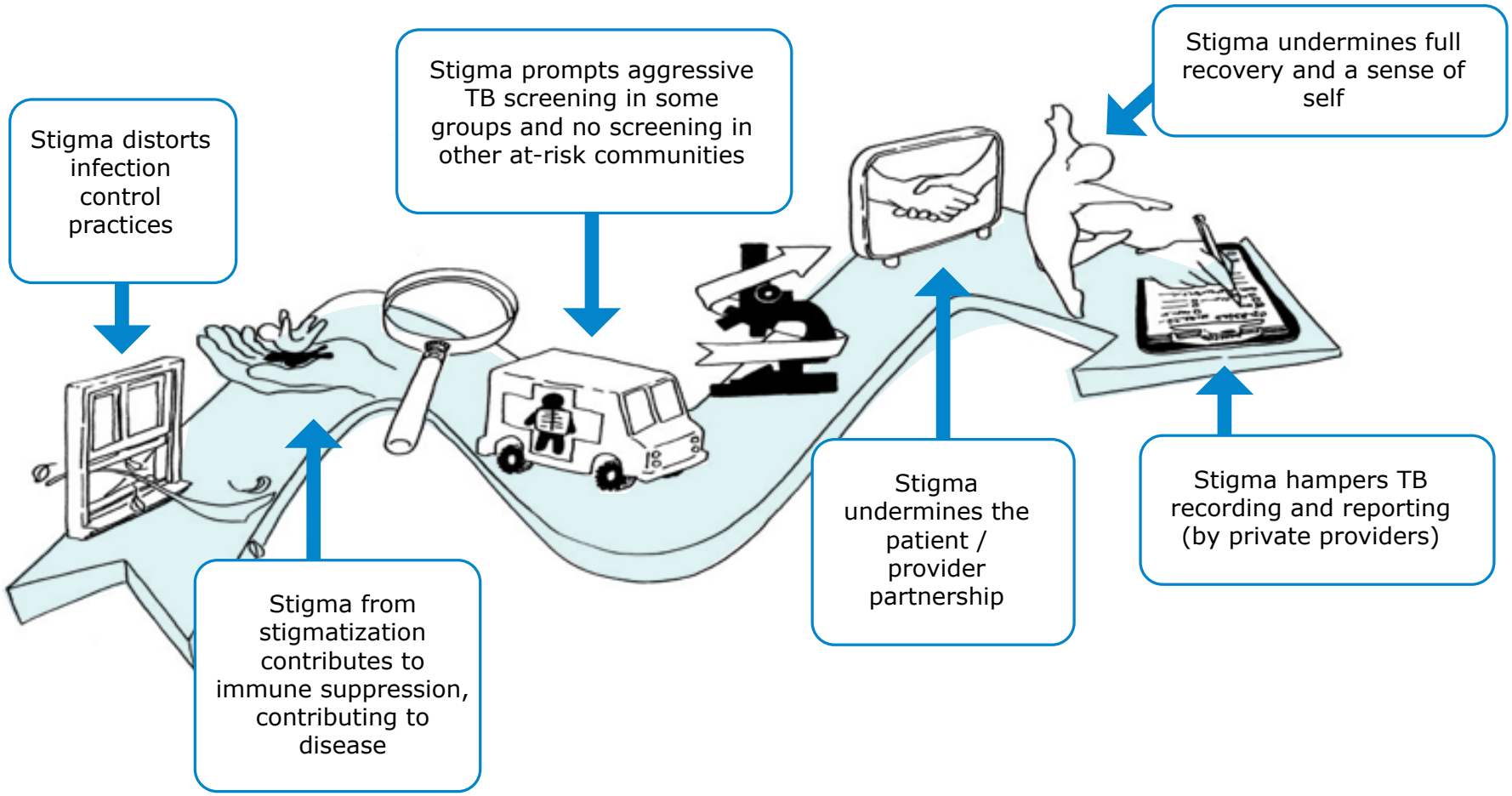


Figure 5. Effects of Stigma in Health Care Institutions.

HOW CAN YOU ADDRESS STIGMA IN HEALTH CARE INSTITUTIONS?

Info slide

During self-learning, you will follow a nurse (Anne) through her everyday work-life in the outpatient department (OPD). You will see how she addresses stigma-related issues and how she could improve her daily practice.

You will learn about:

1. health care workers' rights;
2. TB patients' rights;
3. the effect of transmission control measures during routine care;
4. the impact of commonly used stigmatizing TB terms; and
5. how to improve the patient-provider relationship using effective counselling methods.

Anna works in an outpatient department in an area of high TB burden (prevalence: 254 per 100,000 population). In this area, TB is also still highly stigmatized.

As health care workers, Anna and her colleagues are at the frontline in the fight against TB and stigma. See 'What is Stigma?' exercise.

WHAT ARE HEALTH CARE WORKERS' RIGHTS?

Multiple choice

Anna has been working in the OPD for three years. She likes working as a nurse, and she loves caring for people and helping them become healthy again. However, she also finds her job challenging, and some days the work pressure is overwhelming. Moreover, she thinks she is at risk of TB infection.

Lately, Anna has been very tired and sweating at night. She worries she might have TB. She wonders if she should go to the doctor to get a chest X-ray. She thinks about the possible consequences of getting tested for TB.

Which statements regarding TB testing and treatment of health care workers are true?

According to the "Joint WHO/International Labor Organization (ILO) guidelines on improving health care worker access to prevention, treatment, and care services for HIV and TB"[7], there should be:

- ☐ Priority access for health care workers to TB prevention, treatment and care services.
- ☐ Occupational health services, including regular, free, and voluntary counselling and testing for TB.
- ☐ Free TB treatment for health care workers delivered in a non-stigmatizing, gender-sensitive, confidential, and convenient setting (off-site).
- ☐ Universal availability of Isoniazid preventive treatment for HIV positive health care workers.
- ☐ Reasonable accommodation and compensation in the event of occupationally-acquired TB.

Answer explanation

All statements are true. According to the "Joint WHO/ International Labor Organization (ILO) guidelines on improving health care worker access to prevention, treatment, and care services for HIV and TB"[7], health care workers are entitled to all these services.

HOW ARE HEALTH CARE WORKERS AFFECTED BY STIGMA?

Info slide

Anna went to the doctor for a chest X-ray, and she was informed that she does not have TB. After her shift, she meets with some colleagues (who are not from the OPD) to tell them the good news. She hopes that it will put them at ease, as she has noticed that they behave differently towards her since she started working with TB patients. When she coughs they always get very nervous and move away from her. They often inquire whether she really likes her job and whether she would prefer to do something else. Anna sometimes wonders if her colleagues think less of her because she works with TB patients.

Expert note

Anna may be experiencing dirty work stigma, which is stigma around employment that others regards as degrading or demeaning.[8,9] Professionals who serve the health or social needs of stigmatized persons may be indirectly tainted, and their roles are discredited in the professional hierarchy. There may be a loss of prestige experienced by certain types of health care workers (e.g., addiction counsellors, mental health professionals, and abortion providers).

If health care workers are stigmatized for their work, they in turn may be more likely to stigmatize patients. According to the "Joint WHO / International Labor Organization (ILO) guideline on improving health care worker access to prevention, treatment and care services for HIV and TB,"[7] there should be policies to prevent discrimination against health care workers with HIV or TB and also interventions to reduce stigma among colleagues and supervisors. Discrimination involves enacting stigma through illegal means or denying a person equal treatment.

WHAT ARE SAFE WORKING CONDITIONS?

Select one

The next day Anna has a busy shift. More than 25 people are in the enclosed OPD waiting area, and she and one other nurse, Ezra, are the only health care workers available. Five people in the waiting area are coughing, and Anna immediately suspects TB. There are no fans and no ultraviolet germicidal irradiation lamps (UVGI) in the OPD waiting area.

Anna does not want people waiting outside, as it is cold and rainy, and she does not have face masks for them to wear.

The patients who are coughing might have undiagnosed TB. Is Anna at increased risk of being infected with TB?

- ◯ Yes
- ◯ No

Answer explanation

Anna and other people in the waiting area are at increased risk of being infected with TB, as described transmission control measures do not provide sufficient protection.

To assess, design, and implement proper transmission control measures at the facility level, please see the WHO guide on implementing the WHO Policy on TB Infection Control.[10]

Expert note

Health care workers should not have to choose between their health and performing duties (1). According to the "Joint WHO / International Labor Organization (ILO) guideline on improving health care worker access to prevention, treatment, and care services for HIV and TB,"[7] health care workers have the right to safe working conditions, which are essential in reducing stigma in health facilities.

Video of TB PROOF:
https://www.youtube.com/watch?v=u578RumDhEA

See National transmission control guidelines.

WHICH TRANSMISSION CONTROL MEASURES MAY BE STIGMATIZING, IF MISINTERPRETED?

Multiple choice

There are several things Anna could do to decrease the risk of TB transmission in the waiting area. Some of these measures may be stigmatizing if misinterpreted.

Which of the transmission control measures listed below may be stigmatizing if misinterpreted?

- ☐ Anna opens windows.
- ☐ Anna gives a surgical mask to all persons who cough.
- ☐ Anna asks all persons who cough to sit in one corner.
- ☐ Anna explains good cough hygiene to all people in the OPD.
- ☐ Anna prioritizes those who cough and attends them first ("fast-tracking").

Answer explanation

Giving surgical masks to people with presumptive TB can mark them as different and potentially dangerous. Some experience masking as stigmatizing because it draws attention and may reveals medical information. Nevertheless, teaching and following good cough hygiene, including wearing a surgical mask, is an important transmission control measure, and should be encouraged.

Therefore, it is important to find out if wearing a mask is perceived as stigmatizing in the setting you work in (Stigma Measurement Guidance). If it is, interventions to destigmatize masks should be implemented (e.g. provide masks for all persons in the OPD)

Separating people with presumptive TB can also be stigmatizing. Fast-tracking should be prioritized over separation, is it as effective and less stigmatizing because it is not clear which medical condition is being prioritized. It is also more feasible, as many facilities don't have the space for separation.

Patient quote

"If you are given this mask alone in the facility when other patients don't have them, you feel out of place because other people will start fearing you . . . thinking you may be having a scary disease. So if you are to give it to me and I put it on without any fear, you must give it to other people also." – female person to be evaluated for TB.[11]

Additional resources:

- *Leaflet on good cough hygiene, http://www.cdc.gov/globalaids/resources/pmtct-care/docs/tb-tools/cover-cough_poster.pdf*
- *Hygiene Etiquette & Practice, https://www.cdc.gov/healthywater/hygiene/etiquette/coughing_sneezing.html.*

HOW TO AVOID BEING STIGMATIZING IN STRESSFUL SITUATIONS?

Multiple choice

Anna cannot attend to the people who cough first, as only she and Ezra are in the OPD. To prevent possible TB transmission, Anna walks around and explains cough hygiene to each individual who coughs. Anna is in a rush because there is a child with high fever that she urgently needs to take care of. One of the coughing persons does not immediately understand what Anna is explaining. Anna is impatient and reacts in an unfriendly manner.

What could Anna have done better?

- ☐ There is no need for improvement. Anna's behavior does not have any negative impact on the persons waiting in the OPD.
- ☐ Anna should have given a surgical mask to all persons coughing. Giving masks would be better than an impatient and unfriendly explanation of cough hygiene.
- ☐ Anna should have made a general announcement on cough hygiene, referring to an available cough hygiene poster.

Answer explanation

Explaining cough hygiene to everyone in the waiting area through posters and announcements would save Anna a lot of time, and it would also be less stigmatizing than singling out people.

CAN YOU SEE HOW PEOPLE FEEL?

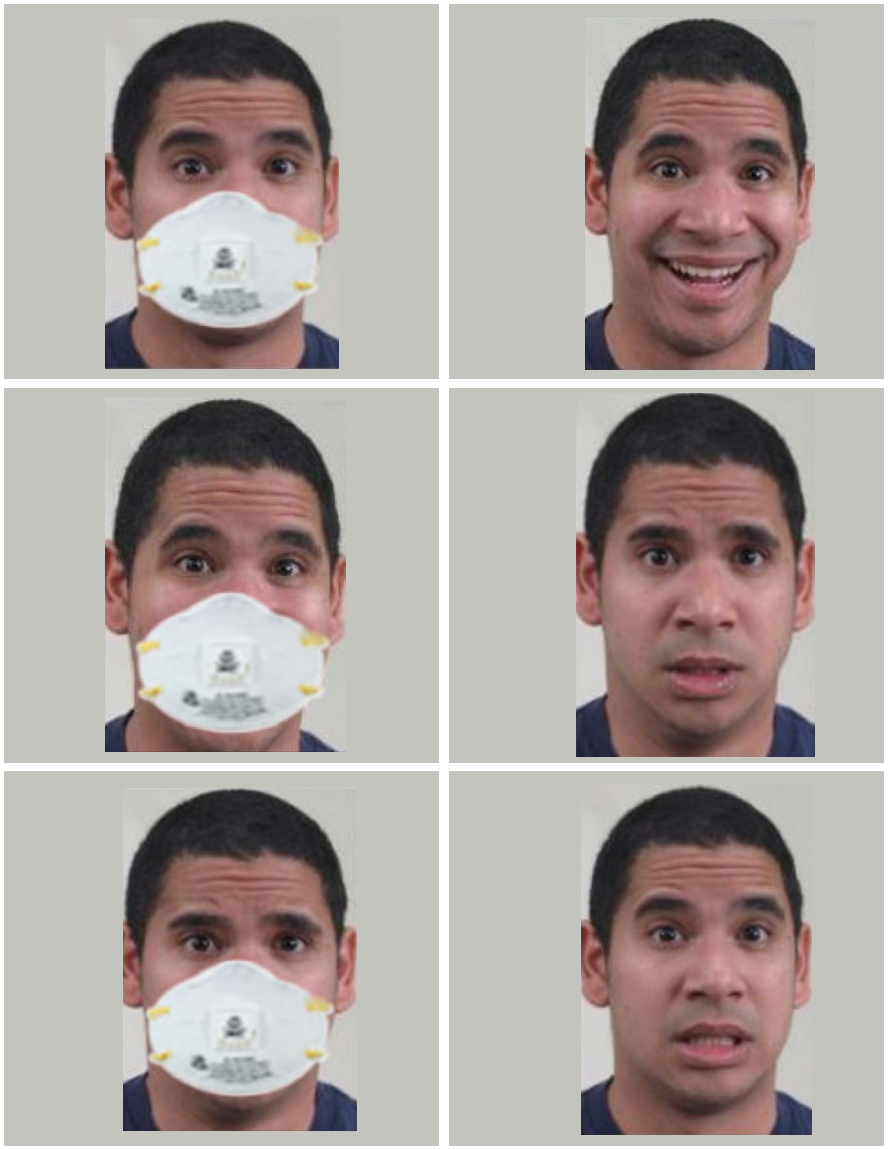
Dragging

After her brief lunch break, Anna examines a person who was coughing (Aki) Anna thinks he might have TB. During the examination, she wears a respirator as a transmission prevention measure. After examining Aki, she refers him to the sputum collection room to provide a sample.

** The sputum sample should be taken outside or in another well-ventilated room.*

Facial covers, however, can have significant impact on the patient-provider relationship. It has been shown that patients perceive health care workers who are wearing a mask to be less empathetic.

Try to match the facial expressions with and without a respirator.



Expert note

It is important for health care workers to realize that they may appear less empathetic when they wear a respirator.[12] They should try to use culturally appropriate body language that shows empathy and interest (for example, maintaining eye contact or nodding the head.)

Can You See How People Feel? (continued)

Look at Figure 6 for the correct answer.

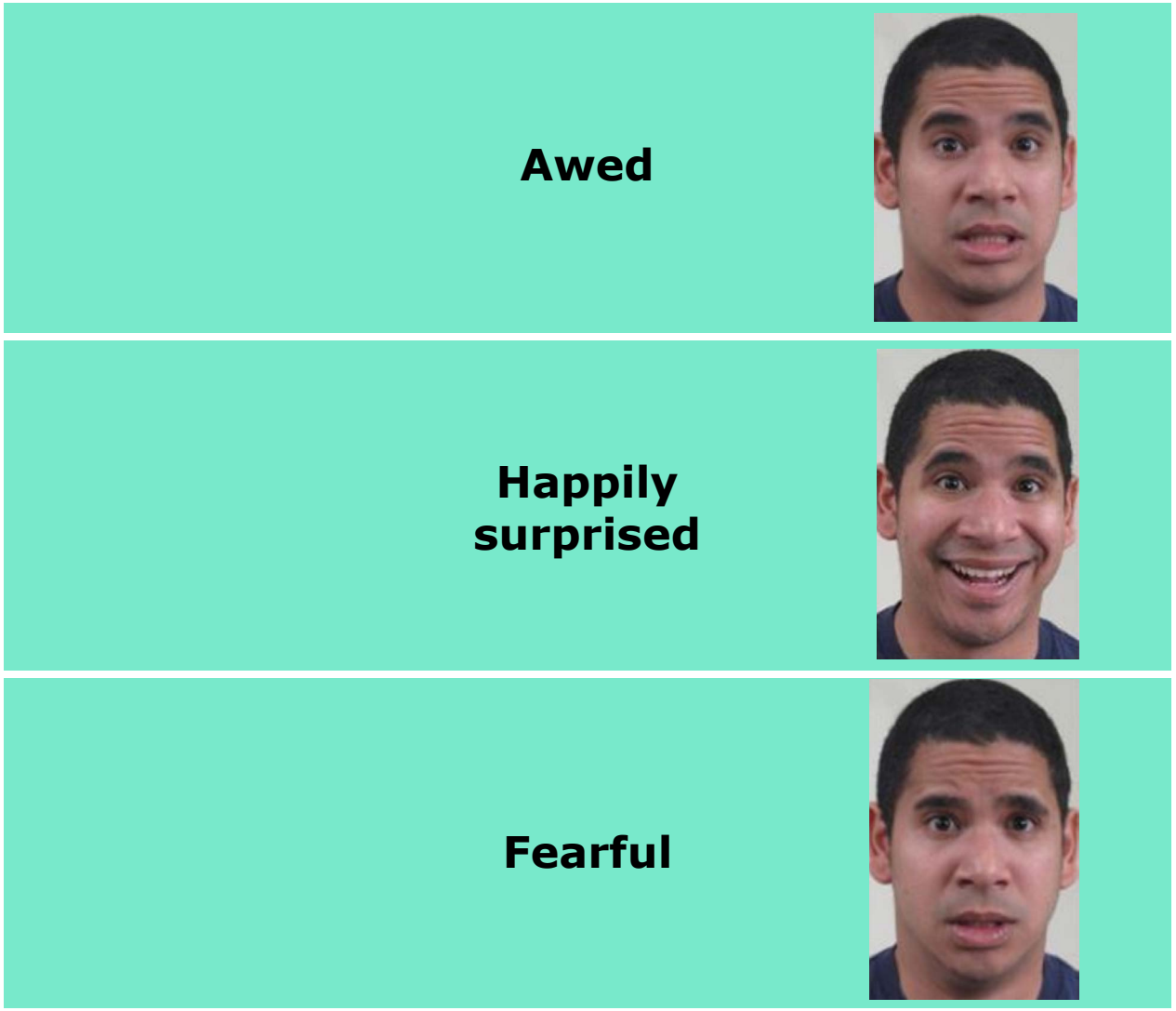


Figure 6. Facial expressions with and without a respirator (answer).

WHICH PATIENTS ARE INFECTIOUS?

Match the statement with an answer

After having addressed all of Aki's questions and worries, Anna accompanies Aki to the TB ward to initiate his treatment. She asks Aki to wear a surgical mask, and she is wearing a respirator. Three other TB patients are waiting in the hallway of the TB ward to undergo prescribed procedures. The nurse working in a TB ward briefly introduces them to Anna.

Match the patients with the respective described infectiousness status. See the answer with Figure 7.

Naaz: Pulmonary DS-TB, HIV-negative, three weeks on effective treatment	**Not infectious in principle**
Kofi: Pulmonary DR-TB, HIV-positive, six months on effective treatment, two consecutive negative cultures	**Not infectious**
Lisa: Extra-pulmonary TB (elbow), not on effective treatment	**Possibly infectious**

Answer explanation

1. Naaz is possibly infectious. Two weeks of effective treatment is the point from which patients are considered non-infectious. Some patients, however, may become non-infectious earlier or later.[17]
2. Kofi is not infectious, as he has two consecutive negative bacteriological culture test results.
3. Lisa is in principle not infectious,* as she currently does not have pulmonary TB.

**There may be risk of TB transmission during some procedures, such as biopsy, for extra-pulmonary TB patients.*

Which Patients are Infectious? (continued)

Expert Note

It is important to know which patients are infectious to avoid unnecessary transmission control measures, which may be perceived as stigmatizing.

Infectiousness is linked to:

- the site of the body affected by TB (lungs/other parts);
- the bacterial load of the patient (how many bacteria are in the patients' sputum); and
- if the patient is on effective treatment.

After sputum conversion, a patient is no longer infectious. Infectiousness is consequently not dependent on the patient's TB resistance status or on HIV status. The only reliable way to find out whether a patient is infectious is by testing sputum.

SUMMARY: TRANSMISSION CONTROL MEASURES IN HEALTH INSTITUTIONS

The following video summarizes transmission control measures in health care institutions (OPD):
https://www.youtube.com/watch?v=tsnGi-eLIQc

Please note, in this video infection control refers to transmission control.

Expert note

It is important to thoroughly assess which transmission control measures are needed in a particular situation and to inform the people, including health care workers, why these measures are necessary.

WHAT ARE SUBCONSCIOUS STEREOTYPES?

Multiple choice

Anna meets Ezra during lunch break. Ezra mentions Anna's cough hygiene teaching approach in the OPD waiting area. The following conversation took place:

Ezra: Why didn't you give a surgical mask to those people who were coughing? That would have protected all of us. They probably had TB!

Anna: I know, but I taught them cough hygiene. I think that is enough to protect all. Also, if I had given them surgical masks, I would have had to check whether they were still wearing them. Today I really did not have any time for that.

Ezra: Why would you have to check whether they are still wearing their masks? You also did not check if they followed the cough hygiene, did you?

Anna: No, I didn't, but that is a different story. Following proper cough hygiene is less obvious than wearing a surgical mask. When you wear a surgical mask, people assume you have a scary disease. People with presumptive TB want to prevent that at any cost, so they will not wear a surgical mask. They care more about keeping their illness a secret than protecting others.

Anna seems to be aware of the stigma associated with masks. However, she may not be sufficiently aware of her own stereotypes about TB patients. From the conversation, can you identify what kind of assumptions Anna has about TB patients in general?

- ☐ Most TB patients do not care that they can infect others.
- ☐ Most TB patients are a threat to others.
- ☐ Most TB patients are untrustworthy.
- ☐ Most TB patients are lazy.
- ☐ Most TB patients are confused.

Expert note

It is important for health care workers to be aware of the subconscious prejudices and assumptions they may have about TB patients. This awareness is the basis of effective stigma reduction in health facilities. Health care workers should become culturally competent. Becoming culturally competent is about knowing yourself and your own biases and assumptions that impact your interactions with people who you view as being different than yourself. This includes the homeless, disabled, those who abuse drugs and alcohol, and those of a different ethnic or racial group.

For more information, see:

» *Heartland National Tuberculosis Center. Beyond Diversity: A Journey to Cultural Proficiency – Facilitator's Guide, 2008 (Rev 4.2010), www.HeartlandNTBC.org*

COUNSELLING PATIENTS

Select one

After two days, Anna gets Aki's laboratory results, and he has Rifampicin-resistant TB. She invites him to discuss his test results and treatment options. After telling Aki that he has DR-TB, how should Anna proceed?

- ○ She should tell Aki all he needs to know about DR-TB and subsequently ask whether he understood everything.
- ○ She should inquire what Aki already knows about DR-TB, explain to him specifically what he needs to know, and work with him to agree on next steps.

Answer explanation

She should ask Aki what he already knows about DR-TB, and then tell him specifically what he still needs to know and agree on next steps.

Expert note

Different people need different information. It is very important to determine what each person knows about TB and DR-TB and what his or her concerns are. This is also an opportunity to dispel any myths and fears the patient may have about TB. Health care workers usually have limited time to communicate with patients, so it is very important for the health care worker to ask appropriate questions to collect as much information as possible and to provide effective help.[13] It is important that the health care worker should not only transfer information, but also build a rapport with the patient. Health care workers should help patients cope with emotional stress and uncertainty and encourage them to start and complete treatment.

For more information see:

- » *Srivastara S. B. The Patient Interview http://samples.jbpub.com/9781449652722/9781449645106_CH01_001_036.pdf*
- » *Drug-Resistant Tuberculosis https://sawbo-animations.org/video.php?video=//www.youtube.com/embed/-aDr4ZdwxBM*
- » *TB in those with HIV https://sawbo-animations.org/video.php?video=//www.youtube.com/embed/Skgn8vUGmyU*
- » *Tuberculosis Management https://sawbo-animations.org/video.php?video=//www.youtube.com/embed/QZR04-wlqVQ*
- » *Tuberculosis prevention https://sawbo-animations.org/video.php?video=//www.youtube.com/embed/nIrfGtAojeQ*

Counselling Patients (continued)

The approach to the patient interview will depend on the setting in which you are practicing. Regardless of the setting, your goal during the interview is to provide patient- centred care; this can be accomplished by combining your medical knowledge with a sloid foundation of excellent communication and patient- interviewing skills.

This is one of the possible ways how to perform patient's interview for a TB diagnosis and treatment initiation visit:

1. Greet a patient and introduce yourself.
2. Inform the patient about the purpose of the interview and ask whether he/she is ready for this
3. Ask a patient about his/ her perceptions about TB and about being diagnosed.
4. Explain the TB diagnosis and help to cope with stress.
5. Explain the following:
    - TB and its symptoms, with an emphasis that TB is a curable disease.
    - TB treatment regimen: medications and duration
    - -Possible side effects of medications.
    - The importance of taking medications regularly for the full course of treatment
    - Options available for treatment and care
    - Transmission control
    - Importance of screening family members for TB to find people with presumptive TB.
6. Assess available support and potential barriers to treatment adherence and completion.
7. Discuss patient's concerns about treatment and follow-up care.
8. Mutually agree on next steps, referrals, and schedule for the next visit.

WHICH QUESTIONS SHOULD I ASK?

Dragging question

Anna asks Aki some questions to find out more about his needs. There are different types of questions, including closed-ended, open-ended, follow-up, and leading questions.

Look at the following questions Anna asked. Can you identify which type they are?

Question	Type
"What questions do you have about your tuberculosis?"	Open-Ended Question
"Don't you know how TB is transmitted?"	Leading Question
"I understand that you are feeling anxious about possibly infecting your wife. What would make you feel more calm or comfortable?"	Follow-Up Question
"When did you last see your doctor?"	Closed-Ended Question

Additional resources:

- *Everyday Words for Public Health Communication, CDC, May 2016 https://www.cdc.gov/other/pdf/everydaywordsforpublichealthcommunication.pdf*
- *Interpersonal Communication and Counseling for Clients on Tuberculosis and Hiv and Aids, PATH 2009, https://path.azureedge.net/media/documents/CP_ukraine_tb_hiv_ipcc_hnd.pdf.*

WHICH QUESTIONS ARE APPROPRIATE?

Multiple choice

Which questions are appropriate to ask during the counselling session?

- [ ] Closed-ended questions
- [ ] Open-ended questions
- [ ] Follow-up questions
- [ ] Leading questions

Answer explanation

1. Closed-ended questions quickly gather important medical and background information.[13]
2. Open-ended questions will invite Aki to give full, honest answers. This helps him to think about his choices.[13]
3. Health care workers should not stop at the first answer provided.[13]
4. NOT appropriate. Leading questions push the person to answer in the way that the questioner wants, and discourage the patient from saying what he or she really feels.[13]

WHAT ARE PATIENT RIGHTS?

Select one

Aki says he is hesitant to start treatment. He is worried about side effects. In particular, he has heard from other people that it is possible to lose your hearing if you take the medicine.

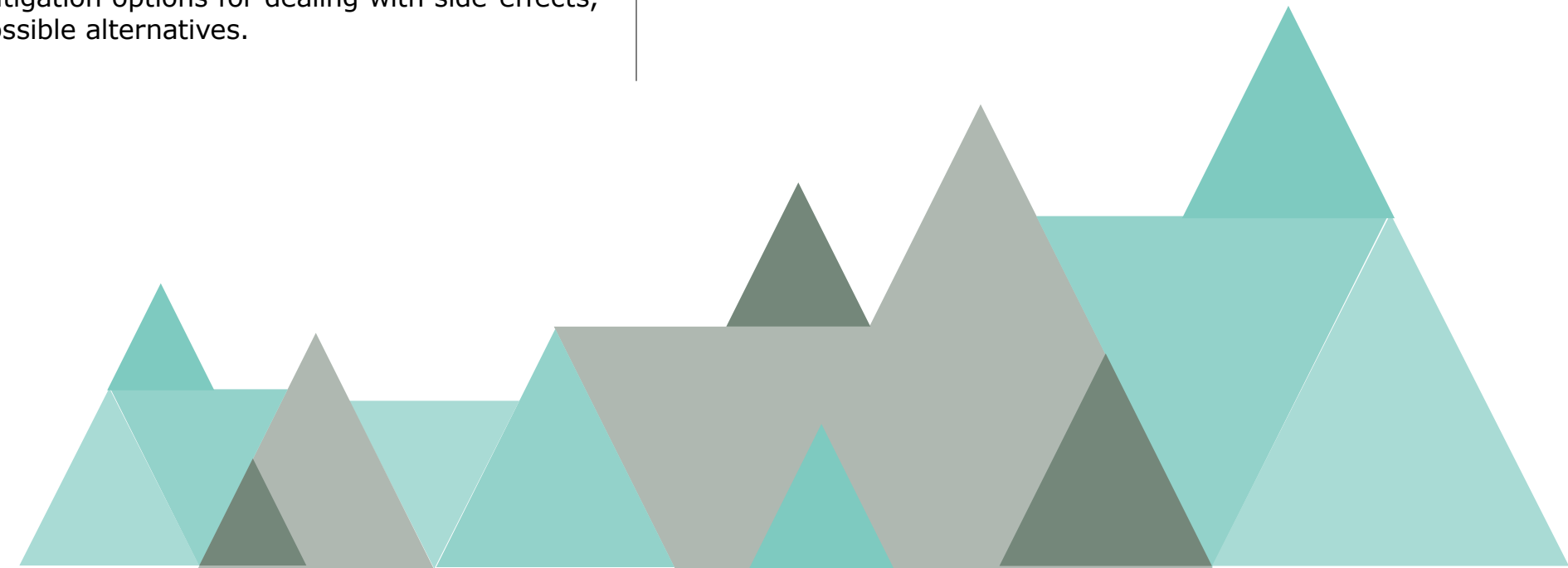
How should Anna address Aki's worries?

She should:

- ○ Provide Aki with only the most necessary information as to not scare him even more.
- ○ Provide Aki with information about all of the risks and benefits of the treatment proposed, the monitoring and mitigation options for dealing with side-effects, and possible alternatives.

Answer explanation

1. (Wrong) According to the "Patient's charter for TB care,"[14] patients have the right to accurate information. Patients should get all the information there is on the medications or interventions prescribed. This includes possible impact on other health conditions, potential side-effects, and how these will be monitored and mitigated.
2. (Right) This would be respecting Aki's right to information according to the "Patient's charter for TB care," and it would also be good counselling practice.



What are Patient Rights? (continued)

Multiple choice

After additional counselling, Aki finally agreed to be treated. He doesn't want his neighbors or colleagues to know that he has DR-TB, as he fears they will not talk to him anymore. He also thinks that he will be fired if his employer finds out that he has DR-TB. How should Anna address Aki's worries?

She should:

- ☐ Explain that she will keep Aki's health status and other health-related information private and confidential, except from those who will be involved in his care.
- ☐ Explain that she will have to inform everyone with whom Aki will be in contact during his treatment course about his health status.
- ☐ Explain that she will keep Aki's health status and other health-related information private and confidential, except from those who will be involved in his care and his contacts who will be examined for TB.

Answer explanation

According to the "Patient's charter for TB care"[14], patients have the right to confidence. Law and policy must establish the right of people with TB to keep their health status and other health-related information private and confidential, with the exception of those who have a direct role in his care and support.

Expert note

Health care workers should always tell their patients that their information is protected. Ensuring patients' privacy is essential in a good patient-provider relationship. In practice, it may sometimes be difficult for health workers to ensure patients' privacy during a contact investigation. Here are some tips:

- Use gender-neutral language. For example, "Someone you have spent time with was diagnosed with TB and they were concerned about you" instead of "A woman you have spent time with was diagnosed with TB and she was concerned about you."
- Do not mention the patient's health care worker, place and dates of diagnosis, or hospitalization history.
- Do not mention the environment in which the exposure occurred. For example, "You have been around someone who has TB" instead of "You have been around someone at work who has TB."
- Do not confirm the name of the patient if the contact correctly guesses his or her identity.

If you would like to have more guidance on making these difficult ethical decisions, please refer to [16].

THE "RIGHT" TO REFUSE OR ENFORCE TREATMENT – AN ETHICAL DILEMMA

Aki is still hesitant to start treatment after he got all of the relevant information.

What are his rights regarding his treatment? Can he go for a second medical opinion? Can he refuse treatment?

What are the rights and obligations of the health care workers in providing the best possible care to Aki and protecting the general public? Can Aki be forced into treatment? Can Aki be involuntarily isolated to prevent transmission to others?

Whose rights are more important – those of the individual, or the public good?

The questions above pose a common ethical dilemma in dealing with infectious diseases, especially those that can be transmitted person-to-person and that can physically harm infected individuals.

Traditional biomedical ethics focus on the individual and emphasize four dimensions: autonomy, beneficence, nonmaleficence, and justice.

Autonomy means the person has the right and freedom to choose a course of action (e.g., treatment) based on an informed decision. Regardless of their choices, they deserve to be treated with respect and confidentiality, including adequate support (e.g., palliative care, in case of refusal of therapy). Public health interventions often infringe on the rights of individuals in favor of the collective (or public) good and protection.

Beneficence means actions are done with the intention of bringing about good. It is often used to justify compulsory and intrusive public health interventions, e.g., compulsory mass-vaccinations or mass-screenings of people at risk. Such actions might reinforce stigma and have negative consequences for affected individuals and groups.

Nonmaleficence means to do no harm. Most TB medicines are very toxic and bear the risk of adverse side-effects, some of which can lead to permanent impairment or may even be life threatening. This is why someone can't be forced to take medicines against their will. However, the "do no harm" principle has been used to justify drastic actions, such as isolation and compulsory treatment for highly infectious diseases.

Justice denotes the right to fair treatment for the individual and fair distribution of costs and benefits. However, there is underlying tension between the rights of the individual and the rights of the collective (or public) good. Is it just if the decisions and behavior of one individual cause harm to another?

The "Right" to Refuse or Enforce Treatment – An Ethical Dilemma (continued)

Expert note

The WHO guidance on ethics of tuberculosis prevention, care, and control (2017)[16] states the following:

> *Individuals who refuse to consent to TB treatment, either for latent TB infection or active TB disease, should be counselled about the risks to both themselves and the community. Providers should seek to understand the reasons why the patient is reluctant about treatment, and they should work together to identify methods for overcoming these concerns. Patients should be informed that, while they have the right to refuse care, if they have active TB disease and do not complete the necessary course of therapy, it is possible that they could be subject to involuntary isolation.*

In TB care, health care workers often have to make difficult ethical decisions. If you would like to have more guidance on this, please refer to [14,15].

HOW TO PROTECT PATIENTS' PRIVACY?

Multiple choice

Anna would like Ezra's feedback on Aki's circumstances. She realizes that they are not in an ideal environment for a consultation, as there are other patients around. However, their heavy workloads may not permit another opportunity to talk. All the consulting rooms are being used to give clinical care, so there is no place where their conversation cannot be overheard by others (auditory privacy).

Anna discusses everything she knows about Aki with Ezra in the waiting area. She mentions his name, her assumptions about his reliability and ability to adhere to treatment, and how she dealt with him.

How would you evaluate Anna's behavior regarding auditory privacy?

- ☐ Anna did not violate patient-provider confidentiality.
- ☐ Anna may have violated patient-provider confidentiality. She should not have shared any personal information of Aki with a health worker who his not involved in his care and she should not have talked about Aki's personal information where conversations can easily be overheard.
- ☐ Anna may have violated patient-provider confidentiality. She may share information with a health worker not involved in Aki's care but she should not have talked with Ezra about Aki's personal information where conversations can easily be overheard.

Answer explanation

Anna violated patient-provider confidentiality. She should not have shared confidential patient information with a colleague who is not involved in Aki's direct care and in a place where she can easily be overheard.

If she would like to talk to a health care worker involved in Aki's care in this setting, she could have talked about Aki without mentioning personal information (such as Aki's full name.) Anna should, however, be aware that even without mentioning personal information, there is still the risk of violating patient-provider confidentiality.

If you want to learn more about how to serve the privacy and confidentiality needs of patients, please refer to [20].

How to Protect Patients' Privacy? (continued)

Multiple choice

Aki has been on DR-TB treatment for two months. Anna comes to Aki's house on the branded health center motorcycle to see how he is doing and to collect a sputum sample for follow-up. When she arrives at his house, no one opens the door. She waits for fifteen minutes, and she is getting impatient as her next appointment is soon. Aki's neighbor comes out. The neighbor tells Anna that Aki has left a half hour ago. Anna introduces herself to Aki's neighbor as a nurse. She asks the neighbor to tell Aki that she stopped by. She leaves the sputum collection container and a surgical mask with the neighbor to give to Aki.[1]

Did Anna protect Aki's privacy sufficiently?

- ☐ Yes, she did. She did not say she was from the TB program.
- ☐ No, she should not have said that she is a nurse and should not have come with a branded bike.
- ☐ No, she should not have gone to Aki's home.
- ☐ No, she could have left a message saying that Anna was looking for him, and could he please contact her.

Answer explanation

You could have left a message saying that you (only stating your name) were looking for him, and could he please contact you as soon as possible, but not other information should be revealed to the third party.

Expert note

Leaving clues that allow others to deduce someone's medical diagnosis or treatment is breaching confidentiality.

Here are some tips to uphold patient-provider confidentiality during a home visit:

- Do not tell neighbors any sensitive information.
- Do not leave any notes for the patients where they can be easily read by third parties.
- Avoid wearing a uniform.
- Park your branded car/motorcycle a few blocks away.

Upholding patient-provider confidentiality is not only the cornerstone of a good patient-provider relationship, it is also a legal obligation and essential to preventing the stigmatization of patients.

Exercise adapted from:

» *Self-Study Modules on Tuberculosis, Module 7, Patient Rights and Confidentiality in Tuberculosis Control, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES Centers for Disease Control and Prevention National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Division of Tuberculosis Elimination, Atlanta, Georgia 2014*

WHAT TERMS SHOULD I USE?

Select one

After Aki was admitted at the TB ward, Anna returns to the OPD. There she meets her colleague Ezra. They have a quick chat. Which of them is using stigmatizing words in the following conversation?

Anna: Hey Ezra, how are you?

Ezra: Hey Anna, I'm fine, but today was such a stressful day.

Anna: Oh, how come? What has happened?

Ezra: Well, I have a lot of TB cases at the moment, and some of them are really difficult. For example, one guy has defaulted already and is now on treatment for the second time. I'm afraid he will not comply to treatment this time either.

Anna: Why do you think so?

Ezra: I don't know. His family is pretty poor but he gets support packages and all. I personally think he might be a drug addict. I can tell by his thin face.

Anna: That might be one explanation. Or it could be that his TB disease caused some weight loss. You should really try to figure out what is bothering him.

Ezra: I know, but I just don't have any time. There are lots of suspects sitting in the waiting room.

Anna: I see…well, I think we should talk with the management about workload.

Answer Options

- ○ Anna
- ○ Ezra

Answer explanation

Ezra uses the terms "TB cases," "defaulter," "comply with treatment," "drug addict," and "suspect," which may be stigmatizing. See Table 2.

To find out why these statements are stigmatizing, and what terms can be used instead see Table 2.[18]

What Terms Should I Use? (continued)

Stigmatizing term*	Replacement	Explanation
Case	Patients	This term is used widely in public health. In health care settings, however, it should be used with sensitivity. If people overhear health care workers describing them as a case, they may find it demeaning. They are not merely cases but fellow human beings.[18]
Compliance/ Non-compliance	Adherence	The terms compliance and non-compliance assign blame to the person receiving treatment. The degree to which the patient takes the required doses of medicine is influenced by many external factors (health system factors, economic reasons).[18]
Defaulter	Person lost to follow-up	By labelling persons who interrupt treatment or fail to start treatment as "defaulters," blame is unfairly placed on them. It is generally the poor quality of health services and a lack of a person-centered approach that leads to treatment interruption or failure to begin treatment.[18]
Drug addict	Substance user, person experiencing an drug problem, patient	These terms are demeaning because they label a person by his/her illness. By making no distinction between the person and the disease, they deny the dignity and humanity of the individual. In addition, these labels imply a permanency to the condition, leaving no room for a change in status. These terms are demeaning because they make no distinction between the person and the disease and they deny the dignity and humanity of the individual.
TB suspect	Person to be evaluated for TB or presumptive client	The term 'suspect' has a negative connotation. "Suspect" implies doubts about the morality or covert behavior of the person.[19]

Table 2. Stigmatizing terms and replacements

** These terms are demeaning because they make no distinction between the person and the disease and they deny the dignity and humanity of the individual.*

WHAT SHOULD BE DONE

Multiple choice

Ezra mentioned that a patient experiences a drug use problem. A urine test confirmed this suspicion: the patient is indeed using drugs. What should Ezra do?

Ezra should…

- ☐ Link the patient to a substance dependency specialist
- ☐ Link the patient to a social worker
- ☐ Ensure the patient is tested for HIV
- ☐ Ensure the patient is tested for Hepatitis B and C
- ☐ Ensure the patient's liver enzymes are closely monitored during TB treatment
- ☐ Ensure that the patient is provided continued socio-economic support
- ☐ Convince the patient to stop using drugs.
- ☐ Stop treating the patient for TB until he stops using drugs.

Answer explanation

1. Patients who use alcohol or drugs should be linked to a specialist in dealing with substance dependencies who will help them to address their substance use and dependency.
2. Patients who use alcohol or drugs should also be linked to a social worker who will help to arrange socio-economic support and to link the patient to a substance dependency specialist.
3. Patients who use injecting drugs should be tested for HIV and Hepatitis B and C as they have a higher risk of suffering from these conditions. These conditions would require careful monitoring and potentially alternative drug-regimens.
4. Liver enzymes of patients who use alcohol or drugs should be closely monitored during TB treatment as alcohol and drug users are at increased risk of liver damage by hepatotoxic TB drugs, such as isoniazid, rifampin, and pyrazinamide.
5. Patients who use alcohol or drugs should receive socio-economic support. People who use alcohol or drugs are often in unstable living and economic conditions. Socio-economic support will increase treatment adherence, especially when it is ensured that the patients are well nourished.

Expert Note

TB patients who have an alcohol or substance dependency problem carry a double burden of stigma. You can help them by employing the actions mentioned before.

Please also note, however, that substance dependency may be difficult to address without the personal motivation of the patient.

It is important to remember that persons using alcohol or drugs are at increased risk of getting TB. That is because:

- Their immune system is weakened due to alcohol or drug use and possibly lack of a healthy diet
- They may spend time in environments where TB is easily spread, such as crowded or poorly ventilated homes or social venues

---

Additional resources:
https://www.tbalert.org/about-tb/global-tb-challenges/tb-substance-misuse
http://www.who.int/bulletin/volumes/91/2/13-117267/en/
http://stoptb.org/assets/documents/resources/publications/acsm/KPBrief_PWUD_ENG_WEB.pdf
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2796667/

HOW TO BE A CHANGE AGENT/KEY OPINION LEADER

Aki meets Max in a TB club during the fifth month of his treatment. Max receives TB treatment in a different facility. Max and Aki talk about their respective experiences:

Aki: I am so happy that treatment is going to be over soon.

Max: I understand you! Do you have side-effects from the drugs too?

Aki: No, I am fine, but I hate going to that OPD all the time. Everyone is always stressed and annoyed there and you have to wait forever. Also, I feel like they do not know what they are doing. The first time I came, I was waiting in the OPD with a lot of other patients. The nurse came to me and said I should cough into a tissue if I needed to cough. Then I heard a discussion among the nurse and a colleague, who said that instead of the coughing in the tissue I should have worn a surgical mask. She seemed really annoyed. And all this was happening in front of all the people in the OPD waiting. It was really embarrassing.

Max: Sounds terrible! Are the nurses who are treating you nice at least?

Aki: They are, the one nurse, Anna, really listened to my concerns. But she is also stressed and mostly preoccupied with her own business. I was also really angry when she left a sputum collection container and a surgical mask with my neighbor. I was not planning on telling him I have TB but now he knows and now he and his family won't come over anymore.

Max: I am sorry to hear that. You should have come to the OPD I am being treated in. I am happy treatment will be over soon, but I will miss the health care workers there. The nurses were always in a good mood and up for some jokes. They also took my concerns seriously. They were not that arrogant as health care workers normally are. They even asked me about my preferences about my treatment and appointments. When I had to go to the OPD during the first few weeks, I was always treated first! I never had to wait!

What are the reasons Max is so enthusiastic about his treatment?

Multiple choice

- ☐ Health care workers are friendly.
- ☐ Max is treated with respect.
- ☐ Treatment decisions where mutually agreed upon.
- ☐ Max is always a happy person. It has nothing to do with his treatment.

Answer explanation

Max probably is so enthusiastic about his treatment, because the health care worker was empathic, showed respect, and involved him in the decision-making. These actions are crucial for a positive patient-provider relationship.

How to be a Change Agent/Key Opinion Leader (continued)

TB stigma reduction interventions may not be implemented by the entire health care institution staff, as stigmatized health care workers are unable to effectively champion the needs of TB patients.[21] Therefore, key opinion leaders who are defined as a "service provider who is respected, trustworthy, and influential among co-workers and peers. They are expected to demonstrate concern for their medical community and be willing to make efforts to improve the quality of services provided".[22]

What can you do to make the health care institution you are currently working at become more like the facility Max has described?

- Be a good example for your colleagues and provide quality people-centered care.
- Talk to your colleagues and share what you have learned.
- If appropriate, talk to your management to initiate policy change at your health institution.
- Plan stigma awareness sessions in your health institution.

Key opinion leaders have substantive expertise and regularly speak at local, regional, and national meetings and conferences. They consider themselves early adopters of new treatments or procedures, and they help to establish protocols for treatment and care. They also communicate well with others.

Additional resources:

» *WHO Framework on integrated people-centred health services http://www.who.int/servicedeliverysafety/areas/people-centred-care/framework/en*

» *Framework on integrated people-centred health services: an overview, http://www.who.int/servicedeliverysafety/areas/people-centred-care/Overview_IPCHS_final.pdf.*

SUMMARY

1. What is TB stigma?

Stigma is defined as the relationship between an attribute and a stereotype that assigns undesirable labels, qualities, and behaviors to a person. Labeled individuals are devalued socially, leading to inequality and discrimination.[1] For example, a TB patient is always assumed to be infectious, and therefore is labelled as dangerous, which justifies behaviors and policies that create social distance.

2. What causes stigma?

Stigma is generated by emphasizing differences and danger, blaming the person for his/her condition, linking the condition to other stigmas, and implying negative traits. TB stigma in health care settings may be reinforced by the lack of safe work conditions of health care workers, poorly designed policies, guidelines, and educational messages, irregular or no supportive supervision, or a lack of privacy and confidentiality training.

3. Why it is important to address stigma?

Stigma undermines a full recovery and a sense of self, prompts aggressive TB screening in some groups and no screening in other communities that are at-risk, distorts infection control practices, hampers TB recording and reporting (by private providers), and undermines the patient-provider partnership.

4. How do people stigmatize, and how are people stigmatized in the health care settings?

In health care settings, both patients and health care workers may be stigmatized. Health care workers may experience dirty work stigma. If health care workers are stigmatized for their work, they in turn may be more likely to stigmatize patients. Health care workers also may have subconscious prejudice of TB patients, and thereby stigmatize or use stigmatizing terms. Patients may perceive infection control measures, such as masking and separation, as stigmatizing.

Summary (continued)

5. How can you mitigate against stigmatization?

Here are some basic things health care workers can do to mitigate against stigmatization:

- Avoid using stigmatizing language.
- Become aware of and challenge subconscious stereotypes. Become culturally competent.
- Develop and nurture a trustful patient-provider relationship by providing good counselling and respectful conduct.
- Be aware of and uphold patients' rights.
- Be aware of the effects of infection control measures on patients and know when and how to apply infection control measures appropriately.

Addressing stigma and discrimination plays an important role in increasing access to health services. The foundation for successful mitigation of stigma in health care settings, however, is in providing a healthy working environment, i.e., protecting health care workers' rights to a safe and positive work environment, free of stigma, discrimination, and undue stressors.

ASSESSMENT

1. If patients who are coughing might have undiagnosed TB, are you at increased risk of being infected with TB?
   - ◯ Yes
   - ◯ No
2. Which of the transmission control measures listed below may be stigmatizing, if misinterpreted?
   - ☐ You open windows.
   - ☐ You give a surgical mask to all persons who cough.
   - ☐ You ask all persons who cough to sit in one corner.
   - ☐ You explain good cough hygiene to all persons in the OPD.
   - ☐ You prioritize the persons who cough to be attended first ("fast-tracking").
3. Instead of walking around and explaining cough hygiene to each individual who coughs in the out-patient department waiting area, what could you do differently?
   - ◯ There is no need for improvement. Your behavior does not have any negative impact on those waiting in the OPD.
   - ◯ You should have given a surgical mask to all persons coughing. Giving masks is preferable than an impatient and unfriendly explanation of cough hygiene.
   - ◯ You should have made a general announcement on cough hygiene referring to a cough hygiene poster (if available).
4. After getting laboratory results (Rifampicin-resistant), you invited a patient to discuss his test results and treatment. After telling the patient that he has DR-TB, how should you proceed?
   - ◯ You should tell patient all he needs to know about DR-TB and subsequently ask whether he understood everything.
   - ◯ You should inquire what the patient already knows about DR-TB, explain to him specifically what he needs to know, and agree on next steps.

5. During the counselling session, the patient is worried about side effects. He has heard from other people that it is possible to lose hearing if you take the medicine. How should you address those concerns?

   5.1. You should:

   - ◯ Tell him only the most necessary information as to not scare him even more.
   - ◯ Provide him with information about all of the treatment risks and benefits, the monitoring and mitigation options available for dealing with side-effects, and possible alternatives.

   5.2. Which questions would be appropriate for you to ask?

   - ☐ Closed-ended questions
   - ☐ Open-ended questions
   - ☐ Follow-up questions
   - ☐ Leading questions

6. You need to visit the patient at home to see his living conditions. The patient is not at home, so you introduce yourself as a nurse to a neighbor. Did you sufficiently protect the patient's privacy?

   - ◯ Yes, you did. You did not say that you were from the TB program.
   - ◯ No, you should not have said that you are a nurse.
   - ◯ No, you should not have gone to a patient's home.
   - ◯ No, you could have left a message saying that you (only stating your name) were looking for him, and could he please contact you.

CLOSING REMARKS

Thank you for participating in the first part of the "Stigma reduction intervention for health institutions." The second part is an interactive course that will take place at your facility. The objectives of this interactive training course are to reflect on the lessons learned during self-learning, and to explore, question, clarify, and affirm values and beliefs about DR-TB.

ASSESSMENT (ANSWERS)

1. If patients who are coughing might have undiagnosed TB, are you at increased risk of being infected with TB?

   - [x] Yes
   - [ ] No

2. Which of the transmission control measures listed below may be stigmatizing, if misinterpreted?

   - [ ] You open windows.
   - [x] You give a surgical mask to all persons who cough.
   - [x] You ask all persons who cough to sit in one corner.
   - [ ] You explain good cough hygiene to all persons in the OPD.
   - [ ] You prioritize the persons who cough to be attended first ("fast-tracking").

3. Instead of walking around and explaining cough hygiene to each individual who coughs in the out-patient department waiting area, what could you do differently?

   - [ ] There is no need for improvement. Your behavior does not have any negative impact on those waiting in the OPD.
   - [ ] You should have given a surgical mask to all persons coughing. Giving masks is preferable than an impatient and unfriendly explanation of cough hygiene.
   - [x] You should have made a general announcement on cough hygiene referring to a cough hygiene poster (if available).

4. After getting laboratory results (Rifampicin-resistant), you invited a patient to discuss his test results and treatment. After telling the patient that he has DR-TB, how should you proceed?

   - [ ] You should tell patient all he needs to know about DR-TB and subsequently ask whether he understood everything.
   - [x] You should inquire what the patient already knows about DR-TB, explain to him specifically what he needs to know, and agree on next steps.

5. During the counselling session, the patient is worried about side effects. He has heard from other people that it is possible to lose hearing if you take the medicine. How should you address those concerns?

   5.1. You should:

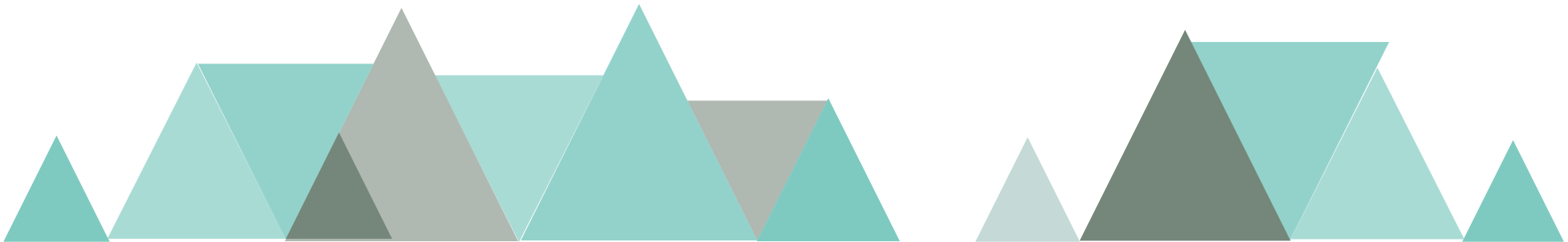
   - ○ Tell him only the most necessary information as to not scare him even more.
   - ● Provide him with information about all of the treatment risks and benefits, the monitoring and mitigation options available for dealing with side-effects, and possible alternatives.

   5.2. Which questions would be appropriate for you to ask?

   - ■ Closed-ended questions
   - ■ Open-ended questions
   - ■ Follow-up questions
   - □ Leading questions

6. You need to visit the patient at home to see his living conditions. The patient is not at home, so you introduce yourself as a nurse to a neighbor. Did you sufficiently protect the patient's privacy?

   - ○ Yes, you did. You did not say that you were from the TB program.
   - ○ No, you should not have said that you are a nurse.
   - ○ No, you should not have gone to a patient's home.
   - ● No, you could have left a message saying that you (only stating your name) were looking for him, and could he please contact you.



REFERENCES

1. Link BG, Phelan JC. Conceptualizing Stigma 2001.
2. Baral SC, Karki DK, Newell JN. Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. BMC Public Health 2007;7:211. doi:10.1186/1471-2458-7-211.
3. Dodor EA, Kelly S, Neal K. Health professionals as stigmatisers of tuberculosis: Insights from community members and patients with TB in an urban district in Ghana. Psychol Heal Med 2009;14:301–10. doi:10.1080/13548500902730127.
4. Tadesse S. Stigma against Tuberculosis Patients in Addis 2016:1–11. doi:10.1371/journal.pone.0152900.
5. Cremers AL, De Laat MM, Kapata N, Gerrets R, Klipstein-Grobusch K, Grobusch MP. Assessing the consequences of stigma for tuberculosis patients in urban Zambia. PLoS One 2015;10:1–16. doi:10.1371/journal.pone.0119861.
6. Cremers AL, Gerrets RPM, Colvin CJ, Maqogi M, Grobusch MP. Resilience and survival: a visual ethnographic health study of patients with tuberculosis in Cape Town. Under Rev n.d.
7. WHO, ILO. Joint WHO / ILO policy guidelines on improving health worker access to prevention , treatment and care services for HIV and TB. 2010.
8. Kreiner GE, Ashforth BE, Sluss DM. Identity Dynamics in Occupational Dirty Work: Integrating Social Identity and System Justification Perspectives. Organ Sci 2006;17:619–36. doi:10.1287/orsc.1060.0208.
9. Ashforth BE, Kreiner GE. Dirty Work and Dirtier Work: Differences in Countering Physical, Social, and Moral Stigma. Manag Organ Rev 2014;10:81–108. doi:10.1111/more.12044.
10. WHO. IMPLEMENTING the WHO Policy on TB Infection Control in Health-Care Facilities , Congregate Settings and Households. 2009.
11. Buregyeya E, Mitchell EMH, Criel B, Kiguli J, Nuwaha F. Acceptability of masking and patient separation to control nosocomial Tuberculosis in Uganda : a qualitative study 2012:599–606. doi:10.1007/s10389-012-0503-1.
12. Ka C, Wong M, Hon B, Yip K, Mercer S, Griffiths S, et al. Effect of facemasks on empathy and relational continuity : a randomised controlled trial in primary care 2013.
13. PATH. Interpersonal Communication and Counselling PART II TTHE MAIN STEPS OF EFFECTIVE COUNSELING 2009:38–67.

14. World Care Council. The Patients' Charter for Tuberculosis Care Patients Rights and Responsibilities 2006.

15. Stop TB Partnership. Legal Environment Assessments for Tuberculosis 2016.

16. WHO. Guidance on ethics of tuberculosis prevention, care and control. Geneva: 2010.

17. Ko Y, Shin JH, Ph D, Lee H, Ph D, Lee S, et al. Duration of Pulmonary Tuberculosis Infectiousness under Adequate Therapy , as Assessed Using Induced Sputum Samples 2017;3536:27–34.

18. Stop TB Partnership, UNOPS. UNITED TO END TB. EVERY WORD COUNTS: SUGGESTED LANGUAGE AND USAGE FOR TUBERCULOSIS COMMUNICATIONS. FIRST EDITION 2015.

19. Frick M, Delft D Von, Kumar B. VIEWS & REVIEWS End stigmatizing language in tuberculosis research and practice 2015;1479:10–2. doi:10.1136/bmj.h1479.

20. Petronio S, Dicorcia MJ, Duggan A. Navigating Ethics of Physician-Patient Confidentiality : A Communication Privacy Management Analysis 2012;16:41–5.

21. Phillips R, Benoit C, Hallgrimsdottir H, Vallance K. Courtesy stigma: A hidden health concern among front-line service providers to sex workers. Sociol Heal Illn 2012;34:681–96. doi:10.1111/j.1467-9566.2011.01410.x.

22. Li L, Guan J, Liang LJ, Lin C, Wu Z. Popular opinion leader intervention for HIV stigma reduction in health care settings. AIDS Educ Prev 2013;25:327–35. doi:10.1521/aeap.2013.25.4.327.

PART 2

INTERACTIVE LEARNING

Authors:
Ieva Leimane
Ellen M.H. Mitchell
Sarah van de Berg

INTRODUCTION

This Interactive Learning Module is designed for a participatory learning workshop. Part I (Self-learning Module) is a web-based or paper-based self-learning module which covers infection control and basic stigma theory and is a pre-requisite to participate in the Interactive Learning. Mastery of the self-learning module content is needed to participate in the exercises and group discussions. The exercises are adapted from other health program trainings and have been redesigned for (DR-) TB stigma.

Goal

The goal of the Intervention Package Part II is to allow participants to explore, question, clarify and affirm their values and beliefs about (DR-) TB stigma, meet with their peers, challenge themselves, improve their environment, and change, such that they develop self-awareness and are comfortable with the provision of people-centered (DR-) TB treatment and care.

Objectives

After the completion of the Intervention Package Part II Module 2, participants should be able to:

- Appreciate their own value in the fight against (DR-) TB.
- Define and identify (DR-) TB related stigma.
- Empathize with patients.
- Serve all patients in a non-judgmental manner.
- Understand and uphold patient-provider confidentiality.
- Address stigma in the context of service provision.

Target Audience

While the primary audience for this Intervention package is health care workers, it is adaptable to a variety of stakeholders, including policymakers, health care workers, managers, advocates, community members, and media. Discuss implementation at the facility level with management.

Participants

There is no need to screen or choose workers in the health care facilities. The intervention is appropriate for all levels and types of staff at the health care institution.

Implementers are encouraged to carefully consider how participants' backgrounds and characteristics will affect the experience and effectiveness of the workshop. It is important for participants to feel safe and comfortable engaging in an honest exploration of their beliefs, opinions, and attitudes. Divergent viewpoints are inevitable and will contribute to the richness of group discussion. A more diverse group can increase the amount of facilitation needed.

Participants should support each other, as a team approach facilitates the application of new competencies. Further, the service providers need to allow post-training follow-up visits for stigma reduction measurement and performance evaluation.

Facilitators (Key Opinion Leaders)

There are three ways to identify opinion leaders in a health care setting who can be trained to facilitate the face-to-face workshops and catalyze the organizational changes.

- Conduct a sociogram. During the baseline assessment, ask workers to nominate the three most innovative/influential staff in their facility (i.e., the three most likely to introduce new good ideas). Instructions for conducting a very simple sociogram to identify change agents and opinion leaders can be found here: http://leaderboardx.herokuapp.com/#/about

  The data can be uploaded and processed here: http://leaderboardx.herokuapp.com/#/graph-editor
- Identify leaders. Union representatives, hospital stakeholders, and department leaders may recommend persons known to be socially influential and well-respected.
- Observe who is a change agent. External observers can conduct field observations of potential candidates' interactions with their coworkers to verify the popularity of nominees and categories of their social network.

Selection of the facilitators will depend on interest, dedication, and time available to apply new competencies on their job.

The facilitators' role is to lead exercises, initiate discussions, answer questions, provide individual feedback, show self-compassion, and catalyze changes in policy and the enabling environment for compassionate care.

A facilitator team of approximately two to three people is the most effective way to deliver modules and exercises in the toolkit. There are many skills required, many of which are not found within one person, hence the choice is for a team approach. Within the team there should be people who have had TB before. Co-facilitation with a TB survivor role models collaboration and mutual respect and will be more effective at transferring the skills than any exercise.

Facilitators should have completed the facilitators' training course on the Allies Approach and engaged in a process to help recognize stigma-related behavior in themselves and others. Those who will facilitate the Intervention Package Part II Module 2 and support the subsequent changes at the health facilities should have first reflected upon their own personal beliefs, attitudes, and values, so that they:

- avoid value-laden terminology in their normal speech;
- are familiar with adult learning principles and methodologies;
- have good technical knowledge of TB;
- have experience working as a group facilitator;
- are skilled to deal with emotions and are vulnerable;
- are good listeners and refrain from giving advice;
- are able to connect well with people;
- are used to working cross-culturally;
- have good organizational skills; and
- model making mistakes, owning these mistakes, showing self-compassion, and then moving on.

Principles of Learning

A successful workshop should employ adult learning principles, including plenary discussion, individual and group work, hypothetical and real dilemmas, stories, case studies, and simulations (i.e., drama or role plays and visualizations). As facilitators, it is important to create a safe, non-threatening space where feelings and fears can be discussed and explored openly.

The complete workshop includes exercises from each of the five modules below, with opening and closing remarks:

1. **VALUES**: a module on the importance, ideals, and ethos of health care workers.
2. **HEART**: a module to explore self-compassion and compassion for patients.
3. **HEAD**: a module to reduce the impulse to judge.
4. **FACE**: a module on interpersonal communication.
5. **HANDS**: a module with practical tools to create an enabling environment for compassionate care work.

All exercises contain worksheets, handouts, and summaries of the exercises taught in the workshop, as well as instructions for facilitators. The intervention is designed for groups of health care staff at health care institutions (participants) who are led and assisted by Key Opinion Leaders (facilitators).

How to use the Allies Approach Intervention Package

The Allies Approach Intervention Package Part II is designed for a participatory learning workshop. The idea is to encourage participants to learn through doing, including sharing experiences, feelings, and concerns, discussing issues, and solving problems. Changing attitudes towards (DR-) TB patients can only be achieved through a participatory learning process.

Dosage

Participants should be exposed to content from each of the modules.

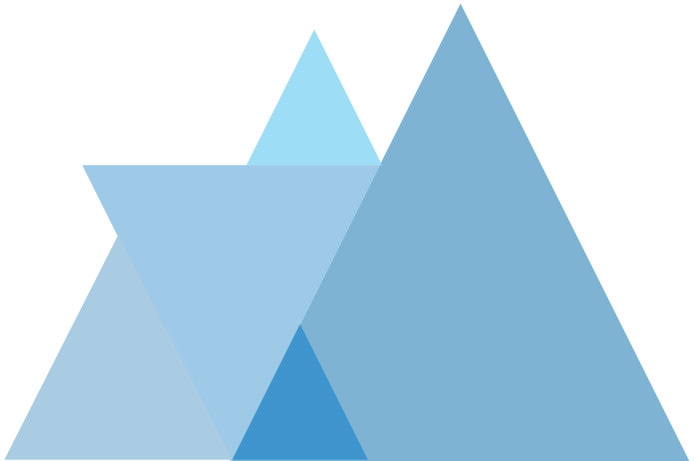
Delivery

The exercises are designed to be combined in a customized training with a minimum of 30 minutes and maximum of 90 minutes per exercise. Each proposed activity has a specific objective, methodology, and duration, so exercises can be carefully selected according to the health care institution's baseline measurement results and available time and resources.

The Allies Intervention Package may be used in several different ways.

1. All of the exercises developed in The Allies Intervention Package may be completed in sequence, without interruption, in intensive workshops.
2. Individual exercises may be selected for use in a series of modular training sessions during staff meetings (for example, one exercise per week.)
3. Selected exercises from each module may be used in a tailored workshop to address stigma-related issues based on the baseline assessment results.
4. Exercises developed in The Allies Intervention Package may be combined with other interventions.

Please see the sample program below aimed to address selected issues at the health care institution (see Table 3: Sample workshop agenda.)



The following guidelines may help the selected Key Opinion Leaders and workshop facilitators:

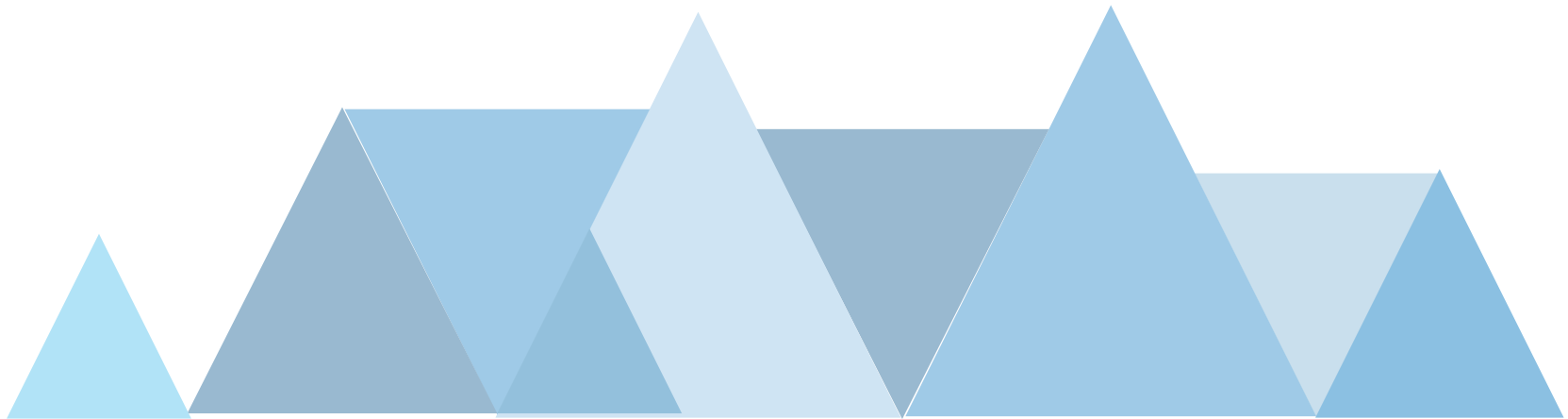
- Set clear ground rules and expectations around confidentiality.
- Be aware of your own feelings and fears* about the topics. Participants are more likely to trust you if you can share your feelings openly and lead by example.
- Remember to always leave enough time for participants to share their feelings and experiences and to ask questions.
- Offer participants a "time-out" if they need to take a break.
- If there are any exercises you do not feel comfortable leading, find a co-trainer who can help.

The duration of the complete set of modules (Part II) intervention with all proposed exercises will take 12 times 30 minutes per day in total, with a minimum time of three working days and a maximum time of 4.5 working days. See Part II: Interactive learning Exercises overview figure.

Sample workshop agenda

Day		
Time (min)	Module	Exercise
30	Introduction	Introductory remarks
30		
30	Value of health care workers	Comfort continuum
30	Break	
30	Heart - compassion exercises	My imperfection, your imperfection
30		Our vulnerability, their vulnerability
30		Our secrets, our shame
60	Lunch break	
30	Head - cognitive exercises	Four corners
30		
30	Face: exercises on interpersonal communication	Safe space, safe boundaries
30	Break	
30	Hands - actions exercises	Revision of facility policies
30		
30	Closing	Closing reflections/A way forward

Table 3. Sample workshop agenda



An Overview of Interactive Learning Exercises

	Exercise Title	Duration	Handouts/materials
Introduction	Introductory remarks	30-60	N/A
Values	Comfort continuum	30-60	Comfort continuum: statements
	Cross the line	30-60	Cross the line statements
	Valuing ourselves and our work- “river of life”	30-60	N/A
	Universality of Self-Stigma and Shame	60	Wall of self-stigma and shame, Wall of effects of self-stigma and shame
	Do you believe everything you think?	60	Belief Tree, Ryff Dimension
	Keeping a TB journal	30	N/A
Heart	My imperfection, your imperfection	30-60	N/A
	Our vulnerability, their vulnerability	30-60	Discussion Q indicated in the exercise
	Our secrets, our shame	30-60	N/A
Head	Introduction to Stigma Theory (optional)	30-60	Dialogue, Figure classical stigma-building cascade (Link & Phelan)
	Underlying structure of stigma (optional)	60	Blank spider web, Underlying structure of stigma
	Choices- the last diagnostic test (Genexpert cartridge)	30-60	Situation description
	Four corners	60-90	Statements
Face	Safe space, safe boundaries	30-60	N/A
	Labeling	60-90	Text for the necklaces
	Speaking with our faces	30-60	Mask, Respirator, Cards with emotions, Cards with messages

	Exercise Title	Duration	Handouts/materials
Hands	Framing (DR-) TB	60-90	Situations, Assessment questions
	Revision of facility policies	60-90	Situation, Assessment questions, Suggestions for text revision
	Creating respect and dignity messages at health care institutions	60	Message tips form
	Countering: dealing with difficult situations	60-90	Cards
	A community free of stigma	60	N/A
	Prioritization and action planning	60-90	Behaviors cards, Frequency cards, Strategy cards
	Upholding the right to privacy	60-90	Situation, Job Aid
Closing	Closing reflections/way forward	30-60	Closing reflections/evaluation worksheet, Evaluation worksheets

Table 4. An overview of interactive learning exercises

PART 2
INTERACTIVE LEARNING
EXERCISES

Introductory Remarks

OBJECTIVE:

To let participants articulate their expectations for the workshop, identify roles and responsibilities, and agree on ground rules.

Flipchart, Markers, PowerPoint presentation (PPT) with workshop goal and objectives, workshop agenda, facilitators' roles, and participants' roles, Labeled flipchart with workshop "expectations" and "parking lot", Evaluation materials, such as pre- and post-workshop surveys and workshop evaluation forms.

30- 60 minutes

Discussion, Q&A

ADVANCE PREPARATION:

Tailor the workshop title, goal, objectives, and agenda to meet program and participants' needs, time, and other constraints. Prepare flipcharts with titles and items for the workshop. Label flipchart with workshop expectations and parking lot. Prepare an icebreaker exercise.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Welcome the participants and introduce the workshop.
2. Introduce yourself and provide some information about your facilitation experience and your background.
3. Ask the participants to introduce themselves, using one of the proposed "ice-breakers" exercises (see below under Facilitators Notes)
4. Discuss and review the prepared flipcharts with the participants.
5. Discuss the facilitators' roles and responsibilities.
6. Ask the participants to share other roles that facilitators should play during the workshop, and add them to the flipchart.
7. Remind the participants that you will not have answers to all the questions that arise. Emphasize that you will facilitate the group in working together to find answers to most questions.
8. Discuss the participants' roles and responsibilities. Ask participants to share other roles that they should play during the workshop, and add them to the flipchart.
9. Establish group norms. Hang the list on the wall where everyone can see it and explain how it will be used throughout the workshop.

Suggested Group Norms:

1. Speak one at a time.
2. Allow each person time to talk.
3. Agree to disagree, but do so respectfully.
4. Value each person's unique perspectives.
5. Participate at your comfort level.
6. Honor everyone's input (regardless of educational de-

grees, professional or community status, or personal experiences with the topic.)

7. Ask questions when you have them.
8. Speak for yourself (begin statements with "I" rather than "everybody" or "you".)
9. Take responsibility for your own learning (e.g., ask for clarification and give input to facilitators.)
10. Feel free not to participate if a certain topic or exercise is too uncomfortable.
11. Turn cell phones and beepers on vibrate.

FACILITATOR'S NOTES:

Ice-breaker exercises

"Learning from Experience"
Have participants introduce themselves and explain one thing they have learned about the topic you are covering. Post their lessons learned on a flip chart. Refer to them throughout the class.

"Challenges and Objectives"
Divide participants into small teams. Instruct teams to identify challenges and objectives for the training. Post work on flip charts. Have them introduce their team and share their work with the rest of the class.

"Questions"
Have each person write a question on a sticky note or a piece of paper. Have them introduce themselves and their question, and post all questions on a chart. Ask the group to answer the questions during the training.

"Hat of fears and questions"
If openly sharing questions at the beginning is not right for the group, an alternative it to have participants write their questions, hopes, and/or fears on papers, and put them into a hat so they can be picked and read by someone else. This allows for anonymity.

"Collective Knowledge"
Have participants work in teams to identify five rules for dealing with issues. Write the rules on flip chart paper.

"Continue following statements"

- My overall hope for this workshop is …
- Right now, I feel hesitant about …
- I am concerned about being asked …
- I feel uncomfortable discussing …
- During the workshop, I hope that I will be able to …
- At the end of this workshop, I hope that I …

Adapted from:

» *Abortion attitude transformation: Values clarification activities for global audience, Ipas, http://www.ipas.org/en/Resources/Ipas%20Publications/Abortion-attitude-transformation-A-values-clarification-toolkit-for-global-audiences.aspx*

VALUES

Stigma occurs when society marginalizes a person based on an attribute or characteristic that has been deemed undesirable by the wider community. However, not only those with an undesirable trait can experience stigma. Those who are affected by secondary stigma can experience marginalization or degradation by society due to their association with a person (courtesy stigma- network) or a profession (dirty work-occupation) that is stigmatized.

Hughes (1953) defines 'dirty workers' as those individuals who are stigmatized due to an occupation and tasks they perform that are perceived by society as degrading, disgusting, or repugnant.[14] In other words, dirty work stigma is courtesy stigma resulting from work. Many people perform jobs that are essential for a viable society, but the stigma that is attached to this profession can make the work challenging beyond its physical demands. The taint of the stigma is in particular high in professions with a low prestige, and others tend to look down on those who are performing the job. Dirty workers might struggle to maintain a positive self-identity, which subsequently results in disengagement, poor performance at work, or leaving the occupation. In comparison to other forms of stigma, an individual's occupation might be perceived as controllable.

Comfort Continuum

OBJECTIVE:

To discuss how varying personal comfort levels and life experiences impact (DR-) TB treatment and care.

Three paper signs labeled "A Lot," "A Little" and "Not At All", Tape, Comfort Continuum statements

30- 60 minutes

Exercise (interactive game)

ADVANCE PREPARATION:

Label three papers "A Little," "A Lot" and "Not At All." Arrange open space. Review and revise statements, if necessary, selecting statements that are most relevant for this group of participants. Prepare information on laws and policies in case questions arise.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Tape the three signs on the floor or the wall in an open area.
2. Read one statement at a time and ask participants to physically move to the point along the continuum that best represents their feelings.
3. After participants have arranged themselves, ask volunteers at different points along the continuum to explain why they are standing there.
4. If participants want to move based on someone's explanation, encourage them to do so.
5. Once you have finished reading the statements, ask participants to return to their seats.
6. Ask two participants to share their feelings about the exercise. Try to solicit a different response from the second person.
7. Refer to the exercise as you facilitate a brief discussion about the different responses and levels of comfort in the room.
8. Facilitate a discussion on how comfort levels impact the provision and quality of services. Emphasize what a large impact providers' attitudes have on services and people's satisfaction with those services.

   Some discussion questions could include:

   - Were there times when you felt tempted to move to a sign based on what the majority of the group did?
   - Did you move (or not?) How did that feel?
   - If you were in the minority, how did that feel?
   - What observations do you have about your own responses? What observations do you have about other people's responses?
   - Why did you have these responses?
   - What about your responses to the statements surprised you? What surprised you about others' responses?
   - What did you learn about your own comfort levels?

Comfort Continuum (continued)

- What observations do you have about the group's overall level of comfort?

9. Correctly answer any questions that arise during the discussion.

10. Solicit and discuss any outstanding questions.

FACILITATOR'S NOTES:

The reasoning behind a person's feelings differ based on personality and circumstances. Nevertheless, health care workers can be stigmatized by others, and therefore may not feel comfortable.

Adapted from:

» *Abortion attitude transformation: Values clarification activities for global audience, Ipas, http://www.ipas.org/en/Resources/Ipas%20Publications/Abortion-attitude-transformation-A-values-clarification-toolkit-for-global-audiences.aspx.*

Comfort Continuum: Statements

Below are some statements for health care workers. You can choose some of the following statements or develop other statements that are most relevant to your setting.

1. How comfortable are you discussing (DR-) TB service provision with colleagues outside your work setting?
2. How comfortable are you discussing (DR-) TB service provision outside of your work setting?
3. How much do you know about your country's laws and policies on (DR-) TB services?
4. How much disapproval would you expect to feel from your family and friends if you told them you provide (DR-) TB services?
5. How much do you think that wearing a N95 mask protects from TB transmission?
6. How much do you think wearing a mask hinders the trust and understanding between health care workers and patients?
7. How fearful are you of XDR-TB?
8. How confident are you that stigma, fear, and distrust of patients does not influence your actions?
9. How scared are you of dying from (DR-) TB?
10. How scared are you of infecting family members with (DR-) TB?
11. How scared are you of contracting (DR-) TB and having the side effects of treatment for drug resistant TB?
12. How urgent do you think it is to develop new drugs with fewer side effects?

Cross the Line

OBJECTIVE:

To describe how stigma affects individual and societal views and reactions to (DR-) TB patients.

String or tape (approximately 2-3 meters long) to mark a line on the floor. If this is not available, ask participants to pretend that there is an imaginary line across the floor, Cross the line statements

30- 60 minutes

Interactive exercise

ADVANCE PREPARATION:

Review and adapt statements, if needed. Clear a large area of the room.

FACILITATORS STEP-BY STEP INSTRUCTIONS:

1. Ask all participants to stand on one side of the line.
2. Explain that you will read a series of statements and that participants should step entirely across the line when a statement applies to their beliefs or experiences. Remind participants that there is no "in between".
3. Ask participants not to talk during the exercise unless they need clarification.
4. Stand at one end of the line and give an easy practice statement, such as: Cross the line if you like dogs.
5. Once some people have crossed the line, give participants an opportunity to observe who crossed the line and who did not.
6. Ask someone who crossed the line and then someone who did not to briefly explain their response to the statement.
7. Invite participants to all move back to one side of the line.
8. Repeat this for several of the statements about TB. After the statements are read, ask participants to take their seats.
9. Discuss the experience. Some discussion questions may include:
   - What did you learn about your own and others' views on TB?
   - Were there times when you felt tempted to move with the majority of the group? Did you move? How did that feel?
   - What did you learn from this exercise?
   - What does this exercise teach us about the stigma surrounding TB?
   - How might stigma impact the experience of health care workers and providers working in TB care?
10. Discuss the statement on access to services. If everyone or no one in the group crossed the line, discuss this commonality. If some crossed the line and some did not, discuss how these different views affect (DR-) TB care and the broader social climate for (DR-) TB in that setting.

Cross the Line (continued)

11. Discuss any outstanding questions, comments, or concerns with the participants.

Adapted from:

» *Abortion attitude transformation: Values clarification activities for global audience, Ipas, http://www.ipas.org/en/Resources/Ipas%20Publications/Abortion-attitude-transformation-A-values-clarification-toolkit-for-global-audiences.aspx.*

Cross the Line Statements

Read some of the following statements, beginning each time with, "Cross the line if …" Choose a maximum of 15 statements according to the group's dynamics. Choose at least three from "Experiences with TB" and four from "Self-experienced stigma/ discrimination." After participants have moved, follow each statement with "observe who crossed the line and who did not … notice how it feels to be wherever you are … now please all move back to the same side of the line".

Experiences with TB

1. You have been asked to keep someone's (DR-) TB secret.
2. You or someone you are close to has had (DR-) TB.
3. You have had to tell someone that they have been diagnosed with (DR-) TB.
4. You have seen a very sick person grow strong and happy again after starting TB treatment.
5. You have stood up for a patient and suffered a personal cost for it.
6. You have helped diagnose someone, only to have them abandon the treatment.
7. You have felt fearful for your safety while doing community work.

Self-experienced stigma/discrimination

1. You have ever felt uncomfortable talking about (DR-) TB.
2. You have been discriminated against for who you are, what you do, or where you were born.
3. You have been discriminated against for your professional association with TB or HIV.
4. You have ever felt uncomfortable talking about risk of TB infection and transmission with your family or friends.
5. You have been criticized by your family for prioritizing TB care so much that you put your own/ their health at risk.
6. You have ever avoided the topic of (DR-) TB to avoid conflict.
7. You have ever avoided the topic of commodity or drug stock-outs or low-quality services to avoid conflict.

Cross the Line Statements (continued)

OPTIONAL

Witnessing other people's stigma

1. You have witnessed others talking about a person's (DR-) TB in a way that ensured their privacy.
2. You have felt pity after seeing someone be mistreated by their family or employer because of their TB.
3. You have witnessed a team member not keeping a diagnosis private and confidential.
4. You have had to incentivize a stakeholder, so they did not obstruct the effort
5. You have experienced community-level challenges because of local politics.
6. You have followed standard operating procedures that you did not agree with.
7. You have not followed rules in order to solve a problem.
8. You have seen a patient with (DR-) TB being looked down upon by their family, friends, or community.

Beliefs about TB patients

1. You believe there is a need for a supportive social environment for those with TB.
2. You believe all people deserve access to safe, high-quality TB services.
3. You believe that anyone can get TB, even you.

Adapted from:
» *KNCV stigma reduction materials.*

Valuing Ourselves and Our Work - "River of Life"

INTRODUCTION:

Many people enter health care professions to be able to help others in their communities. These motives can get lost under the weight of the work. This exercise helps people to reconnect with their ideals and intentions, and to recall their calling to serve others. This exercise can also be used as the 'getting to know each other' exercise.

OBJECTIVE:

To revisit and refresh health care workers' motivations for joining the health field.

Flipchart, Markers, Paper, Pens

30- 60 minutes

Exercise

ADVANCE PREPARATION:

Make sure that you have all necessary materials in advance.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Explain to participants the metaphor of the river as a symbol for life.
2. Indicate that a river sometimes flows slower and sometimes faster, and that there may be obstacles. Invite participants to reflect on their own trajectories and how they came to be working at the health care institution. Make participants understand that their task is to point out the significant elements (events, turning points, or choices) that have contributed to shaping their professional life.
3. Give participants a few minutes to think about why they became a health care worker. What were the opportunities, road blocks, unexpected things/experiences that moved them toward this direction? Encourage them to try to remember the feelings, expectations, and wishes they had. What was important to them then?
4. Ask participants to apply their drawing skills during the exercise. Allow 15 minutes for participants to create rivers representing their lives.
5. Ask for few volunteers to talk about the experiences and feelings that influenced their trajectory. Allot five to seven minutes per person. Note: If there is a larger group, you might consider dividing them into smaller units so that everyone has a chance to share their thoughts. When the presentations are over, allocate time for reflection with the whole group.
6. Ask them to reflect on:
   - Do you remember a patient for whom you feel that you may have altered the 'river of their life' in a positive way? How did it feel the first time you helped a patient?
   - How would life's direction have been different if you were born a different gender or in a different place?

Valuing Ourselves and Our Work - "River of Life" (continued)

7. Discuss within a group:
   - What was it like for you to tell your story to this group?
   - What was it like for you to hear others' stories?
   - What surprised you?
   - What insights have you gained about the group?
8. Ask each person to describe briefly if they have ever felt stigmatized during their lives and whether they think they stigmatize others.
9. Solicit and discuss any outstanding questions.

Universality of Self-Stigma and Shame

OBJECTIVE:

To get in touch with the feeling of self-stigma and shame and to understand how it affects people.

Flipcharts, Post-its, Markers

60 minutes

Discussion

ADVANCE PREPARATION:

Prepare two flipcharts with the titles "Wall of self-stigma and shame" and "Wall of effects of self-stigma and shame."

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Ask participants to close their eyes and answer the following question:

   "How many of you have ever thought 'I'm not good enough'?"

2. When you have this thought:

   - How does this make you feel?
   - Can you understand how it limits you, makes you feel small, and separates you from those around you?
   - Can you imagine how many things you believe you can't do when you believe this?
   - Can you see how you compare yourself to others?

3. Invite the group to think about a specific work-related situation where they thought they were not good enough. Ask participants to be as specific as they can:

   - Where were you?
   - What time of the day?
   - With who?

4. Now pair up the participants. Ask them to turn to their partner and share a situation and express how it made her/ him feel.

5. Give each person a three minutes turn. Let them know when it's time to switch.

6. Ask them to write down on post-its the emotions they felt associated with that situation "I was not good enough." Write one emotion per post-it.

7. Invite participants to come forward and place their emotions on the "Wall of self-stigma and shame" flipchart.

8. Now invite participants to write down all the things they think they cannot do or won't have when they are believing they are not good enough.

9. Invite participants to come forward and place their emotions on the "Wall of effects of self-stigma and shame" flipchart.

Universality of Self-Stigma and Shame (continued)

10. Discuss with the group, using prompts such as:
    - What surprised you about this exercise?
    - Are you surprised by the power of self-stigma?
    - What similarities exist between people's experiences of self-stigma (this is a prompt on the prevalence of self-stigma?)
11. Discuss what can be done about self-stigma. Discuss with the group how did they feel if in some situations they were encouraged and said" You are good enough to do it". How did it help them to succeed?
12. Solicit and discuss any outstanding questions.
13. Thank participants.

FACILITATOR'S NOTES:

Self-stigma and shame live inside all of us and are a big influence on our lives. It is important to recognise self-stigma and try to limit its impact on our lives.

> The next time you think you are not good enough in some way, ask yourself if it is really true. Find an example of when you have been good enough.

Adapted from:

» *We are the change: Dealing with HIV-related self-stigma. Facilitators Guide Using the Work of Byron Katie: Inquiry-based stress reduction, www.theworkforchange.org.*

Do you believe everything you think?

"I work with people who have TB and that means that…"

INTRODUCTION:

This exercise will help people understand the powerful effect believing negative thoughts and judgements about TB have on their lives. We all have many negative self-judgements. We must see the power our thinking has on our lives first and then take steps to break these patterns. Other's judgements can only have power if we believe them. We have no control over the judgements made against us, but we can choose to apply meaning to those judgements.

OBJECTIVE:

To understand more about the impact beliefs have on our lives.

Flipchart with belief tree, Handout "Belief Tree", Handout "Ryff Dimension

60 minutes

Exercise

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Ask participants to think about how society views people working with TB.
2. Invite participants to make a list of what it means to work in the TB field.
3. When everyone has a list, ask them to circle the top two items that cause them the most stress, and invite them to share with the group.
4. Now take one belief that is in more than one person's list and bring it to the "Belief Tree." Put the belief (for example "This is my fault") into the space in the middle of the tree.
5. Ask participants to name the causes of this belief (including personal, such as low self-esteem, and societal, such as cultural norm, media, etc.) Write them each as roots of the tree.
6. Ask participants to name the consequences of thinking a negative thought, such as "People will think I'm contagious." This may include:

   - Isolation.
   - Shame.
   - No self-agency.
   - No support.
   - No interpersonal interactions.

   Write them as branches of the tree.

Do you believe everything you think? (continued)

7. Now ask them to consider who they would be without the negative thoughts. Write down each effect, such as:
   - Peaceful.
   - Confident.
   - Hopeful.
8. Each participant should work alone to find three examples of this being true. They should complete two "Belief trees" using the beliefs circled at the beginning the exercise.
9. Invite participants to discuss how self-stigma can impact a person. Guide the participants through one or two simple examples to help them understand that even if a person is doing well in some areas of life, self-stigma might cause them to do poorly in others. For instance, a person who has many positive relationships with other people and has a lot of support could still have a poor level of self-acceptance around their appearance.
10. When this exercise is complete, invite participants to share what they have learned.
11. Solicit and discuss outstanding questions.

FACILITATOR'S NOTES:

Examples:

I have TB and that means that….

- People will think I'm contagious.
- People won't want to talk to me.
- People will discriminate against me.
- People will discriminate against my children.
- My family will be discriminated against.

We need to first be able to recognise self-stigma and shame. Then we can start to address it to be free of any shame, blame, or guilt. Our role as Facilitator is to allow participants to discover their own solutions and make their own realisations.

Adapted from:

» *We are the change: Dealing with HIV-related self-stigma. Facilitators Guide Using the Work of Byron Katie: Inquiry-based stress reduction, www.theworkforchange.org.*

"Belief Tree"

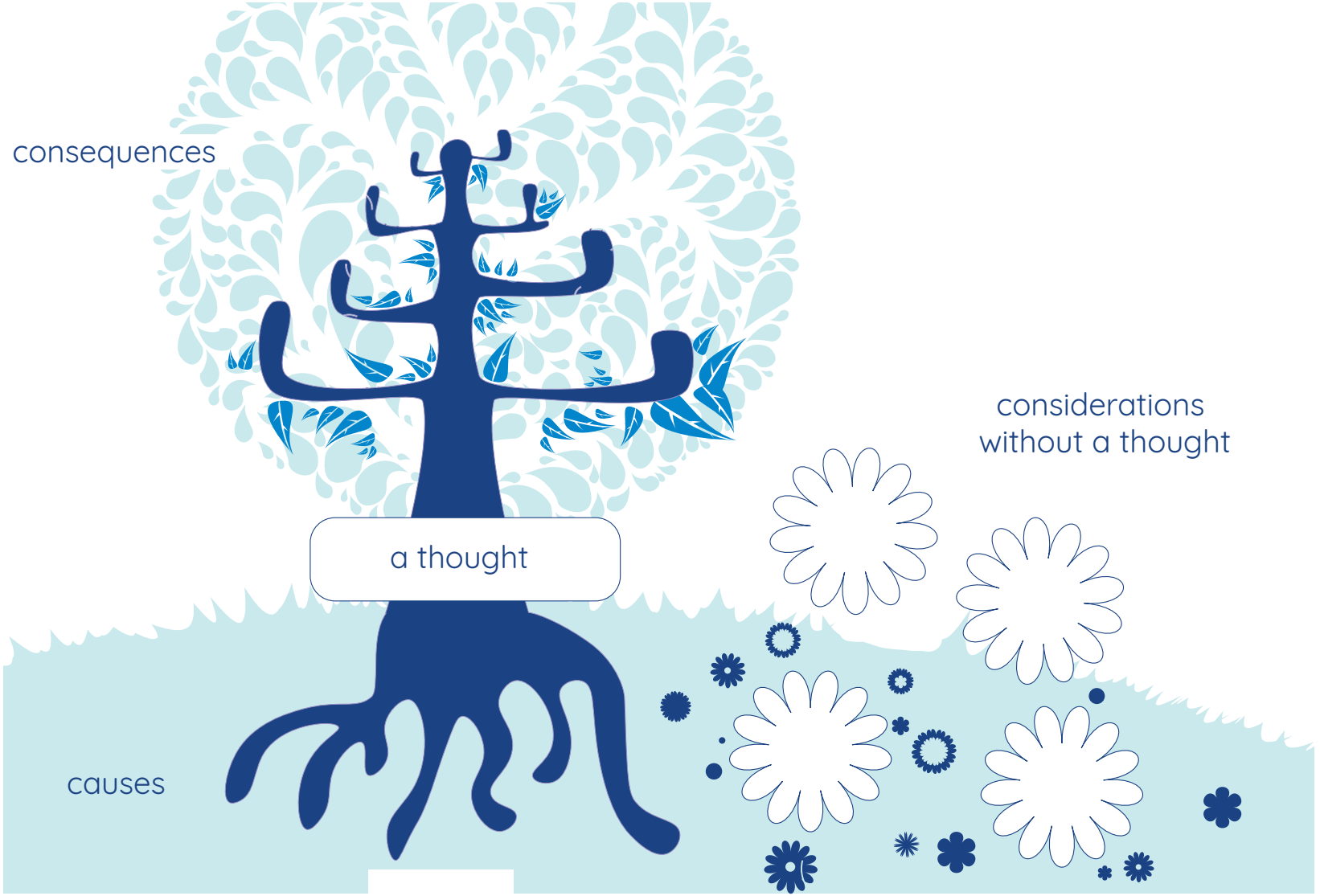


Figure 8. Belief Tree

Keeping a Journal - "My Saving Lives Journal"

OBJECTIVE:

Journaling helps HCW to reflect on their daily situation and explore solutions to challenges in a personal and safe space. Keeping a journal helps develop self-reflection skills that are critical for changing attitudes and behavior. The journals provide text for developing stigma analysis skills and can be used by HCWs to assess their own assumptions and negative/positive frames. Participants should journal at least three times a week for a month or more, but the periodicity and length will depend on the intervention.

Journaling template. Facilitators should print out templates and make them into a stapled booklet with at least 30 blank templates.

Introduction to the journal: 30 minutes

People will use the journal daily while caring for people with TB.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

To help deal with self-stigma, record your experiences using a journal.

1. Set aside time to write or draw in your journal each day. Make sure that you are somewhere where you can think and write properly without interruptions. Use happy/sad faces to illustrate your emotions if you prefer.
2. You do not have to write everything all at once. You can add to or change material as the day progresses.
3. Be honest with yourself. You are the only person who will read this journal, and it will be more useful to record things accurately.
4. Do not over-think. Write what you are thinking and feeling, without worrying if it sounds strange or embarrassing.
5. Explore the way you are feeling. Can you identify the triggers that make you feel happy or sad at work? If so, include them in your writing.
6. Consider different perspectives other than your own. What would others think?
7. Write only for yourself.
8. Things you are grateful for or proud of do not have to be big, important events. Small, personal successes are just as useful.
9. Try to write in the journal for 15-20 minutes each day.
10. Solicit and discuss any outstanding questions.

FACILITATOR'S NOTES:

Research has shown that expressive writing can produce measurable changes in physical and mental health and can positively influence sleep, work efficiency, and connection with others.[17] By keeping a daily journal, participants will be able to track their positive and negative thoughts and emotions.

HEART

My Imperfection, Your Imperfection

OBJECTIVES:

1. To connect with the universal human fallibility and make participants perceive similarities between themselves and patients who may have behaviors, identities, habits, histories, or diagnoses that we judge negatively.
2. To practice observation without evaluation, judgement, and labelling.
3. To practice assuming positive or neutral intent in the behavior of patients, or at least not assuming negative intent.

Flipchart, Markers, Chairs, Paper, Pens

30-60 minutes

Exercise

ADVANCE PREPARATION:

Review and adapt exercise as necessary.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Ask everyone to stand-up and introduce this exercise by saying "We all do things that we know we should not do, even though we know the consequences." Now sit down if... (read the statements form the list on the next page)
2. Continue with similar statements until no one is left standing.
3. The facilitator points out that: "We have all done something we know isn't good for us even though we know what the consequences could be".
4. Make some conclusions such as:
   - Health care workers have unsafe sex.
   - Health care workers break laws.
   - We are all as human as other people.
   - Our humanity makes us good health care workers when we can connect with our patients as people.
   - We all have the right to "make bad choices."
5. Ask participants to jot down on a paper one or two behaviors or characteristics of (DR-) TB patients which they have judged negatively. They should write down any judgmental thoughts they have had, even if they kept these thoughts to themselves or they later regretted thinking such things. Ask them not to put their names

My Imperfection, Your Imperfection (continued)

You found yourself lifting patients or medical equipment without proper back support.

You worked too hard or too many hours, potentially putting your health at risk.

You ever smoked cigarettes or hung out with people who smoke.

You went long periods without exercising.

You have ever eaten foods that you knew were not good for your health.

You stayed up too late.

You did not finish a course of antibiotics prescribed by your doctor.

You have ever crossed the road in heavy traffic without waiting for the light.

My Imperfection, Your Imperfection (continued)

on the papers. Ask them to fold up the papers. Collect the papers and put them in a hat or an envelope so they can be anonymous.

6. Go around the room, and have each person pick out a folded paper. Have participants read loud the judgmental thoughts.

7. Ask them to separate each thought into the behavior, and the judgement of the behavior. Ask people to think of the potential reasons for such behavior.

8. Discuss with participants:

   - How can we feel our feelings without letting our judgements harm others?
   - How do we learn to note behaviors without evaluating them, labelling them, judging them, and chastising patients for their choices?
   - How do we provide high quality care and empathetic service to imperfect patients? What will help us to give our best to people?

9. Make some closing remarks. Having self-compassion and accepting our own imperfections can help us to accept the imperfections of our patients. It is very hard to become non-judgmental, because health care workers are often required to make decisions on incomplete information and to use experience as guidance when under time pressure. We can become more open to alternative, and more positive, explanations of patient behavior, and this can help us to convey a less judgmental attitude. If not, we must separate the personal from the professional and respectfully relate to patients.

10. Solicit and discuss any outstanding questions, comments, or concerns with the participants.

FACILITATOR'S NOTES:

Patients are people. To acknowledge the person and his/her behavior can be challenging. Try to understand their behaviors as expressions of unmet needs.

Our Vulnerability, Their Vulnerability

OBJECTIVES:

1. To appreciate how stigma operates in the context of a power differential. There is the potential for shameful feelings when we are vulnerable.
2. To develop empathy for (DR-) TB patients.

Flipchart, Markers, Discussion questions

30-60 minutes

Discussion

ADVANCE PREPARATION:

Review and adapt discussion questions as necessary.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Asks the group to close their eyes and think of a time when they had a problem or were in a crisis and went to someone for help (an employer, teacher, family member, or someone with a specialized skill, not a friend or loved one.)
2. Ask each of participants to write down how it felt to be helped? Once it is done ask participants to share this information with their peer. Note: The facilitator should stress that when participants are listening to their partners to their peers, they can use "minimal encouragers" ("uh huh" or "mm") but they are not to ask questions or give any verbal responses.
3. Ask participants to share their experiences.
4. Once all participants have shared their experiences ask them to discuss the following:
   - How did it feel to ask for help during that situation?
   - What was helpful? What was NOT helpful?
5. Ask to discuss the following with the whole group participants and ask someone form the group to write the answers on a flipchart:
   - What did it feel like talking for two minutes without interruption?
   - What is important to remember when dealing with someone in a crisis?
6. Solicit and discuss any outstanding questions. Ask the participants if it helped them to speak about it during the session and if they think patients would benefit from getting counseling too.

Adapted from:

» *Patient privacy and confidentiality, PATH, http://www.path.org/publications/files/RH_ensuring_privacy.pdf.*

Our Secrets, Our Shame

OBJECTIVE:

To sensitize participants to the shared value of privacy by having them appreciate/recall how powerful anticipated stigma is and how it can affect everyone.

Flipchart, Markers

30-60 minutes

Exercise

ADVANCE PREPARATION:

Prepare a newsprint (flipchart) page with two columns, the first labeled "Feelings" and the second labeled "Consequences."

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

A. Telling secrets

1. Have participants close their eyes and think of a secret they know about someone else that few people know. Emphasize that they will not have to share this secret.
2. Without writing down the secret itself, ask them to write down one or more reasons why they might reveal the person's secret to someone they trust. List responses on the flipchart.
3. Add any of the following, if not mentioned by participants:
   - It is natural/tempting to tell your friend/best friend/ spouse everything.
   - I wanted advice on what to do about a problem that someone else confided in me.
   - I wanted to look important.
   - I just let it slip.
   - I felt pressured into telling it.
   - Someone asked if I knew about the situation and I did not want to lie.
   - I wanted to hurt somebody I do not like or get revenge on someone who has hurt me.
4. Reassure participants that it is natural to want to confide in someone for the many reasons that they just discussed.

B. Revealing Secrets

1. Ask participants how they would feel if they confided their secret in someone and that person told the secret to someone else without their permission. List responses under the column labeled "Feelings".
2. Discuss what might be the consequences of someone telling their secrets to other people without their permission. List responses under the column labeled "Consequences". Mention that health care workers often need to ask patients sensitive questions about who they

Our Secrets, Our Shame (continued)

spend time with and what behaviors they are practicing in order to ensure the best diagnosis and treatment and to minimize the risk of transmission.

3. Ask how a client might feel if sensitive information about him or her were revealed to another person who did not need to know the information. List the responses on the flipchart.
4. Compare the responses with the participants' list of feelings.
5. Ask what would be the consequences of revealing this sensitive information to others.
6. Ask how the consequences would affect the health center, the person's health, and the provider's reputation, etc.
7. Mention that revealing private information about a person to someone else without the authorization of the client is a violation of the person's rights.
8. Explain that a person is entitled to know his/her provider is not allowed to give any information to anyone else without written permission (except for other health care workers directly involved in care.)

Adapted from:

» *Patient privacy and confidentiality, PATH, http://www.path.org/publications/files/RH_ensuring_privacy.pdf.*

HEAD

Introduction to Stigma Theory

OBJECTIVE:

To understand Link & Phelan's construction of stigma through a layered, gradual process of dehumanization.

Flipchart, Markers

60-90 minutes

Role play

ADVANCE PREPARATION:

Tailor the dialog to the participants' needs and time constraints. Prepare flipcharts with the main conclusions.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Invite several participants to act out the scenario below. Give them 5-10 minutes to prepare the dialogue.
2. Hand a script to the rest of the participants. Ask them to review the script and circle any overt naming, blaming, or shaming.
3. After the actors have prepared, ask them to role play in the center of the circle.
4. After the role play, ask the participants (observers) to:
   a. Describe what they saw and break it down to the building blocks of stigma (see Figure 9)
   b. Discuss the following questions:
      - What happened in this scene?
      - How did the doctors re-define people with diabetes through the course of the scene?
      - How was the framing of the problem at the end different than at the beginning?
      - How was stigma demonstrated in this scene?
      - Based on what you saw, how did they justify curtailing the rights of patients?
      - Was there any overt naming, blaming, or shaming? If not, was it stigmatizing?
5. Discuss the subtle nature of stigma and the role of pathologizing, infantilizing, and microaggressions.
6. To clarify any remaining issues, show the cascade (Figure 9) and ask how these steps were manifested in the role play.
7. Solicit and discuss any outstanding questions. Inform the group about stigmatizing language.

Suggested language for tuberculosis communications can be found at:

» *http://stoptb.org/assets/documents/resources/publications/acsm/LanguageGuide_ForWeb20131110.pdf*

Introduction to Stigma Theory (continued)

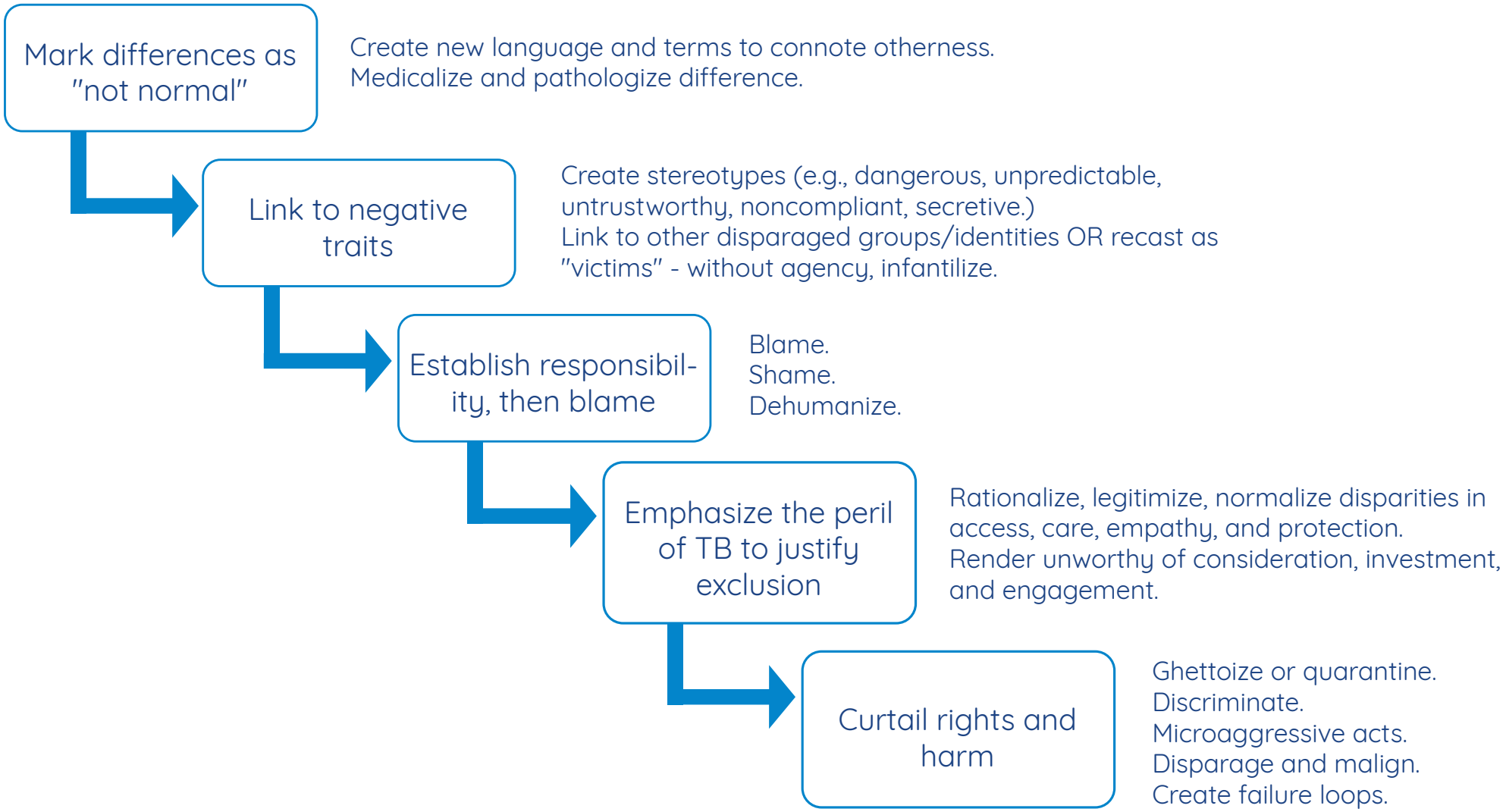


Figure 9. Classical stigma-building cascade[20]

Introduction to Stigma Theory (continued)

FACILITATOR'S NOTES:

Understanding the way that stigma is constructed is important for measuring and reducing it. Most theorists see stigma as a maladaptive social structure.[15,16] TB stigma is neither a natural nor inevitable part of having tuberculosis.[17] Stigma requires an enabling environment.[18]

Being able to pinpoint which ideas, norms, rhetoric, and routines fuel and sustain particular stigmas requires in-depth study.

However, there are some classical hallmarks of stigma production that have been defined over the years which apply to almost all forms of "othering" (racism, sexism, ageism, elitism, xenophobia, homophobia, etc.)[16, 17, 19] These include conscious and unconscious processes that generate prejudice. They can be envisioned as a series of progressive, sequential steps and conditions under which it may become socially permissible to reclassify a person as somehow less valuable.

The dramatic scene illustrated the mechanisms by which stigma can be created, normalized, and ultimately institutionalized in policy. We use the example of Type II diabetes, a chronic disease that carries some stigma. Like TB, it has a complex set of conditions that foster it, including both genetic and lifestyle factors. Try to listen closely and see how this group of health care workers manages their mixed feelings and comes up with an unorthodox intervention to address their concerns.

Almost all stigmas involve the social construction of dangerousness. This creates fear. This requires amplifying or exaggerating the risk that a disease or condition poses to society.

The building blocks of stigma include:

- Responsibility for the mark (essential precursor for blame.)
- Peril/danger to others (specifically unpredictability and mortality.)
- Links to other stigmatized or negative traits and stereotypes.

These justify or rationalize behaviors that exclude or further diminish. This includes blaming, shaming, pathologizing, infantilizing, and microaggressions.

Note: see annex Glossary for definitions.

DIALOGUE

Huda: *Good morning everybody, it's so nice to have such a diverse group today. I am your facilitator, Dr. Huda Morha. I am a psychologist and I want to welcome you to the doctor's support group, Doctor's United. This is a safe space for sharing some of the stressful situations that we face as care givers and clinicians. What we share in this room is kept strictly confidential. I see we have some new faces. Let's do a round of introductions.*

Sugar: *Hi my name Sugar van der Ijs, I am an endocrinologist. I work primarily with diabetes patients. I am providing care to inpatients and outpatients at Holy Heart hospital.*

Huda & Farma: *Welcome to Doctors United Sugar!*

Farma: *Yes, my name is Farma Covigilance and I am a TB doctor with 12 years of experience.*

Two people on either side say 'Welcome Farma', but move to the outer edge of their chairs.

Huda: *Ok well how are we feeling today? Tough day? I see a lot of tiredness in our faces. Sugar, what brought you here today?*

Sugar: *Well I am feeling a bit… worn out, perhaps. It so tough to support my patients day in and day out. I am just spending a lot of personal energy monitoring the insulin levels and adherence of my patients. I sometimes feel drained by the level of effort it takes. It can be a real uphill battle to keep them on their diets.*

Farma: *Well that's really our job though, to keep them on track – when they try to veer off.*

Sugar: *Well they have their lives to lead. Everyone likes some fruit in the summer. I must learn to trust. But they just don't stay on their diets, and they forget to monitor. Then I get called to account. They have amputations. It's so sad sometimes.*

Farma: *Have you ever tried obtaining a court mandate for insulin treatment?*

Sugar: *What? No. wouldn't that be unethical?*

Huda: Well uncontrolled diabetes can be… dangerous.

Sugar: *How so?*

Huda: What if a diabetic is driving a city bus and they go into hypoglycemic shock?

Sugar: *Oh…well I never thought about it that way*

Farma: What if it's your dentist in the middle of a root canal?

Sugar: *Oh.*

Huda: *Dentists don't have uncontrolled diabetes, Farma. It is primarily patients without education. People who don't know how to take care of their health.*

Dialogue (continued)

Farma: *Oh yes. True. It's so hard for them to take the initiative to improve their lives. You give them the health education brochures, but patient literacy also takes responsibility. You just never know whether they will follow through, they can be so erratic.*

Sugar: *Dieting does take self-discipline. Reminders are not always effective.*

Farma: *You should check out if you cannot get the court to monitor your diabetics' insulin treatment. It really makes it easier for me when I have defaulters that just cannot (or will not) take charge of their illness.*

Sugar: *Ok, I'll think about it. If they cannot take the initiative to say "no" to sweets and monitor their sugar, I guess they could be a risk to others if they have a hypoglycemic event.*

Huda: *Something should be done to protect the public. And to protect you from all the stress of worrying about them. You have to think about your well being too. All that care giving is really weighing you down and draining your energy. You try to stay positive, but they just don't take steps to save their own lives.*

Farma: *How about video monitoring of their insulin monitoring?*

Huda: *And snacks. Good to monitor their calorie intake between meals.*

Sugar: *Yah, maybe ankle monitoring. So they don't sneak out to buy candy.*

Huda: *Well that's all the time we have today.*

Underlying Structure of Stigma

OBJECTIVE:

To learn the underlying structure of stigma.

Flipchart, Markers, Post-it note pads, Handouts of the Spider Web

60 minutes

Brainstorm, Mind mapping

ADVANCE PREPARATION:

Prepare flipchart with the spider's web. Print-out spider's web. Adapt or adjust scenarios. Photocopy scenarios handout, one per participant

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. The exercise involves a step 1 (brainstorm) and step 2 (develop a structure).
2. Divide participants into groups of three to five people and provide them with post-it notes.
3. Ask them to brainstorm examples of TB stigma and write them on the post-it notes (e.g., stereotyping, isolating, branding, and masking). Encourage them to think broadly. Exercise should run for 7-10 minutes.
4. Hand out the blank spider web and ask participants to arrange the post-it notes on the web corresponding to the appropriate domain of stigmatization.
5. Tell participants that if they believe that some types of stigmatization belong in more than one category, they should draw a line linking the domains. They should draw as many links as they think of, until the drawing resembles a spider's web.
6. When they have finished arranging the post-its and making the requisite links, discuss the following:
   - What domains of stigmatization were listed first and which were mentioned later on?
   - Did the group spontaneously mention items for all the "spokes" of the spider's web?
   - Does the group recognize the five core "spokes" of the web (emphasize difference, imply negative traits, link to other stigmas, emphasize peril, and locate fault?)
   - Are there "spokes" which seem to be missing?
   - Was the spider's web a useful structure to hang the ideas on? Why or why not?
   - How challenging was this exercise? What was challenging about it?
7. Solicit and discuss any outstanding questions.
8. Hand out a blank spider's web and ask the participants to repeat the exercise with another stigmatized condition, behavior, or identity, such as seen in the following handouts.

Underlying Structure of Stigma (continued)

9. When the second spider web is complete, assess whether participants can embrace a common set of stigma dynamics. Ask the following:
    - Does the spider web exercise change your view about how stigma is generated?
    - Who is the spider? Given that stigma is produced, who benefits from it? Who sets this trap?
10. Solicit and discuss any outstanding questions.

FACILITATOR'S NOTES:

When we take an X-ray, we see the structure of the body. When we see a spider's web, we also see a structure. A spider's web is a carefully laid trap, much like stigma (see Figure 10).

Stigma is also created from small pieces assembled over time, and maintained by supporting structures. Stigma around the world takes on many different shapes, but all stigma is built on related core ideas, actions, and common elements.

In this exercise we will utilize the concept of a spider's web to learn to appreciate how the stigma that we see and experience forms part of an inter-related web. Using a critical anti-oppression approach, we highlight the actions needed to generate stigma. This clarifies the intentionality behind stigma.

Underlying structure of stigma

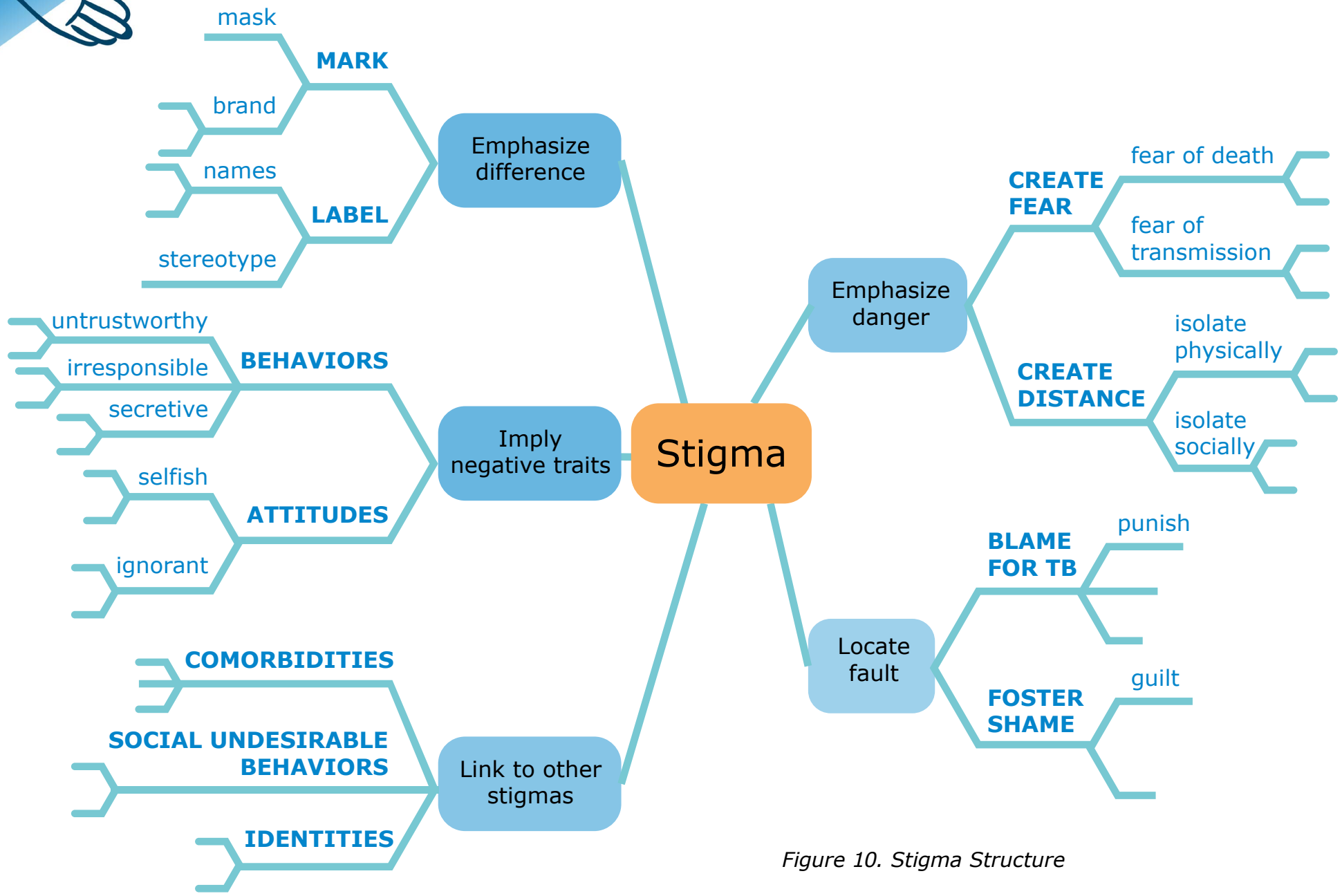


Figure 10. Stigma Structure

Stigmatized condition, behavior, or identity

Mental illness	Addiction
Physical deformity	Leprosy
HIV	Criminal history
Obesity	Smoking
Racial, ethnic, or religious minority status	Homosexuality
Sex work	Homelessness

Choices - The Last Diagnostic Test (GeneXpert Cartridge)

OBJECTIVES:

1. To explore how attitudes and preferences can influence programmatic decisions.
2. To explore the concepts of vulnerability, equity, and transmission risk, and how programs have different prioritization.

Scenarios handout for each participant

30-60 minutes

Group work

ADVANCE PREPARATION:

Photocopy one scenarios handout per participant

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Explain that in some countries there are legal, policy, financial, and other restrictions on diagnostic and treatment services that impede access to and quality of treatment.
2. Divide participants into small groups of three to four people each.
3. Tell participants that according to this (fictitious) situation, only three more diagnostic tests can be performed. Explain that you will give them a handout that describes a large group of people who have been in the same room for several hours with a symptomatic patient (pulmonary (X/DR-) TB). Everyone has been screened, and some need to be tested, but the cartridges must be rationed. The small groups of participants represent the policymakers who will decide who should receive testing.
4. Give each participant a copy of the scenarios handout and ask them to spend five minutes silently reading the scenarios.
5. Tell participants they have five minutes to discuss the scenario in their small groups and to decide which three persons they will grant the tests to. They must appoint a spokesperson to briefly present their decision in plenary.
   - Why did they choose these three people?
   - How do they feel about rationing diagnostics?
6. Rotate from group to group to ensure that participants understand the instructions.
7. Explain that each small group will have up to two minutes to present their decision and rationale.
8. Ask others not to comment on individual presentations.
9. Once all small groups have presented, ask each participant to silently reflect on biases or assumptions they may have. And how these biases may have affected their decision.
10. Ask participants to return to the large group. Facilitate a discussion about the selections and rationales given.

Choices - The Last Diagnostic Test (GeneXpert Cartridge) (continued)

Try to maintain neutrality while discussing participants' rationales.

11. Ask participants how this exercise relates to how TB services are rendered in their health care institution.
12. Ask "Who has the right to make judgments for another human being?" Point out that the stakes are extremely high when providers or policymakers ration or restrict access to care.
13. Solicit and discuss any outstanding questions, comments, or concerns.

Adapted from:

» *Understanding and challenging TB Stigma, Toolkit for action, HIV Alliance, http://www.aidsalliance.org/assets/000/000/831/4_Stigma_F_and_G_original.pdf?1407244500.*

Situation description

You are living on an island in the ocean. One day you are a guest of a big wedding party. Six months after the wedding is over, it becomes clear that there was someone with XDR-TB coughing during the event. Everyone who was at the wedding party goes for an X-ray, and the following people have chest abnormalities:

- Your brother, age 34.
- The two singers and three musicians in the band, ages 22-28.
- The bride, age 25.
- The groom, age 24.
- One of the cleaning staff, age 56.
- An uncle with diabetes, age 41.
- The alcoholic brother-in-law, age 55.
- The religious leader who performed the ceremony, age 65.
- The groom's grandmother, age 73.
- The niece of the groom, age 5.
- The sister of the bride, age 28 (who is thin and may have HIV.)

There are a total of ten people who need testing. However, there are only three GeneXpert cartridges left. This would help make a quick and early TB diagnosis. You need to decide who should get these three cartridges. Seven will need to wait for the next shipment of cartridges to the island (which is coming by boat from the mainland), which may take six to eight weeks.

Four Corners

OBJECTIVE:

To explore individual's values and feelings toward (DR-) TB patients.

Large signs printed with STRONGLY AGREE, AGREE, DISAGREE, STRONGLY DISAGREE, and NOT SURE/ DON'T KNOW, Tape, Statements

60-90 minutes

Exercise

ADVANCE PREPARATION:

- Adjust and tailor statements according to the specific audience and circumstances. Prepare signs: STRONGLY AGREE, AGREE, DISAGREE, STRONGLY DISAGREE, and NOT SURE/DON'T KNOW.
- Free wall space in a large room.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Cut the statements out of paper, fold the slips, number them, and hand them out.
2. Instruct participants that this is not an exercise to convince anyone, but just to make the differing values and views that drive the prioritization process more transparent.
3. Ask participants to read the statement marked as "1" and instruct participants to silently (without debate) position themselves in front of the signs STRONGLY AGREE, AGREE, DISAGREE, STRONGLY DISAGREE, and NOT SURE/DON'T KNOW according to their opinion.
4. After each statement, have the group silently observe the distribution of participants. Invite them to notice any patterns. Do not discuss these. Move in silence.
5. After 5 or 10 statements, invite the participants to reflect on what they learned from the exercise:
   - How does it feel to positions themselves without saying why?
   - What does it feel like to have a minority position?
   - Were they surprised by the diversity of viewpoints?
   - Were there moments of tension or times when they felt they had to debate the issue? What makes certain topics so intense for them?
6. Solicit and discuss any outstanding questions.

FACILITATOR'S NOTES:

This exercise can be used to reveal stakeholders' values and feelings about patient support and stigma, and help to make the value of group members more transparent. In the case of policy, it is important to show the diversity among members' values. It is also vital to acknowledge that feelings do not need to be acted on. Attitudes do not invariably lead to stigmatizing behaviors.

Adapted from:

» *Abortion attitude transformation: Values clarification activities for global audience, Ipas, http://www.ipas.org/en/Resources/Ipas%20Publications/Abortion-attitude-transformation-A-values-clarification-toolkit-for-global-audiences.aspx*

Statements

1. MDR-TB treatment side effects often make MDR-TB patients unpredictable.
2. TB patients are all brave and honorable.
3. If I knew a friend had (DR-) TB I would still visit him/her at his/her house.
4. If I was diagnosed with TB, I would emphasize that I do not have HIV.
5. It's impossible to know when someone with TB infection can become ill with TB.
6. (DR-) TB disease often transforms a person into someone unpleasant.
7. (DR-) TB disease often transforms a person into someone dangerous.
8. Most people with MDR-TB are at least partly responsible for the disease.
9. People can be educated and empowered to avoid TB disease.
10. TB disease is an equal opportunity affliction-everyone is equally able to get it.
11. TB patients know what support services they need.
12. TB patients need directly observed therapy to stay adherent.
13. TB patients whose treatment is not monitored will be lost to follow up.
14. Children with TB are innocent victims.
15. The way people with (DR-) TB behave, it's not surprising people don't want them around.
16. People with TB who do not take treatment can infect their households and communities.
17. Health care workers should be screened at work for TB to make sure if they have TB that they get treated.

FACE

Safe Space, Safe Boundaries

OBJECTIVE:

To observe different people's preferences for social distance and imagine how that may impact the care they give and their own comfort in care-giving situations.

30- 60 minutes

Moving exercise and debrief discussion

ADVANCE PREPARATION:

None.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Have people break into pairs of two.
2. Have each one stand about five meters apart from his/her partner.
3. One person is the infectious TB patient and the other person is the health care worker.
4. The health care worker stands still and closes his/her eyes.
5. Explain to the participants that the TB patient will take a step toward the health care worker. Each time the patient takes a step, they should cough a little, so the health care worker can feel the proximity. The exercise continues until the health care worker feels that the patient is about to get too close for comfort. As soon as the health care worker feels that the patient may cross into a zone where they are unwanted, have the health care worker say "Stop!" The TB patient stops and stands still.
6. Explain transmission control and cough hygiene principles.
7. The health care worker can open her/his eyes. Notice where the different stopping places are among different pairs.
8. Then switch roles and repeat the exercise.
9. Emphasize that there is no right physical distance for comfort zones.
10. Solicit and discuss any outstanding questions, comments or concerns with the participants.

Safe Space, Safe Boundaries (continued)

Discussion Questions:

1. What do you notice about people's different personal spaces? How wide are they?
2. What do you notice about your own space needs?
3. How does your comfort zone change based on the infectiousness of the patient?
4. What are the possibilities for maintaining this space in real work situations?
5. Do you practice "high touch" medicine? In other words, do you tend to put your hands on patients to reassure, greet, comfort, and model fearlessness? How does your style work with different cultures?
6. How do you think your boundaries relate to your (DR-) TB patients' boundaries?

Labeling

OBJECTIVE:

To identify labels used to stigmatize patients.

Positive and negative labels on string (necklaces), Markers, Chairs

60-90 minutes

Exercise

ADVANCE PREPARATION:

Review and adapt exercise as necessary

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Ask people to stand in two lines, patients and health care workers.
2. Have the facilitator put a necklace (with positive and negative label) on each participant without showing the person what the label says. Put the negative side of the label face up on their backs so they cannot see it.
3. Explain that the label can be interpreted from a positive or negative view.
4. Tell patients and health care workers to walk through the room and read the label of each person. Each person should have a TB treatment monitoring interaction talk with each other, while treating the patient and health care worker as if they really had the characteristics on the label. So, treat people using negative assumptions about them.
5. After three minutes, shout "Change!" and ask people to turn each other's labels over to the positive side.
6. Raise the following questions:
   - How did you feel people behaved toward you during the first part versus the second part?
   - What differences did you observe in people's behavior and words when the label was flipped?
7. Ask people to try to guess what their label reads.
8. Have them take the label necklace off and read the two terms.
9. What is the difference between the negative and the positive side?
10. Ask them to reflect on the behaviors and characteristics of someone who is labelled this way.
11. Solicit any reflections on the power of labels and how they impact a working environment.

Text for the Necklaces

1.	Eager	1.	Reckless
2.	Strong	2.	Willful
3.	Brave	3.	Irresponsible
4.	Resilient	4.	Defiant
5.	Responsible	5.	In authority
6.	Honest, direct	6.	Callous, tactless
7.	Careful	7.	Indecisive
8.	Expressive	8.	Difficult
9.	Pro-Active	9.	Driven
10.	Dutiful	10.	Complicit
11.	Kind	11.	Solicitous
12.	Resolute	12.	Stubborn
13.	Proud	13.	Arrogant
14.	Conscientious	14.	Reluctant
15.	Courteous	15.	Fake
16.	Peaceful	16.	Passive
17.	Communicative	17.	Talkative
18.	Trusting	18.	Unprofessional

Text for the Necklaces (continued)

19.	Self-Motivated	19.	Non-Cooperative
20.	Persistent	20.	Obstinate
21.	Adherent	21.	Submissive
22.	Committed	22.	Obsessed
23.	Transparent	23.	Thoughtless
24.	Free-Thinking	24.	Confused
25.	Smart	25.	Know-It-All
26.	Vulnerable	26.	Disadvantaged
27.	Creative	27.	Disorganized
28.	Overwhelmed	28.	Non-Adherent
29.	Hard Working	29.	Workaholic
30.	Able	30.	Non-Compliant
31.	Private	31.	Secretive
32.	Principled	32.	Moralistic
33.	Relaxed	33.	Lazy

Speaking with Our Faces

OBJECTIVES:

1. To become more aware of feeling or emotions.
2. To understand communication challenges.
3. To improve patient-provider communication by engaging in a fuller range of communication tools (face, tone, and body language.)

Face masks, Cards with emotions, Cards with messages

30-60 minutes, depending on the size of the group

Small group practice, role play

ADVANCE PREPARATION:

Review and adapt exercise as necessary

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

Part I:

1. Divide the group into two teams.
2. Place a packet of cards, each of which has a particular emotion typed on it, on a table.
3. Have a participant from Group A take the top card from the table and act out (pantomime) the emotion for his/her group. Ask them to use their face, shoulders, arms, and hands to convey the message to the group. This is to be done in a fixed time limit.
4. Now have a participant from Group B act out an emotion.
5. Rotate the acting opportunities between the two groups.
6. After 10-15 minutes, end the exercise.
7. Discuss the following
   - How was trying to communicate without words?
   - What non-verbal cues are we sending?
   - What strategies did you use to try to overcome the challenge of not being able to verbalize your emotions?
   - How can this exercise help you?

Part II:

1. Divide the group into small groups of three.
2. One person is the health care worker, and they receive a respirator.
3. One person is the patient, and they receive a mask.
4. One person is the observer. They get a worksheet with the following question: "What is the message?"
5. Have both the patient and provider put on their face masks.
6. Each receives a card with a message printed on it.
7. Don't show the card(s) to the observer!
8. Using only your face, your shoulders, arms, and hands, convey the message to the other person. You may start the exercise with "Here is the message that I want you

Speaking with Our Faces (continued)

to have" using different tones and pitches, but no other words can be used

9. The observer records what he/she thinks is the message of the patient and health care worker on the sheet of paper.
10. After each health care worker and patient conveys their message non-verbally, and the receivers try to guess what the message was, the health care worker and patient reveal what their actual message was.
11. After each person has delivered one message wearing the mask, switch roles, until all three people in each group (health care worker, patient, and observer) have had a chance to play all roles.
12. Return to plenary when everyone in each group has played all the roles once.
13. Discuss the following:
    - Were there miscommunications or misunderstandings?
    - Was it easier to convey "positive" or "negative" messages accurately?
    - What parts of our faces do we use to convey our main messages?
    - What non-verbal cues are we sending? How they were different from Part I?
    - Does wearing a mask/respirator make a difference in the effectiveness of conveying a message? How does the presence of the mask/respirator influence the communication process?
    - What strategies did you use to try to overcome not being able to speak and wearing a mask/respirator? How successful were these strategies?
    - How does age, gender, class, and hierarchy influence the communication between patient and provider?
    - How can this exercise help you in practice? What do you learn from how others perceived you?
14. Solicit and discuss any outstanding questions, comments, or concerns with the participants.

Part III:
Discuss the following:

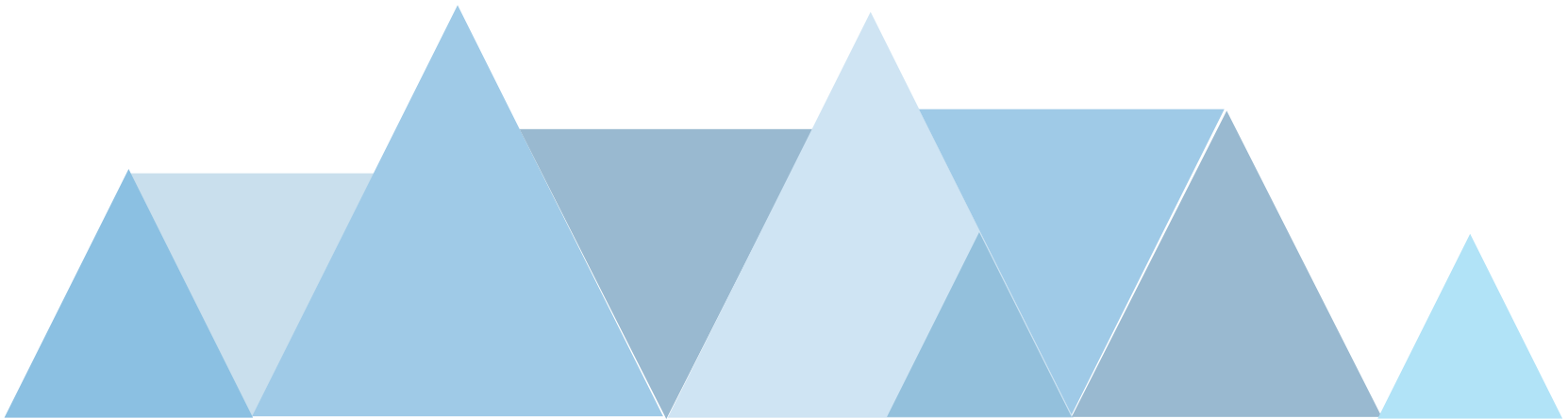
1. What is the role of infection control measures during interpersonal communication?
2. What can be done to improve the how people sit and face each other?
3. What infection controls measures can be implemented if covering the face during communication is not an option?

Cards with emotions

Disgust	Affection
Embarrassment	Anxiety
Fear	Determination
Anger	Confusion
Depression	Disappointment
Shame	Frustration
Vulnerability	Self-pity

Cards with messages for Health Care Worker

1 I need your cooperation.	2 I believe we can work together.
3 Feel free to ask questions.	4 I am sorry.
5 I hear you.	



Cards with messages for Patients

1 This is taking too long.	2 I don't understand you.
3 I don't believe you.	4 That is not possible at this moment.
5 I need to ask my family their opinion.	6 I can't take these drugs.

HANDS

Framing (DR-) TB

OBJECTIVE:

To develop the individual's competencies to detect stigma-related language in a text.

Situation description, Assessment questions

60-90 minutes

Group work, critical discourse analysis

ADVANCE PREPARATION:

Revise questions. Print out text. Prepare and print out critical discourse analysis questions.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Divide participants into groups of three or four.
2. Distribute a copy of the text to all participants, and ask participants to read the text silently.
3. Ask groups how the text might be revised to reduce its stigma (see Assessment Questions below).
4. Encourage discussion.
5. If questions arise during the text revision, provide correct information once participants have finished the exercise.
6. Ask participants to revise the text in order reduce its stigmatizing impact. Revised version of the text should be agreed upon by the group.
7. Solicit and discuss any outstanding questions.

FACILITATOR'S NOTES:

Discourse analysists examine text and language and what the implications are for assigning responsibilities and solutions. A discourse analysis of TB stigma would, for instance, examine explanations of the problem of TB, who is being blamed for it, how solutions are justified and legitimized, and what the underlying value claims are in these explanations, justifications, and legitimizations.[23]

TB control efforts entail many different words and text that can contain stigma, and are useful for an analysis of discursive stigma. These include, for instance, not only those words spoken between patients and care takers, but also between healthcare workers, program officers, and policymakers, written text in TB policy documents, guidelines education material, leaflets, records and registers, treatment cards, package inserts of diagnostics and drugs, as well as articles in media and government reports.

Situations

EXAMPLE 1

This curable disease, known to humanity for thousands of years, is now the top infectious disease on the planet, with 4,400 victims dying every day. TB and HIV/AIDS often affect the same persons, and reduce quality of life, especially in those with resistant forms of TB.

EXAMPLE 2

Drug-resistant TB poses a grave challenge. More than half a million people develop multidrug-resistant TB (MDR-TB) each year. Extensively drug-resistant TB (XDR-TB), an even more severe form of the disease, has been reported in 105 countries. Three out of four people with drug-resistant TB are not accurately diagnosed, and less than a quarter of those estimated to have the disease start treatment each year. While two promising new MDR-TB drugs have been developed, the prevailing full course of treatment for MDR-TB is expensive, extremely toxic, and requires two years of treatment. Moreover, the treatment success rate among those who start treatment for drug-resistant TB is only 50%.

According to the Antimicrobial Resistance (AMR) Review, an initiative that UK Prime Minister David Cameron commissioned in 2014, by 2050 drug-resistant TB could kill as many as 2.5 million people per year and cost the global economy as much as USD 16.7 trillion – the equivalent of the annual economic output of the European Union. In addition to the human and economic costs posed by drug-resistant TB, its airborne nature makes it a threat to global health security.[24]

Situations (continued)

EXAMPLE 3

In general, tuberculosis is spread through human-to-human contact and through the air, when an infected person coughs or sneezes. But there are two main ways that people get drug-resistant TB. The first occurs when people with TB fail to take a full course of antibiotics, and the bacteria develops a resistance to drugs. The second way is that a person is infected with a strain of the bacteria that's resistant to antibiotics. Extensively drug resistant TB, sometimes called "total drug-resistant TB," is an even more severe category of multi-drug resistant TB.

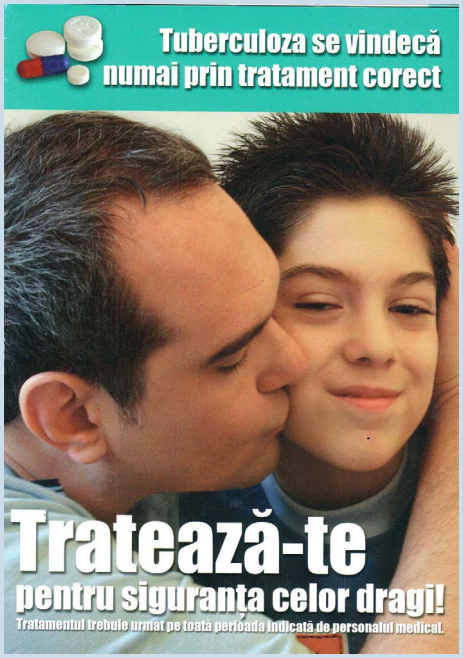
Drug-resistant tuberculosis in the United States is still quite rare. There were 91 cases in the U.S. in 2014 according to the Centers for Disease Control and Prevention. But foreign-born people in the United States are more likely to have drug-resistant tuberculosis than those born in the United States; 88 percent of the U.S. cases of antibiotic-resistant tuberculosis in 2014 were among foreign-born patients. These figures are meaningful, especially in a country where immigrants face deep discrimination.

"For the United States, the challenge is probably people coming in from immigrant populations who are already stigmatized," said Glenda Gray, the president of the South African Medical Research Council and an expert on tuberculosis and HIV. "You need an environment that's not going to be punitive [to care for] the people that are the refugees, the people that are on the fringes of society, and the people who are less educated."[25]

Situations (continued)

EXAMPLE 4

Evaluate the images below using the questions used to evaluate the text examples above.



"Tuberculosis heals only through proper treatment. Treat yourself for the safety of your loved ones! The treatment must be applied as long as indicated by the medical staff. "

- *http://www.spitalleordeni.ro/doc/pliante/01.Tuberculoza%20se%20vindeca.pdf*
- *http://tuberkuloosi.fi/en/wp-content/uploads/sites/2/2015/10/tuberkuloosi.fi-juliste_EN.jpg*
- *http://nddaily.blogspot.com/2014/02/trickle-down-economics-and-snake.html*
- *https://www.wnyc.org/story/biological-and-social-aspects-of-tuberculosis-26th-hermann-m-biggs-memorial-lecture/*

Assessment Questions

1.	How is the problem defined?
2.	What are the rhetorical instruments? What story lines, metaphors, and numbers are used to convince other people of the intended message?
3.	What are underlying norms?
4.	What solutions are assigned?
5.	How do these actions impact stigma?
6.	What cannot be said?
7.	What must the individual(s) know?
8.	What must the individual(s) do?

TB Terminology: Moving to non-stigmatizing terminology in tuberculosis

Treatment default = loss to follow up

Tuberculosis suspect = Person to be evaluated for presumptive tuberculosis

Tuberculosis control = Tuberculosis prevention and care

Compliance = Adherence

Research subjects = Research participants

The Stop TB Partnership's Tuberculosis Terminology Guide (www.stoptb.org/assets/documents/about/cb/meetings/22/2.12-13%20Closing/2.12-13.2%20TB%20language%20guide.pdf) contains additional suggestions.

Adapted from:
» *Stigma Measurement Guide, Chapter 11.*

Revision of Facility Policies

OBJECTIVE:

To assess health care institution policies to identify and revise stigmatizing language

Tool presented in "Stigma Measurement Guide" (Chapter 6: Measuring Structural Stigma- Human Rights and Legal Discrimination Health Care Institution Policy), Assessment questions

60-90 minutes

Group work, Situation analysis

ADVANCE PREPARATION:

Revise questions and print out text. Prepare and print out assessment questions.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Divide participants in to groups of three or four.
2. Distribute a copy of the text to all participants.
3. Ask participants to read the text silently.
4. Ask groups to consider how the policies might be revised in order to reduce stigma.
5. Encourage discussion about each assessment question. Each group's answers should be considered, and any discrepancies or important omissions should be discussed.

   Assessment questions:

   - Do the policies use stigmatizing terms? If so, why are they stigmatizing?
   - What is the objective or purpose of the regulation? Is the regulation appropriately tailored to achieve this objective?
   - How is the policy likely to impact people with TB, including enjoyment of specific human rights?
   - Does the policy prohibit people with TB from working in certain professions? If so, which professions and which key populations might be affected?
   - Does the policy respect the rights to privacy and confidentiality of people with TB?

6. Answer questions once participants have finished the exercise.
7. Ask participants to revise the text to improve the law and reduce its stigmatizing impact. Revised versions of the text should be agreed upon by the group.
8. Solicit and discuss any outstanding questions.

SITUATION:

TEXT:

Use the Health care institution policy document provided by the facility hosting this exercise.

Assessment Questions for Current Text

1.	Does the policy use stigmatizing terms? If so, what are they are why are they stigmatizing?
2.	What is the objective of the policy? Is the policy appropriately tailored to achieve this objective?
3.	How is the policy likely to impact people with (DR-) TB?
4.	Does the policy prohibit people with TB from any particular role?
5.	Does the policy respect the privacy and confidentiality of people with TB?

Suggestions for Text Revision

1.	Replace stigmatizing language with non-stigmatizing language.
2.	Clarify vague or overly broad terms and phrases.
3.	Tailor the policy to fit the objectives more closely.
4.	Include new language that protects the human rights of people with (DR-) TB.

TB Terminology

FACILITATOR'S NOTES:

Traditional biomedical ethics focus on the individual and emphasize autonomy, beneficence, nonmaleficence, and justice.

Autonomy denotes liberty, privacy, and informed consent of individual persons. This means the person has the right and freedom to choose a course of action based on the necessary information provided to them to make an informed decision. Furthermore, the person has the right to protection, privacy, and confidentiality. In practice, all options and potential consequences of each need to be provided to a person to empower and enable them to choose for themselves (this includes getting a second opinion).

Regardless of their choices, people deserve to be treated with respect and confidentiality and provided with adequate support (e.g., palliative care, in case of refusal of therapy). Public health interventions often infringe on the rights of individuals in favor of the collective (or public) good and protection. While a patient has the right to refuse treatment, this refusal might lead to involuntary isolation. Also, contact investigation might lead to involuntary disclosure of a person's disease status, if not done carefully.

Beneficence denotes actions done with the intention of bringing about good. This definition of beneficence especially for the "public good" is often used to justify compulsory and intrusive public health interventions, e.g., compulsory mass-vaccinations or mass-screenings of "risk-groups". It is easy to see how such goodwill actions might reinforce stigma and have negative consequences for affected individuals and people groups.

Nonmaleficence denotes the principle of "do no harm." Most TB medicines are very toxic and bear the risk of adverse side-effects. We cannot force someone to take medicines against their will, and all necessary information about side-effects should be provided to allow the individual to make an informed decision. This principle has been used to justify drastic actions, such as the quarantine, isolation, and compulsory treatment for highly infectious diseases. It is also important to remember that nonmaleficence also applies to psychological distress and socio-economic harm.

Justice denotes the right to fair treatment for the individual and fair distribution of costs and benefits. However, there again is the underlying tension of the rights of the individual over the rights of the collective. Is it just if the decisions and behavior of one individual cause harm to another?

Adapted from:

» *TB Stigma Measurement Guidance, Chapter 6, www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf*

Creating Respect and Dignity Messages at the Health Care Institution

OBJECTIVE:

To develop basic TB stigma reduction messages according to basic standards of health literacy, including lay language and culturally appropriate visuals for the target audience.

Newsprint/Flipchart, Markers, Paper, Pen, Colored pencils and crayons, Clippings of pictures

90 minutes

Individual and group work, Discussion and Q&A

ADVANCE PREPARATION:

Prepare handouts. "Check readability of your messages," "Checklist for understanding," and the ORPA method. Make sure that each participant has a copy.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Welcome the participants and introduce the session.
2. Ask participants to share their views on the necessity of the information and education of staff, patients, and families, etc.
3. Tell participants that the goal of health literacy is that health care provider's offer a clear understanding of what, how, and why they improve health.
4. Ask participants to take a moment to think about the health messaging around them, and ask each of them to write down one health message to the TB patient.
5. When everyone has written their message, ask them to pass the papers clockwise.
6. Ask each participant to simplify the message they were passed by using more simple language.
7. Ask two to three volunteers to share the original and re-written messages.
8. Ask the rest of the group for feed-back, or how the message can be even more simplified.
9. Ask participants to form small groups of three to four participants.
10. Ask each group to take a moment to think about the assigned health messages and to develop a poster with text and visuals on one of the following topics:
    - Protecting oneself from TB infection by following standard procedures
    - People with TB deserve the same quality health care services as like everybody else (patient- provider re-lationship)
    - People with TB have rights
11. Ask each group to share the poster. Others should assess if:
    - The indented user is identified
    - The number of messages is limited to three, with a maximum of five.

Creating Respect and Dignity Messages at the Health Care Institution (continued)

- The language is simple.
- The focus of the poster is on behavior.

12. Visuals (if used) should be supplementary and culturally appropriate. Once the group presentation is done, ask others to give constructive feedback.
13. Repeat the same activity for all groups.
14. Once all groups have presented their poster, allow time to re-design the poster according to the feedback. Re-emphasize that visuals should be complimentary to the text, understandable without text, culturally appropriate, and aimed on behavior change. While choosing a visual, apply the OPRA (Observe, Reflect, Personalize, and Act) method.
15. Refer to the handouts "ORPA method," and tell the groups to discuss their visual aids before presenting them to others.
16. Refer to the handout "Checking for understanding."
17. Before presenting the messages, ask each group to check for readability using Word readability statistics (explained in the Facilitator's notes.)
18. Tell the group they will need to evaluate the messages developed by others using the "Checklist to develop and evaluate health messages."
19. Ask one to two groups to share their re-designed poster.
20. Facilitate the feed-back session and discussion period.
21. Advise participants to assess and alter health messaging in their respective facilities.

FACILITATOR'S NOTES:

Basic standards of health literacy include using lay language and culturally appropriate visuals for the target audience. It is important that the indented user is identified, and the number of messages is about three (with a maximum of five). Language should be simple, and the most important points should come first. Information should be broken down into sections that are easy to comprehend, avoid medical jargon, and use the active voice.

Avoid using all capital letters, italics, and fancy script. Keep line length between 40 and 50 characters. Use headings and bullets to break up text. Be sure to leave plenty of white space around the margins and between sections. The focus should be on behavior, not medical principles, and should include specific actions and recommendations. Clearly state the actions you want the reader to take.

Visuals should be supplementary and culturally appropriate (race, ethnicity, roles of elderly, youth, men, and women, favorite and forbidden foods, manner of dress, and body language, particularly whether touching or proximity is permitted in specific situations.) They should help convey your message, not distract from it. See example: How to take your medicine.

Picture source: *What You Need to Know about Tuberculosis Infection, CDC.*[26]

Check Readability of Your Messages

Word

Click the **File** tab, and then click **Options**.

Click **Proofing**.

Under **When correcting spelling and grammar in Word**, make sure the **Check grammar with spelling** check box is selected.

Select **Show readability statistics**.

After you enable this feature, open a file and check the spelling. When Outlook or Word finishes checking the spelling and grammar, it displays information about the reading level of the document.

» *https://support.office.com/en-us/article/test-your-document-s-readability-85b4969e-e80a-4777-8dd3-f7fc3c8b3fd2*

If someone uses a **Mac**, the following applies:

On the **Word** menu, click **Preferences**.

Note: To open Word Preferences, you must have a document open.

Under **Authoring and Proofing Tools**, click **Spelling and Grammar**.

Under **Grammar**, select the **Check grammar with spelling** check box.

Select the **Show readability statistics** check box and close the Spelling & Grammar dialog box.

On the **Tools** menu, point to **Spelling and Grammar** and click **Spelling & Grammar**.

After Word finishes checking spelling and grammar, it displays information about the reading level of the document.

Adapted from:

» *Quick Guide to Health Literacy, U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion.*

Check for Understanding

Number	Question
1.	Ask participants to restate the information in their own words, not just repeat it. This ensures that the message is clearly understood and remembered.
2.	Ask participants to act out a desired behavior. For example, "Would you tell and show me what to do, so that I can be sure you know what is important?"
3.	Summarize the main message again.
4.	Refer to additional information.

Adapted from:

» *Doak CC, Doak LG, Root JH. 1996. Teaching Patients with Low Literacy Skills. JB Lippincott Company: Philadelphia, PA.*

Apply ORPA Method While Using Health Literacy Materials

O	Observe	What is going on? What is the reason for such a behavior?
R	Reflect	What do you disagree/agree on? What are the reasons for this? What is advantage of such a behavior? What are the main ideas?
P	Personalize	What would people in your surroundings do in such a situation? Why? What would you do in such a situation? What would be the obstacles? Would you be able to overcome them? How?
A	Act	Repeat the main messages. Discuss what is expected. Agree on next steps.

Checklist to Develop and Evaluate Health Messages

Please respond to the following statements. Your answers and comments will help us improve the information.

Key Element 1: Content	Yes	No	N/A
Material is limited (three max, five points) and action-focused (what to do/need to know.)			
Content is evidence-based and up to date.			
Content is framed to gain a positive audience response.			
The information includes a clear call to action, as appropriate.			
Material encourages interaction.			
Is the target audience directed to other sources of information or support if needed?			
Is the material free from bias and commercial endorsement?			

Key Element 2: Structure/Organization	Yes	No	N/A
Content broken into small chunks, with important points first.			
Subtitles/headings are statements, questions, or action phrases that guide the reader.			
Content sequenced according to what the reader needs to know.			
Key points are emphasized, repeated as appropriate, and summarized.			

Key Element 3: Writing Style	Yes	No	N/A
Personal and conversational (use pronouns appropriately and consistently.)			
Short words and sentences and lay language are used, and technical terms are explained.			
Writing is mostly active voice.			
Short paragraphs (about three to five sentences) stick to one point.			

Checklist to Develop and Evaluate Health Messages (continued)

Key Element 3: Writing Style	Yes	No	N/A
Short lists (three max, five points) use bullets, not comma strings.			
Tone of the writing is positive (not formal or clinical.)			

Key Element 4: Appeal/Document Design	Yes	No	N/A
Attracts attention.			
Text design makes it easy to skim and scan content.			
Overall design reflects plain language standards.			
Images, lists, and charts are clear and support the message.			
White space is used around margins and between sections of text.			
The use of color emphasizes the information.			
Pictures and illustrations show people, activities, and objects that are familiar, realistic, age-appropriate, and positive.			
Body parts are shown within the context of the whole body.			

Adapted from: A guide to Creating and Evaluating Patient Material, Guidelines for effective Print communication, Maine health. How to choose and develop written educational Materials. Rehabilitation Nursing, Vol. 35, No.3. May/June 2012. Canadian Council on Learning, 2007a, 2007b and 2008; Rootman & Gordon-El-Bihbety, 2008.

» *See: CDC Clear Communication Index A Tool for Developing and Assessing CDC Public Communication Products User Guide, CDC, https://www.cdc.gov/ccindex/pdf/clear-communication-user-guide.pdf*

» *CDC Clear Communication Index Score Sheet, https://www.cdc.gov/ccindex/pdf/full-index-score-sheet.pdf.*

Countering: Dealing with Difficult Situations

OBJECTIVE:

To develop individuals' competencies to counter and deflect attempts at stigmatization.

Flipchart, Markers, Cards, Pens

60-90 minutes

Role play

ADVANCE PREPARATION:

Review and adapt situations as necessary.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Ask participants to brainstorm difficult situations they have had to deal with at work. Write each situation on a card. Give an example before brainstorming. Ask participants' to keep it personal.
2. Ask participants (in groups of three, with one groups as observer) to role play out some of the situations and look for solutions.
3. After each trial, invite others to try out the same situation or another from the list.
4. List proposed solutions on the flipchart.
5. Discuss what works and what doesn't work.
6. Solicit and discuss any outstanding questions, comments, or concerns with the participants.

Adapted from:

» *Understanding and challenging TB Stigma, Toolkit for action, HIV Alliance, http://www.aidsalliance.org/assets/000/000/831/4_Stigma_F_and_G_original.pdf?1407244500.*

A Community Free of Stigma

OBJECTIVES:

1. To envision a community without stigma.
2. To identify specific activities (at the individual and community level) that support this vision.

Flipchart, Markers

60 minutes

Small group practice

ADVANCE PREPARATION:

Review and adapt exercises as necessary.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

PART I:

1. Divide into groups by category of health care worker and patient if it is a joint workshop. Ask each group to discuss the following:
   - What forms of stigma do you see in your own facility?
   - Which forms of stigma are the biggest problems in your facility?
2. Hand out flipchart paper and markers.
3. Ask pairs to draw word that describe "a world where there is no stigma."
4. Discuss the following:
   - What does this world without stigma look like? What has changed?
   - What can we do to build this kind of world?
   - What are the obstacles? What factors support this vision?
   - What are the first steps in bringing about change?
5. Solicit and discuss any outstanding questions, comments, or concerns.

FACILITATOR'S NOTES:

Discuss the question "What are the first steps in bringing about change?" Encourage participants to come up with activities they can do themselves.

For example, individual health care workers can:

1. Change their own attitudes about TB and TB stigma.
2. Avoid stigmatizing language.
3. Visit and support people living with TB.
4. Encourage people with TB to use available health services.
5. Encourage people to talk openly about their TB fears and concerns and correct myths and misconceptions about TB and TB stigma.
6. Do a community talk to identify points of stigma in the facility.

A Community Free of Stigma (continued)

7. Use real life stories some examples to put stigma into a practical context.
8. Educate the community to stop shaming and isolating people with TB.
9. Get health care workers and community leaders to model/promote the new non-stigmatizing behaviors.
10. Encourage people with TB to get involved in educating the community about stigma reduction and supporting other patients to complete their treatment.

Adapted from:

» *Reducing HIV Stigma and Gender-Based Violence. Toolkit for Health Care Providers in India. ICRW, www.icrw.org.*

Prioritization and Action Planning

OBJECTIVES:

1. To have health care workers reflect on stigma that may occur at work.
2. To have health care workers identify ways to reduce stigma at work.

Laminated cards (see below), Blank cards, Tape

60-90 minutes

Group work, Presentation

ADVANCE PREPARATION:

Make enough copies of the "Behaviors cards", "Frequency cards", and "Strategy cards"

Make additional Behavior cards

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Divide groups into teams of five to eight people, and give everyone cards with a stigmatizing behavior listed on it. Ask them to arrange cards according to the frequency with which these behaviors occur in their setting.

   Frequency Cards:
   - Very common
   - Common
   - Uncommon
   - Extremely rare

2. Then ask participants to arrange the cards according to what strategies could reduce the frequency of these behaviors.

   Strategy Cards:
   - Training
   - Policy change
   - Supervision
   - Advocacy

3. Finally, ask each group to prioritize the strategies.

   Priority Cards:
   - Top priority
   - Short-term priority
   - Long-term priority

4. Bring the group back together, and have them present their top problem, strategy, and priority.

5. Solicit and discuss any outstanding questions, comments, or concerns with the participants.

Behavior Cards

MANAGEMENT SYSTEMS	
Denial of health care workers' rights to safe working conditions and effective transmission control.	No recognition of health care workers' risk and need for support.
Assigning staff to (DR-) TB service who are unqualified as a form of punishment.	Rotating staff as a form of favoritism.

ORGANIZATIONAL STRUCTURES AND STRATEGIES	
Lack of visual and auditory privacy for patients.	Lack of safe waiting areas.

TRANSMISSION CONTROL PRACTICES	
Lack of safe waiting areas.	Unnecessary and prolonged masking.
Unnecessary separation of (DR-) TB patients.	Unnecessary isolation of (DR-) TB patients.
Unnecessary hospitalization of TB patients.	Denial of health care workers' needs for N95 masks, UVGI, and negative pressure.

Behavior Cards (continued)

PROVIDER BEHAVIOR	
Negative and disparaging behavior towards (DR-) TB patients.	Use of value-laden terminology and labels.
Gossiping.	Breaches of trust and confidentiality.
Demeaning patients with (DR-) TB by name-calling, etc.	Non-specific rudeness or insensitivity.

TB POLICIES AND PRACTICES	
Authoritarian treatment supervision of people with (DR-) TB.	Use of coercion, punishment, and threats of people with (DR-) TB.
Task-shifting of people with (DR-) TB to unqualified staff.	Over-referral of people with (DR-) TB to other facilities.
Denial of TB services.	Lack of promotion and professional development for staff with (DR-) TB or HIV.

Frequency Cards, Strategy Cards and Priority Cards

FREQUENCY CARDS	
Very common	Common
Uncommon	Extremely rare

STRATEGY CARDS	
Training	Policy change
Supervision	Advocacy

PRIORITY CARDS	
Top priority	Short-term priority
Long-term priority	

Upholding the Right to Privacy

OBJECTIVE:

To develop health care workers' competencies to uphold patient-provider confidentiality.

Flipchart, Markers, Job aid "Supporting Client Privacy and Confidentiality: A Checklist for Supervisors and Managers"

60-90 minutes

Discussion, case study

ADVANCE PREPARATION:

Make copies of the job aids for each participant.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

PART I - DISCUSSION:

1. Ask participants for ways that supervisors/managers can ensure privacy and confidentiality in their health settings. List responses on a flipchart.
2. Ask for ways that supervisors/managers can help staff protect the privacy and confidentiality of patients.
3. Ask how supervisors/managers can ensure that health center staff is protecting a client's privacy and confidentiality.
4. Ask participants to describe the role of supervisors/managers in handling breaches of privacy and confidentiality.
5. Ask how intentional and unintentional violations are handled.
6. Ask who determines the consequences for privacy and confidentiality breaches.
7. Ask how the following are handled at their respective health centers:
   - Disclosing a patients' (DR-) TB disease to other family members.
   - Disclosing a patients' (DR-) TB disease to his/her partner.
   - Disclosing the results of a positive HIV test to a TB patient, when proper counseling mechanisms are not in place.
   - Disclosing a patients' (DR-) TB status while identifying and screening contacts during a contact investigation.
   - Finding confidential (DR-) TB patients records when other staff members find or may view them.
   - Hearing a receptionist ask a (DR-) TB patient a personal question in the presence of others.
8. Ask what current policies are in their workplace for handling the situations mentioned in # 7 above.
9. Discuss the differences, if any, which exist between policies and actual practice.
10. Explain that some providers, for example, are unaware of privacy and confidentiality laws and assume that they

Upholding the Right to Privacy (continued)

are required to notify family members. Others apply their own cultural or religious standards when serving patients.

11. Ask how supervisors/managers should handle when discrepancies exist between policy and practice. Rules may exist to protect privacy and confidentiality, but health staff do not actually behave according to the rules.

12. If policies are needed, ask who sets these policies and how supervisors and managers can influence them.

13. Ask how health care institution staff can be made more aware of privacy and confidentiality policies and how these policies can be better enforced.

14. Distribute the job aid "Supporting Client Privacy and Confidentiality: A Checklist for Supervisors and Managers," and discuss ways that some of the action items are implemented or could be implemented in the workshop participants' health facilities.

15. Solicit and discuss any outstanding questions, comments, or concerns with the participants.

PART II – PRACTICE:

1. Divide participants into groups of three to four people.

2. Distribute a case study to each group.

3. Ask them to read their case study and answer the related questions.

4. After about 20 minutes (or when participants are ready), have one group present their answers.

5. After a group's presentation, initiate a discussion about the group's responses, and ask other participants how they might have responded.

   - How could this incident have been avoided?
   - What issues do the provider/supervisor/manager need to address in this case?
   - What impact will this incident have on the health care institution ?
   - Why did this happen?
   - What kinds of policies need to be in place to avoid such incidences?
   - What can supervisors/managers do to ensure that the client's confidentiality is maintained?
   - What can supervisors/managers do to encourage providers and frontline staff to maintain confidentiality at all times?

6. After the discussion, ask which suggestions are applicable to each participant's health care institution . List responses on a flipchart.

7. Solicit and discuss any outstanding questions.

Situation

Esme lives in a rural village. She is four months pregnant with her first child. Her husband is away a lot working in another district to earn income. Esme has had a cough for three weeks and decided to attend the health care institution to get some cough syrup.

While at the health care institution the nurse tells her that she will need to see a doctor for more in-depth examination, and she would like to do blood tests to determine if she has HIV. The nurse explains the risks of HIV to both the unborn baby and her and encourages her to take the test. The nurse explains that if a pregnant woman is HIV-positive, she and her baby can receive medicine that will help to protect the baby from becoming infected. Esme decides to take the tests.

While in the waiting room to see the doctor, before Esme has received her HIV results, Esme overhears the nurse tell another nurse that Esme's HIV test was positive. Esme is so horrified about her status and ashamed that other people now know that she is HIV-positive that she leaves the clinic without seeing a doctor.

Adapted from:

» *Patient privacy and confidentiality, PATH, http://www.path.org/publications/files/RH_ensuring_privacy.pdf.*

Job Aid

Supporting Client Privacy and Confidentiality: A Checklist for Supervisors and Managers

PROVIDER BEHAVIOR:

- Treat (DR-) TB patients with dignity and respect.
- Never discuss (DR-) TB patient's health matters in public.
- Knock and/or ask permission to enter a room when staff is working with a (DR-) TB patient.
- Ask permission before observing staff performing an examination or consulting with a patient.

SUPERVISOR BEHAVIOR:

- Make respecting privacy and confidentiality a specific requirement in each staff's job description.
- Make sure every person who has contact with patients or information about patients has a specific role in ensuring privacy and confidentiality, and that they know how to do this.
- Make sure all employees have a clear understanding of their responsibility to protect privacy and confidentiality, and ask them to sign a statement that they will uphold this commitment.
- Encourage staff to always ask permission for another person to enter the room while he/she is being examined or counseled.
- Recognize that vulnerable people, e.g., youth, poor women, and indigenous people, may have little understanding of their rights. Encourage staff to be especially committed to protecting the rights of vulnerable people.
- Respect the fact that staff are also entitled to privacy. Do not discuss a staff member's private matters in public.
- Create incentives for staff that exemplify good privacy and confidentiality practices. For example, integrate this as part of employee of the month achievements or workstation performance.
- Use supportive supervision techniques, such as complimenting staff for treating (DR-) TB patients with respect and protecting confidentiality.
- Analyze patient-staff interactions to identify where privacy and confidentiality may not be protected, and discuss possible solutions.
- Make posters or job aids to remind staff how to protect privacy and confidentiality. Reinforce concepts and practices through ongoing supportive supervision and evaluation.

POLICIES AND PROCEDURES:

- Make policies that respect a person's rights and maximize their safety, such as personal choice in deciding about contact notification, or choosing a treatment supporter.
- Act quickly if a violation of privacy or confidentiality occurs. Policies are not useful unless they are enforced.
- Deal with early breaches in a supportive manner as staff are learning.
- Create consequences for privacy and confidentiality violations, such as suspension or demotion for serious breaches.
- Post a statement in waiting rooms and examining rooms indicating that the clinic observes the people's right to privacy and confidentiality.
- Get community input on how to improve and protect privacy and confidentiality through interviews and meetings with local nongovernmental organizations and community members, and implement their suggestions.

Closing Reflections/Way Forward

OBJECTIVE:

To identify areas where each participants' values, beliefs, and/or behaviors still conflict with each other.

Closing Reflections worksheet.

30-60 minutes

Discussion and individual work

ADVANCE PREPARATION:

Review and adapt the worksheet statements and photocopy one worksheet per participant.

FACILITATOR'S STEP-BY STEP INSTRUCTIONS:

1. Review what participants said they would like to learn about stigma reduction.
2. Give each participant a Closing Reflections Worksheet (below) and ask them to reflect on the workshop and what impact it might have on them.
3. When participants have finished, ask each one to read one of their completed statements out loud. Participants may decline if they do not feel comfortable sharing with the group. Ask one or two participants to share their observations about the completed statements.
4. Debrief about the statements and observations. Some possible debriefing questions are:
   - What are the similarities among our feelings and intentions?
   - Where are the greatest differences in the group?
   - What is the impact of this workshop on our group?
5. Brainstorm about how participants can get the information or support that they need for issues that remain unclear or were not addressed.
6. Ask participants what they will do differently as a result of this workshop. (Note: List responses on a flipchart.)
7. If possible, tell participants that the list of action items on the flipchart will be typed up and distributed to all participants and their management.
8. Thank participants for their valuable contributions and suggestions, and encourage them to teach others what they have learned.
9. Ask participants to complete evaluation forms.
10. Solicit and discuss any outstanding questions, comments, or concerns.

Adapted from:

» *Abortion attitude transformation: Values clarification activities for global audience, Ipas, http://www.ipas.org/en/Resources/Ipas%20Publications/Abortion-attitude-transformation-A-values-clarification-toolkit-for-global-audiences.aspx*
» *Patient privacy and confidentiality, PATH, http://www.path.org/publications/files/RH_ensuring_privacy.pdf.*
» *Patients' rights and confidentiality in tuberculosis control, U.S. Department of Health and Human Services Centers for Disease Control and Prevention. Ensuring Privacy and Confidentiality, PATH.*

The KNCV Stigma Reduction Tool Box

Allies Approach

PARTICIPANTS

INSTRUCTIONS

This form should be completed by participants as a self-reflection to provide useful information for future adjustments to the Allies Approach interventions and materials. Please complete the statement according to how you feel now.

Closing Reflections/Evaluation Worksheet

Please complete the statements below according to how you feel now.

My ideas about _____ have changed because _____.

What I have learned here makes sense, but _____.

I still do not fully understand _____.

I want to explore _____ further.

This workshop has helped me to _____.

As a result of this workshop, I have improved _____ skills.

Please indicate yes or no.

As a result of this workshop, I will intend to do the following within the next six months.	Yes	No
Try out new communication skills.		
Advocate for respectful policies for people with TB.		

Closing Reflections/Evaluation Worksheet (continued)

As a result of this workshop, I will intend to do the following within the next six months.	Yes	No
Educate my peers about TB stigma.		
Practice compassion for my co-workers.		
Treat myself with compassion and respect.		
Treat patients with compassion and respect.		
Raise awareness about the need for safe working conditions for workers in the health care facility.		
Raise awareness of healthy work environment in the health care facility.		
Practice good infection control procedures.		
Train other staff to uphold the privacy and confidentiality of patients.		
Work to reduce the barriers faced by TB patients.		
Help re-write policies to make them more respectful for patients.		

Other (please specify_____).

If you answered "no" to all of the questions above, pls indicate any other interventions which you are planning to implement in your respective health care facility.

-
-
-

If you answered "yes" to all of the questions above, pls indicate any other intervention(s) which you are planning not to implement in your respective health care facility.

-
-
-

Closing Reflections/Evaluation Worksheet (continued)

Please mark the box that most appropriately reflects how you feel about interactive learning:

- ☐ Very Good
- ☐ Satisfactory
- ☐ Needs Improvement.
  (Please specify:_____).

Your feedback is appreciated. Thank you.

Adapted from:

- *Abortion attitude transformation: Values clarification activities for global audience, Ipas.*
- *Training Module: Ensuring Privacy and Confidentiality PATH.*

MONITORING

of TB Stigma Reduction Interventions in Health Facilities

Authors:
Ellen M.H. Mitchell
Veriko Mirtskhulava

It is important to monitor workshop implementation. This should be done in two ways:

1. Monitoring participants' feedback on the facilitator, content, organization and venue via the Participants Closing Reflections/Evaluation Worksheet and the Participants Feedback Form (see Closing Reflections/Way Forward, pgs. 99-102)
2. Monitoring the number, type, and way exercises were included via the facilitator pilot feedback form (below.)

Monitoring Participant Feedback

Evaluation Tools for Participants: Closing Reflections/ Evaluation Worksheet and Participant's Pilot Feedback Form

The closing reflections/evaluation and participant feedback form can be found at the end of the Closing Reflections/Way Forward session. See pages 153/155.

Gathering participant feedback on the workshops will reveal any technical, personal, organizational, or environmental challenges that can be addressed. To monitor the intervention, participants should be invited to share their ideas about the organization, the venue, the facilitators, and workshop content.

Samples for evaluating satisfaction with the organization:

- We had enough time to complete the exercises during the workshop (7-point Likert scale).
- Our needs were met during the workshop (7-point Likert scale).

Samples for evaluating venue satisfaction:

- The workshop venue was comfortable.
- The air was safe (7-point Likert scale AND free text response).
- The workshop venue had enough sound and visual privacy (7-point Likert scale AND free text response).
- The workshop venue was easily accessible (e.g., for participants with disabilities) (7-point Likert scale AND free text response).

Facilitator feedback can be provided by participants, peers and supervisors, or facilitators themselves. The aim of this feedback should be to help the facilitator understand their strengths and weaknesses, and find areas for improvement. Ultimately, monitoring tools should focus on gathering information, complements, and tips to help the facilitators become as capable and knowledgeable as possible.

It is vital to assess the coverage and saturation of the intervention. This can be obtained by asking questions about how many sessions and which ones the individuals attended.

Monitoring Facilitator Feedback

Facilitator Feedback Form

This form (next page) should be completed by facilitators as a way to self-reflect, which can be useful for future adjustments to the package.

Feedback forms should be reviewed after each workshop to ensure that improvements can be made in the future. Example questions are given below. Responses can be recorded using a five-point Likert-type scale of:

1= Strongly disagree;
2=Disagree;
3= Undecided;
4= Agree;
5 = Strongly Agree.

Facilitators can also help improve the workshops and intervention toolkit.

The KNCV Stigma Reduction Tool Box

Allies Approach

PARTICIPANTS

Participants Feedback Form

Workshop Name: _____ Location: _____

Date: _____ Job Title: _____

Years in present position? <5 6-10 11-15 16+

INSTRUCTIONS

This form should be completed by participants to help improve the Allies Approach interventions and materials. Please evaluate the content, design, facilitators, and results of this workshop. Read through all the options before you make a choice, and rate each on a 5-point Likert scale.

5 = Strongly Agree

4 = Agree

3 = Undecided

2 = Disagree

1 = Strongly Disagree

Choose N/A if the item is not applicable to this workshop.

Do not write your name on this sheet.

Participants Feedback Form (continued)

(Circle your response to each item.)

1.	WORKSHOP CONTENT	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	I was well informed about the objectives.	5	4	3	2	1
2	This workshop lived up to my expectations.	5	4	3	2	1
3	The content is relevant to my job.	5	4	3	2	1

2.	WORKSHOP DESIGN	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	The workshop's objectives were clear to me.	5	4	3	2	1
2	The workshop's activities stimulated my learning.	5	4	3	2	1
3	The activities in this workshop gave me sufficient practice.	5	4	3	2	1
4	The facilitators gave me sufficient feed-back.	5	4	3	2	1
5	The difficulty level of this workshop was appropriate.	5	4	3	2	1
6	The pace of this workshop was appropriate.	5	4	3	2	1

3.	WORKSHOP FACILITATOR(S)	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	The facilitator was well prepared.	5	4	3	2	1
2	The facilitator was able to appropriately handle participants' emotions.	5	4	3	2	1

Participants Feedback Form (continued)

3.	WORKSHOP FACILITATOR(S)	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
3	The facilitator was a good listener and refrained from giving advice.	5	4	3	2	1
4	The facilitator showed self- compassion.	5	4	3	2	1
5	The facilitator did not try to fix me.	5	4	3	2	1
6	The facilitator was knowledgeable and answered questions satisfactorily.	5	4	3	2	1
7	The facilitator explained the exercises and information satisfactorily.	5	4	3	2	1
8	The facilitator kept good time and ensured that the workshop ran smoothly.	5	4	3	2	1

4.	WORKSHOP RESULTS	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	I accomplished the objectives of this workshop.	5	4	3	2	1
2	I will be able to use what I learned in this workshop during my daily routine.	5	4	3	2	1
3	The workshop was appropriate for the needs of this health care facility.	5	4	3	2	1
4	The workshop helped to remind me why I am a health care worker who serves TB patients.	5	4	3	2	1

Participants Feedback Form (continued)

5. WORKSHOP IMPROVEMENTS

(Check all that apply.)

How would you improve this workshop?

- ☐ Provide better information before the workshop.
- ☐ Clarify the workshop objectives.
- ☐ Reduce the content covered in the workshop.
- ☐ Increase the content covered in the workshop.
- ☐ Update the content covered in the workshop.
- ☐ Improve the instructional methods.
- ☐ Make workshop activities more stimulating.
- ☐ Improve workshop organization.
- ☐ Make the workshop less difficult.
- ☐ Make the workshop more difficult.
- ☐ Slow down the pace of the workshop.
- ☐ Speed up the pace of the workshop.
- ☐ Allot more time for the workshop.
- ☐ Shorten the time for the workshop.
- ☐ Add more visuals to the workshop.

What is least valuable about this workshop? _____ .

What is most valuable about this workshop? _____ .

Your feedback is sincerely appreciated. Thank you.

The KNCV Stigma Reduction Tool Box

Allies Approach

FACILITATORS

Facilitators Feedback Form

Workshop Name: _____ Location: _____

Date: _____ Job Title: _____

Years in present position? <5 6-10 11-15 16+

INSTRUCTIONS

This form should be completed by facilitators to help improve the Allies Approach interventions and materials. Please evaluate the organization, content, and methodologies of the workshop.

Do not write your name on this sheet.

The "ALLIES Approach" toolkit

1. What were the objectives of your intervention?

2. Who was the target audience of your intervention?

Facilitators Feedback Form (continued)

3. Which exercises from the "ALLIES Approach" toolkit did you use during your intervention?

4. How did you select the exercises from the "ALLIES Approach" toolkit?

5. Which exercises worked well? Why?

6. Which exercises did not work well? Why?

7. Please describe any changes or improvements you made to any of the exercises.

8. What additional topics need to be added to the "ALLIES Approach" toolkit?

9. Have you developed any case studies, exercises, or visuals on TB stigma reduction in health care institutions?[1]

1. If possible, send exercises to KNCV so they can be added to the "ALLIES Approach" toolkit (if appropriate). You will be appropriately acknowledged.

Facilitators Feedback Form (continued)

INSTRUCTIONS

Read through all of the options before you make a choice, and rate on a 5-point Likert scale:

5 = Strongly Agree

4 = Agree

3 = Undecided

2 = Disagree

1 = Strongly Disagree

1.	METHODOLOGIES AND TECHNIQUES	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	The techniques taught are expected to reduce stigma and miscommunication. [free text response]	5	4	3	2	1
2	The techniques taught are expected to improve current practices. [free text response]	5	4	3	2	1
3	The techniques taught are expected to improve patient-provider inter-personal communication.	5	4	3	2	1

Facilitators Feedback Form (continued)

1.	METHODOLOGIES AND TECHNIQUES	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
4	The workshop reminded me why I am in health care and work with TB patients.	5	4	3	2	1
5	The innovations presented are consistent with socio-cultural values and/or perceived needs.	5	4	3	2	1

2. I will use the selected techniques (_____, _____, _____) during my daily work because they are:

- ☐ Easy to implement.
- ☐ Not time consuming.
- ☐ Simple.
- ☐ Appropriate for daily practice.

Your feedback is appreciated. Thank you.

Baseline and Endline Evaluation (Including Participant Exposure)

The Baseline evaluation includes a structured review checklist for the existing regulatory documents at the HCF level, structured observation checklist, and questionnaires for HCWs and patients. Results will serve as a baseline for the TB stigma reduction interventions and as a comparison for the endline measurement after the intervention.

Six months after the baseline assessment, the endline assessment should be conducted using the same tools for TB stigma measurement in all selected TB facilities. The baseline and endline assessment results should be compared both within and across the selected facilities.

Sample Evaluation Plan

Here is an example of pre-post intervention control design.

Step	Indicators to be measured/addressed	Tools
1. Baseline Measurement	1. Individual factors: a. Knowledge b. Self-compassion c. Self-efficacy d. Attitudes	a. PART I: Self-learning b. Neff's self-compassion scale and Pommier's compassion scale c. Corrigan Attribution Questionnaire Short Form, Wouter's Respondents External TB Stigma scale (RES), Others' External Stigma toward TB (EOS)
	2. Facility policies, infrastructure, and organizational norms and culture	Structured observation tools, mystery patients or surrogate patients, exit interviews with TB patients
	3. TB patient's self-stigma	TB patient assessment[2]
	4. Innovativeness/influence of health workers (for dentification of KOLs)	Sociogram[3]
	5. Organizational/individual readiness to change	Hage and Dewar's instrument for measuring openness to organizational change (five items)
	6. Work environment (confounder)	The Maslach Burnout Inventory (MBI)

2. The TB patient assessment tool can be found in the "From the inside out – Dealing with TB-related self-stigma and shame" toolkit.
3. To develop the sociogram, refer to the Competency Development: Change Agent/Key Opinion Leaders tool.

Sample Evaluation Plan (continued)

Step	Indicators to be measured/addressed	Tools
2. Health Workforce Intervention Package	Individual health care worker's behavior and attitudes	PART I: Self-learning
		PART II: Interactive learning
	Usability/acceptability/curriculum performance	Monitoring implementation of PART II
3. Post Intervention	1. Individual factors: a. Knowledge b. Self-compassion c. Self-efficacy d. Behavioral intentions e. Attitudes	a. PART I: Self-learning b. Neff's self-compassion scale and Pommier's compassion scale c. Closing Reflections/Evaluation Worksheet, pg. 99 d. Corrigan Attribution Questionnaire Short Form, Wouter's Respondents External TB Stigma scale (RES), Others' External Stigma toward TB (EOS)
	2. Facility policies, infrastructure and organizational norms and culture	Structured observation tools, mystery patients or surrogate patients, exit interviews with TB patients
	3. TB patient's self-stigma	TB patient assessment[4]
	Facilitators assist with policy reforms feedback, problem solving, social support, and reinforcement.	

4. The TB patient assessment tool can be found in the "From the Inside Out – Dealing with TB-related self-stigma and shame" toolkit.

Validated TB stigma scales are valuable tools to measure intervention outcomes that address stigma. The scales should be applied at baseline and follow-up. Qualitative inquiry can then add meaning to the findings. For example, a quantitative scale might show increased compassion, respect, or intention to uphold confidentiality after a stigma intervention. Qualitative methods can also improve the intervention by identifying difficulties. For further examples and validated scales, refer to the TB Stigma Measurement Guidance: www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf.

Measuring Organizational Readiness and Change

If the intervention takes place within an institution (e.g., health care institution , prison, or lab), then the unit of analysis is the institution as well as the individuals exposed. To assess organizational openness to change, leaders can be surveyed with Hage and Dewar's instrument for measuring openness to organizational change (five items):

There is really something refreshing about enthusiasm for change	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
If I were to follow my deep convictions, I would devote more time to change movements. This seems to me to be a primary need today.	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The current situation in the community calls for change, we should do something now (we must respond at once).	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
If you want to get anywhere, it is the policy of the system as a whole that needs to be changed, not just the behavior of isolated individuals.	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Any organizational structure becomes a deadening weight in time and needs to be revitalized.	Strongly disagree	Disagree	Neutral	Agree	Strongly agree

Measuring Structural Stigma (Policies, Infrastructure and Organizational Norms and Culture)

It is important to measure the adequacy of policies that protect health care workers and policies that protect patients both at baseline and after the intervention. The review of policies should involve both survey about specific provisions and protections, as well as a narrative analysis of individual policies and guidance.

Field observations can identify architectural features or health messaging that promotes stigma. There are structured and unstructured forms of observation. Field observations can elicit novel insights into discriminatory practices and norms that are less likely to be discussed by interview or focus group participants because they are considered socially undesirable or totally normal (Tables 5-7). There are a variety of observational study designs, including studies in which the researcher becomes fully immersed in their research setting (assumes the role of a participant).[27]

Measuring Structural Stigma (Policies, Infrastructure and Organizational Norms and Culture) (continued)

Setting-architectures	Location in community/city, signposts, clinic layout, proximity between queue and provider offices, spacing/crowding, type of seating, posters/flyers, ventilation/UV lighting
Human behavior	Frequency and types of interactions between people (patterns/types of communication, body language/touching between clients and clients and providers), masks/ cough hygiene, social distance, microaggressions, tone, eye-contact
Social environment	People characteristics (types of people: clients, caregivers, providers, allied workers; gender; ethnicity/race; religion, clothing; physical appearance), human traffic (numbers, entries/exits, accompanying persons, client intake/output, waiting times)
Clinical behavior	Clinical care provided (who receives which services, tests, treatments, advice, free samples, support, length of consultations, etc.)
Surprises and non-occurrences	Observations that stand out: people or activities receiving more attention; unexpected activities: expected observations that are not observed, observations that do/do not appear congruent with the literature or interview/focus group responses; and/or absence of staff/resources that are typically present

Table 5. Examples of what to observe and document at clinics to examine TB stigma

	Yes	No
1. Is there a space dedicated to TB consultations?		
2. Can conversations in the exam room be heard outside of the room?		
3. Can the client be seen from outside of the exam room?		
4. Are there any interruptions during the TB consultation?		
5. Is there any physical wall or glass between the client and provider?		
6. Is there sufficient air ventilation in the room (e.g., open window) to protect the HCW?		
7. Are there educational materials (e.g., posters, videos, pamphlets, and job aids) about TB in the TB clinic?		
8. If yes, do images or text of materials convey fear, danger, pity, or death?		

Table 6. Example of a structured observation tool to measure the enabling environment for TB stigma

Measuring Structural Stigma (Policies, Infrastructure and Organizational Norms and Culture) (continued)

	Yes	No
1. Was the client greeted in a friendly manner by the HCW?		
2. Was the PWTB asked by the HCW if they had any questions or concerns?		
3. Did the provider listen carefully to the client?		
4. Were value-laden terms or labels used by the HCW?		
5. Were negative stereotypes or motives of clients expressed or implied?		
6. Was there blaming or shaming by the HCW?		
7. Was there exaggeration of dangerousness or risk by the HCW?		
8. Were there any threats made or coercive language used by the HCW?		

Table 7. Example of a structured observation of a client-provider encounter

---

For further examples and validated scales:

» *TB Stigma Measurement Guidance, www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf.*

Measuring Impact on Clients

Structured Observational Measures

One way to evaluate whether the TB stigma intervention has reduced stigma is to conduct structured observation at baseline and end line. These measures are complex to develop, The World Health Organization has several handbooks in multiple languages on observation of client interactions:
http://apps.who.int/medicinedocs/en/d/Js2289e/

The process is described in detail in Chapter 5 of the TB Stigma Measurement guidance:
www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf

Mystery Patients or Surrogate Patients for Studying Stigma in Institutions

Techniques such as "surrogate patients," "standardized patients," "simulated patients," or "mystery patients" may also be appropriate for the study of stigmatization. These terms refer to the use of trained actors to measure the quality of health care.[36] The actors are trained to follow a script, describing a series of symptoms and characteristics.[37–39] They observe and describe any stigmatizing experiences.[40] The advantage of using trained actors posing as TB patients is the ability to measure the variability of responses with a specific type of client, especially those who may be at more risk for stigmatization (e.g., a female TB client who uses alcohol). Mystery patients have been used extensively in the field of family planning to measure the quality of care.

The use of mystery patients raises a host of ethical and informed consent issues. Consent is often only sought from the institution and, therefore, health care workers often do not realize that they are participating in research. Health care workers therefore need to be protected from professional harm associated with the use of such techniques.

Exit Interviews with TB Patients

Exit interviews with actual TB patients are also a common approach for collecting data on the quality of interactions between providers and patients.[41–44] Exit interviews are conducted as a client is leaving a health service encounter to explore the quality of that encounter before recall bias limits the quality of the information.[45] There is no validated exit interview measure, but below are the types of items that could be used as part of an M&E exercise.

The following are exit interview items for measuring respectful care adapted from Sheferaw et al.[46]:

Friendly care:

- I felt that health care workers cared for me with a kind approach.
- The health care workers treated me in a friendly manner.
- The health care workers talked positively about my recovery.
- The health care worker showed his/her concern and empathy.

Measuring Impact on Clients (continued)

Abuse-free care:

- The health provider threatened me with negative consequence if I did not obey with their orders.
- The health care workers shouted at me because I hadn't done what I was told to do.
- I was assured that information about me and my health status would be protected.

Discrimination-free care:

- Some of the health care workers did not treat me well because of some personal attributes.
- Some health care workers insulted me or my companions due to my personal attributes.
- I was treated the same as any other client.
- Once I was no longer infectious, I was not segregated from others.

Respectful care:

- I was kept waiting for a long time before receiving service.
- Service provision was delayed due to the health facilities' internal problems.
- All health care workers treated me with respect as an individual.
- The health care workers spoke to me in a language that I could understand.
- The health provider called me by my name.
- The health care workers discussed with me how best to engage my close contacts while preserving my privacy.

Empowering care:

- I was encouraged to choose my treatment supporter.
- I was given enough control over my own treatment decisions.
- I was given enough information to understand TB disease.
- I received information and tools to help me protect my family and friends.

Measuring Changes in Individual Health Care Workers Attitudes

Neff's self-compassion scale and Pommier's compassion scale are good barometers to measure changes evoked by the HEART module.[28,29] They can be used to measure attitudinal changes due to exposure to the Allies approach.

INSTRUCTIONS

Please read each statement carefully before answering. To the right of each item, indicate how often you behave in the stated manner, using the following scale: 1 = almost never and 5 = almost always

How I typically act towards myself during difficult times	**Score** (1 = almost never and 5 = almost always)
1. When I fail at something important to me I become consumed by feelings of inadequacy.	1 2 3 4 5
2. I try to be understanding and patient towards those aspects of my personality I don't like.	1 2 3 4 5
3. When something painful happens, I try to take a balanced view of the situation.	1 2 3 4 5
4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.	1 2 3 4 5
5. I try to see my failings as part of the human condition.	1 2 3 4 5
6. When I'm going through a very hard time, I give myself the caring and tenderness I need.	1 2 3 4 5
7. When something upsets me I try to keep my emotions in balance.	1 2 3 4 5
8. When I fail at something that's important to me, I tend to feel alone in my failure.	1 2 3 4 5
9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.	1 2 3 4 5
10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	1 2 3 4 5
11. I'm disapproving and judgmental about my own flaws and inadequacies.	1 2 3 4 5
12. I'm intolerant and impatient towards those aspects of my personality I don't like.	1 2 3 4 5

Table 8. Neff's self-compassion scale - short form (SCS-SF)

Measuring Changes in Individual Health Care Workers Attitudes (continued)

How I typically act towards others		Score (1 = almost never 5 = almost always)
1.	When people cry in front of me, I often don't feel anything at all.	1 2 3 4 5
2.	Sometimes when people talk about their problems, I feel like I don't care.	1 2 3 4 5
3.	I don't feel emotionally connected to people in pain.	1 2 3 4 5
4.	I pay careful attention when other people talk to me.	1 2 3 4 5
5.	I feel detached from others when they tell me their tales of woe.	1 2 3 4 5
6.	If I see someone going through a difficult time, I try to be caring toward that person.	1 2 3 4 5
7.	I often tune out when people tell me about their troubles.	1 2 3 4 5
8.	I like to be there for others in times of difficulty.	1 2 3 4 5
9.	I notice when people are upset, even if they don't say anything.	1 2 3 4 5
10.	When I see someone feeling down, I feel like I can't relate to them.	1 2 3 4 5
11.	Everyone feels down sometimes. It is part of being human.	1 2 3 4 5
12.	Sometimes I am cold to others when they are feeling down.	1 2 3 4 5
13.	I tend to listen patiently when people tell me their problems.	1 2 3 4 5
14.	I don't concern myself with other people's problems.	1 2 3 4 5
15.	It's important to recognize that all people have weaknesses and no one's perfect.	1 2 3 4 5
16.	My heart goes out to people who are unhappy.	1 2 3 4 5
17.	Despite my differences with others, I know that everyone feels pain just like me.	1 2 3 4 5
18.	When others are feeling troubled, I usually let someone else attend to them.	1 2 3 4 5
19.	I don't think much about the concerns of others.	1 2 3 4 5
20.	Suffering is just a part of the common human experience.	1 2 3 4 5

Measuring Changes in Individual Health Care Workers Attitudes (continued)

How I typically act towards others	Score (1 = almost never 5 = almost always)
21. When people tell me about their problems, I try to keep a balanced perspective on the situation.	1 2 3 4 5
22. I can't really connect with other people when they're suffering.	1 2 3 4 5
23. I try to avoid people who are experiencing a lot of pain.	1 2 3 4 5
24. When others feel sadness, I try to comfort them.	1 2 3 4 5

Table 9. Pommier's Compassion Scale

To measure stigmatizing attitudes, Corrigan's nine domain Attribution Questionnaire (AQ-9) maps elements of dignity and rights-based TB treatment (See Table 10)[30]. The scale uses a 10-point Likert scale.

AQ-9 Domain	Illustrative items	Score (1 = not likely/true 10 = very likely/true)
Fear	How nervous are you treating patients?	1 2 3 4 5 6 7 8 9 10
Pity	How much pity do you feel for TB patients?	1 2 3 4 5 6 7 8 9 10
Help	How likely are you to help a TB patient?	1 2 3 4 5 6 7 8 9 10
Avoidance	I would stay away from a TB patient.	1 2 3 4 5 6 7 8 9 10
Blame	I think developing TB is a person's own fault.	1 2 3 4 5 6 7 8 9 10
Anger	How angry do you feel towards TB patients?	1 2 3 4 5 6 7 8 9 10
Segregation	I think it would be best for TB to be isolated in the intensive phase.	1 2 3 4 5 6 7 8 9 10
Danger	How dangerous do you feel TB patients are?	1 2 3 4 5 6 7 8 9 10

Measuring Changes in Individual Health Care Workers Attitudes (continued)

AQ-9 Domain	Illustrative items	Score (1 = not likely/true 10 = very likely/true)
Coercion	I think treatment should be forced, if necessary.	1 2 3 4 5 6 7 8 9 10

Table 10. Illustrative items based upon Corrigan Attribution Questionnaire Short Form

To measure stigmatizing attitudes toward health care workers who care for TB patients or people who may have TB, Wouters et al., developed and validated two brief TB secondary stigma scales. These which perform well.

1. **Others' External Stigma toward TB (EOS):** How respondents perceive stigmatizing behavior and attitudes of health providers towards TB-associated HCWs (EOS) (five items.)
2. **Respondent's external stigma toward TB (RES):** How respondents behave and think about TB-associated HCWs (three items.)[31,32]

Wouter's Respondents External TB Stigma scale (RES) for HCWs includes three items that reflect the desire for social distance, fear of HCWs who treat TB, and linking TB care to stigmatized comorbidities.[31–33] The decision on whether to use Wouters or Corrigan should depend on available space and whether you plan to intervene only on TB stigma or more broadly on a range of stigmas (e.g., TB and HIV stigma).

For further examples and validated scales:
» *TB Stigma Measurement Guidance, www.challengetb.org/publications/tools/ua/TB_Stigma_Measurement_Guidance.pdf.*

Behavioral Intentions of Participants

An important aspect to measure is how participants plan to make use of the skills and approaches in the near term (e.g., within six months). To evaluate participants' assessment of the acceptability and feasibility of implementing the Allies Approach in their daily work lives, participants should rate the intervention immediately following PART II. (See Participants Closing Reflections/Evaluation Worksheet, pg. 151.)

Confounders

Work environment/ health care worker well-being

The demands and emotional challenges on health professionals and their patients can result in occupational stress that causes hostility unrelated to TB stigma. Hence, it is recommended to include the Maslach Burnout Inventory (MBI) scale and Eisenberg et al., Perceived Organizational Support scale as a means of capturing issues that may confound the interpretation of stigmatizing attitudes, such as a hostile work environment.[34]

The Maslach Burnout Inventory (MBI)[34]

The following statements deal with how you may or may not feel about your work as a TB health provider. Response categories are a seven-point Likert scale ranging from 1 (very mild) to 7 (very strong).

Emotional exhaustion/regret of professional choice (Consequences)	**Score** (1 = very mild 7 = very strong)
1. I feel emotionally drained from my work.	1 2 3 4 5 6 7
2. I feel used up at the end of the workday.	1 2 3 4 5 6 7
3. I feel fatigue when I get up in the morning and have to face another day on the job.	1 2 3 4 5 6 7
4. Working with people all day is really a strain for me.	1 2 3 4 5 6 7
5. I feel burned out from my work.	1 2 3 4 5 6 7
6. I feel frustrated by my job.	1 2 3 4 5 6 7
7. I feel I'm working too hard on my job.	1 2 3 4 5 6 7

Behavioral Intentions of Participants (continued)

Emotional exhaustion/regret of professional choice (Consequences)	**Score** (1 = very mild 7 = very strong)
8. Working with people directly puts too much stress on me.	1 2 3 4 5 6 7
9. I feel like I'm at the end of my rope.	1 2 3 4 5 6 7

Depersonalization (Consequences)	**Score** (1 = very mild 7 = very strong)
1. I feel I treat some patients as if they were impersonal 'objects'.	1 2 3 4 5 6 7
2. I've become more callous toward people since I took this job.	1 2 3 4 5 6 7
3. I worry that this job is hardening me emotionally.	1 2 3 4 5 6 7
4. I don't really care what happens to some patients.	1 2 3 4 5 6 7
5. I feel patients blame me for some of their problems.	1 2 3 4 5 6 7

Personal accomplishment (Consequences)	**Score** (1 = very mild 7 = very strong)
1. I can easily understand my how my patients feel about things.	1 2 3 4 5 6 7
2. I deal very effectively with the problems of my recipients patients.	1 2 3 4 5 6 7
3. I feel I'm positively influencing other people's lives through my work.	1 2 3 4 5 6 7
4. I feel very energetic.	1 2 3 4 5 6 7
5. I can easily create a relaxed atmosphere with my patients.	1 2 3 4 5 6 7
6. I feel exhilarated after working closely with my recipients.	1 2 3 4 5 6 7
7. I have accomplished many worthwhile things in this job.	1 2 3 4 5 6 7

Behavioral Intentions of Participants (continued)

Personal accomplishment (Consequences)	**Score** (1 = very mild 7 = very strong)
8. In my work, I deal with emotional problems very calmly.	1 2 3 4 5 6 7

Table 11. Maslach Burnout Inventory (MBI)

Perceived organizational support scale by Eisenberger (1997)[35]

Response categories: seven-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree) (Drivers).

When thinking about my place of employment, I feel:	**Score** (1 = strongy disagree 7 = strongly agree)
1. My organization cares about my opinion.	1 2 3 4 5 6 7
2. My organization really cares about my well-being.	1 2 3 4 5 6 7
3. My organization strongly considers my goals and values.	1 2 3 4 5 6 7
4. Help is available from my organization when I have a problem.	1 2 3 4 5 6 7
5. My organization would forgive an honest mistake on my part.	1 2 3 4 5 6 7
6. If given the opportunity, my organization would take advantage of me.	1 2 3 4 5 6 7
7. My organization shows very little concern for me.	1 2 3 4 5 6 7
8. My organization is willing to help me if I need a special favor.	1 2 3 4 5 6 7

Table 12. Perceived organizational support scale by Eisenberger (1997)

Transmission control policies

It is important to keep in mind that not all stigmatizing behavior is intentional. Indeed, some behaviors may be mandated. For example, standard TB transmission control practices, such as masking, separation, contact investigation, and direct

observation of treatment can be perceived as stigmatizing and discrediting (see Table 13)[47–49].

What mask wearing means varies widely by region and country? Wearing masks is normative in many Asian urban areas in response to air pollution or as a fashion accessory[50–52]. In health care settings, there are often many different interpretations of infection control (IC) practices[49,53–56]. The over-use, misuse, or prolonged use of personal protection has been a potent manifestation of stigma[56].

Because transmission control can be conflated with stigmatization, it is important to assess the meanings attached to transmission control[56].

Transmission Control Practices	Stigmatizing Interpretation
Person with TB separation	Shunning of person with TB (PWTB)
Person with TB masking (e.g surgical masks)	Marking of person with TB (PWTB) (disclosure)
Health care workers masking (e.g. respirators)	Fear of person with TB (PWTB)

Table 13. Diverse interpretations of health care worker behavior

ANNEXES

HOW TO PREPARE YOUR WORKSHOP

Checklist

- ☐ Read the introductory material and annexes before the workshop.
- ☐ Arrange the workshop site.
- ☐ Arrange to have two flipchart stands, flipchart paper, and markers.
- ☐ Prepare flipcharts for the different exercises (see "Preparation" under each individual exercise).
- ☐ Make enough copies of the job aids for each participant in the workshop.
- ☐ Make enough copies of the case studies for each participant in the practice session.
- ☐ Make enough copies of the Participant Evaluation Form for each participant.

Adapted from:

» *Patient privacy and confidentiality, PATH. http://www.path.org/publications/files/RH_ensuring_privacy.pdf.*

GLOSSARY

Anticipated Stigma	The fear of disparagement (fear of enacted stigma), even in the absence of actually having the disparaged 'mark' or characteristic (condition).
Blame	A common rhetorical framing and a domain of stigma. This is when responsibility for a health condition is attributed to a particular person, or when a causal attribution is constructed, whether or not it is plausible or evidence based.
Change Agent	Any person within an institution that has enough social capital, respect, and leadership to catalyze new behaviors among the staff, through example, mentoring, advocacy, or other means.
Change Process	An effective change process is a recipe for selecting, adapting, implementing, and scaling up effective practices to achieve and sustain health results.
Compassion	Compassion is defined through five elements: 1) recognizing suffering/injustice; 2) understanding the universality of suffering in human experience; 3) feeling moved by the person suffering and emotionally connecting with their distress; 4) tolerating uncomfortable feelings aroused (e.g., fear, distress) so that we remain open to and accepting of the person suffering, and 5) acting or being motivated to act to alleviate suffering/injustice.
Courtesy Stigma	This is a type of secondary stigma. It is the vicarious social taint experienced by those who interact with stigmatized people.[57] Courtesy stigma may reduce the social standing of family, friends, and caretakers.
Deconstruct	To demystify a phenomenon by revealing its supporting structures and ideas
Defaulter	A stigmatizing word used to describe a TB patient who interrupts treatment or is not compliant with treatment. No longer used. Now called a "person lost to follow up".
Destigmatization	The process of countering the drivers of stigma through intervention to reduce discrimination, name calling, and feelings of blame and shame.
Dirty work	Dirty work stigma refers to employment that others regard as degrading or demeaning.[58,59] Professionals who serve the health or social needs of stigmatized persons may be indirectly tainted, and their roles are discredited in the professional hierarchy. A type of loss of prestige experienced

	by certain types of health care workers (e.g., addiction counsellors, mental health professionals, and abortion providers).
Discrimination	To enact stigma through illegal means or denying a person the equal treatment to which they are entitled.
Enacted Stigma	Behaviors designed to discredit or diminish. A synonym of discrimination.
Label Avoidance	Avoiding overt self-identification with a stigmatized group.
Infantilizing	This is to treat an adult in a child-like manner, such as not accepting their right to autonomy (e.g., not letting them make their own decisions)
Maladaptive	Unsuitably adapted or adapting poorly to a situation.
Microaggressions	Subtle forms of hostility (e.g., verbal slights, facial expressions) and denigration.
Pathologizing	This is the practice of viewing behaviors as a symptom indicative of a disease or disorder. In mental health, the term is often used to indicate over-diagnosis or the refusal to accept certain behaviors as normal.
Self-stigma	Refers to the internalization of public stigma by a person.[60] This internalization can lead to denial of symptoms and rejection of treatment, and may contribute to isolation from valuable social support.[61]
Social distancing	When someone tries to avoid a person, e.g. a TB patient.
Stigma	The relationship between an attribute and a stereotype that assigns undesirable labels, qualities, and behaviors to a person. Labeled individuals are devalued socially, leading to inequality and discrimination.[20] For example, a TB patients is always assumed to be infectious, and therefore is labelled as dangerous, which justifies behaviors and policies that create social distance (e.g., triage, separation.)
Stigmatization	The social process by which a condition affects the lives of those who are impacted by it.
Structural Stigma	Societal-level conditions, cultural norms, and institutional practices that constrain the opportunities, resources, and wellbeing of stigmatized populations.[62]
Symbolic devices	Narrative conventions such as metaphors or story lines that are used to represent problems in policy text.

UNIVERSAL BASIC NEEDS

Universal Basic Needs

PHYSICAL WELL-BEING

air
nourishment (food, water)
light
warmth
rest / sleep
movement / physical exercise
health
touch
sexual expression
shelter / security / protection from pain / emotional safety / preservation
comfort

HARMONY

peace
beauty
order
calm / relaxation / equanimity / tranquility
stability / balance
ease
communion / wholeness
completion / digestion / integration
predictability / familiarity
equality / justice / fairness

CONNECTION

love
belonging
closeness
intimacy
empathy / compassion
appreciation
acceptance
recognition
reassurance
affection
openness
trust
communication
sharing / exchange
giving / receiving
attention
tenderness / softness
sensitivity / kindness
respect
seeing (see / be seen)
hearing (hear / be heard)
understanding (understand / be understood)
consideration / care / that my needs matter
inclusion / participation
support / help / nurturing
cooperation / collaboration
community / companionship / partnership / fellowship
mutuality / reciprocity
consistency / continuity

MEANING

purpose
contribution / enrich life
presence
centeredness
hope / faith
clarity
to know (be in reality)
learning
awareness / consciousness
inspiration / creativity
challenge / stimulation
growth / evolution / progress
empowerment / power / having inner strength / competence / capacity
self-value / self-confidence / self-esteem / dignity / efficacy / effectiveness
liberation / transformation
to matter / take part in / have my place in the world
spirituality
interdependance
simplicity
celebration / mourning

FREEDOM

choice / acting out of my own spirituality
autonomy
independence
space / time

HONESTY

self-expression
authenticity
integrity
transparency
realness / truth

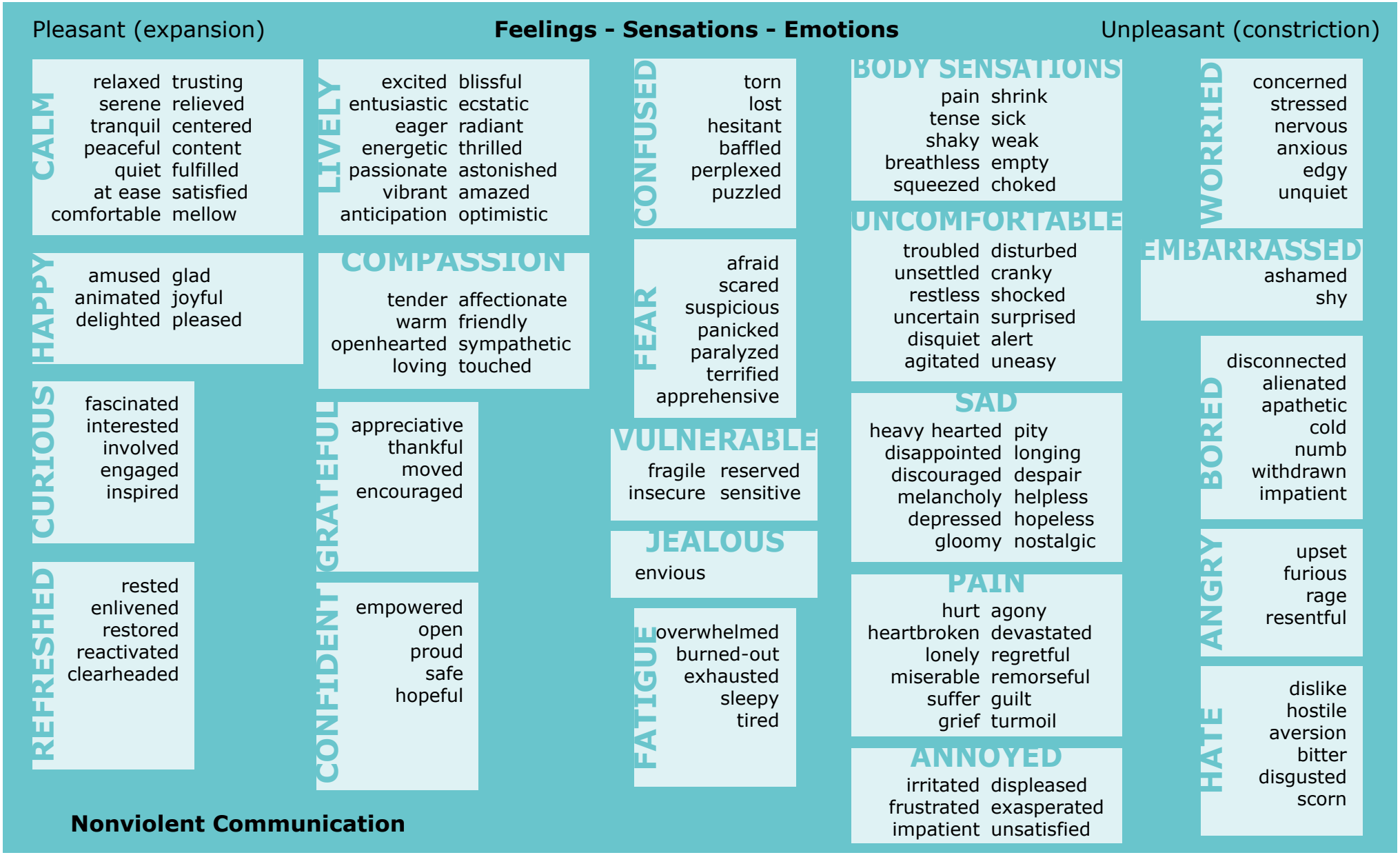
PLAY

liveliness / alive / vitality
flow
passion
spontaneity
fun
humor / laugh / lightness
discovery / adventure
variety / diversity

Adapted from:

» *Connect2life, by Yoram Mosenzon, www.connecting2life.net. info@connecting2life.net*

FEELINGS-SENSATIONS-EMOTIONS



(DR-) TB NUMBERS

TB CARE AND PREVENTION

TB treatment saved 49 million lives globally between 2000 and 2015. In 2015, 6.1 million new TB cases were notified to national authorities and reported to WHO. This reflects a 4.3 million gap between incident and notified cases, with India, Indonesia, and Nigeria accounting for almost half of this gap.

Globally, the treatment success rate for people newly diagnosed with TB was 83% in 2014.

DRUG-RESISTANT TB

Globally in 2015, there were an estimated 480,000 new cases of multidrug-resistant TB (MDR-TB) and an additional 100,000 people with rifampicin-resistant TB (RR-TB) who were also newly eligible for MDR-TB treatment.

A total of 125,000 patients (20% of those newly eligible for treatment) were enrolled and started on MDR-TB treatment, an increase of 13% as compared to 2015.

Globally, data show an average cure rate of only 52% for treated MDR-TB patients.

In 2015, an estimated 9.5% of people with MDR-TB had extensively drug resistant TB (XDR-TB). XDRTB patients had a treatment success rate of 28% in 2013.

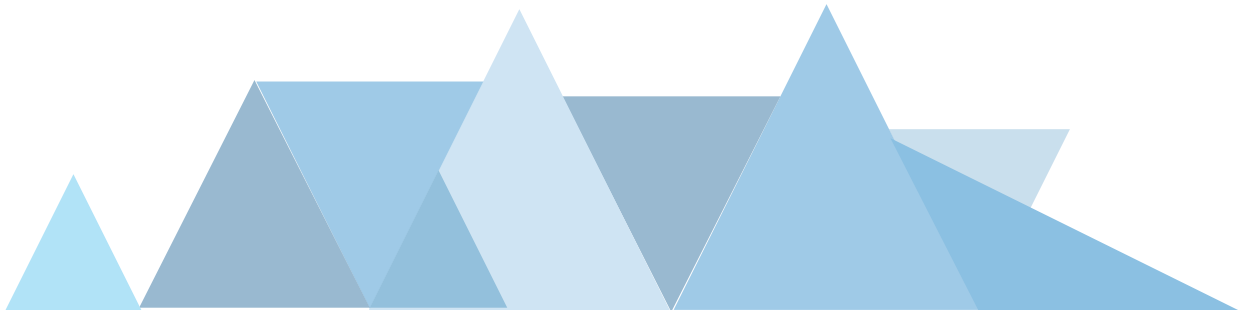
ADDRESSING THE CO-EPIDEMICS OF TB AND HIV

In 2015, 55% of TB patients globally had a documented positive HIV test result. In Africa, which has the highest rate of TB/HIV burden, 81% of TB patients knew their HIV status.

Globally, 78% of HIV-positive TB patients in 2015 were started on antiretroviral therapy. Nevertheless, only a third of the 1.2 million people living with HIV who are estimated to have developed TB in 2015 have received antiretroviral therapy.

TB PREVENTIVE TREATMENT

A total of 910,000 people who were newly enrolled in HIV care were started on TB preventive treatment in 2015. In addition, 87,000 children under the age of five (7% of the 1.2 million children eligible) were provided with it.

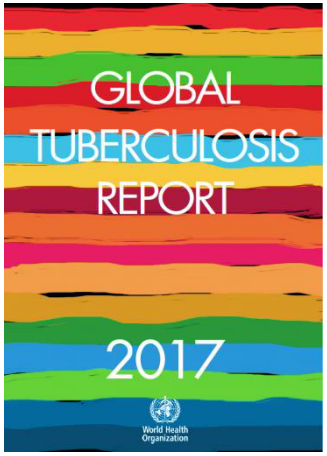


GLOBAL TB REPORT 2017

World Health Organization

TUBERCULOSIS

Global Tuberculosis Report 2017



53 million lives saved between 2000 - 2016

TB deaths fell by 22% in the same period

1.7 MILLION TB DEATHS

INCLUDING 0.4 MILLION TB DEATHS AMONG PEOPLE WITH HIV*

TB is the top infectious killer worldwide

TB is also the leading cause of deaths due to antimicrobial resistance and among people with HIV

MDR-TB crisis with gaps in detection and treatment

Only 1 in 5 needing MDR-TB treatment were enrolled on it

US$ 2.3 BILLION GAP

Funding shortfall for TB implementation

Gap of over US$1.2 billion per year for TB research

DESPITE PROGRESS AND MILLIONS OF LIVES SAVED, GLOBAL ACTIONS AND INVESTMENTS FALL FAR SHORT OF THOSE NEEDED

ETHICAL ISSUES IN TB PREVENTION, TREATMENT, AND CARE

ETHICAL ISSUES IN TUBERCULOSIS PREVENTION, TREATMENT & CARE

World Health Organization

BACKGROUND

- In 2015, over 10.4 million people fell ill and about 1.8 million people died of tuberculosis (TB) including 0.4 million among people with HIV.
- Major achievements have been made in the fight against TB with 49 million lives saved since 2000.
- However, TB remains a crucial health threat, in particular to the most vulnerable populations all over the world.
- Development of, and active transmission of drug-resistant strains of TB (MDR-TB and XDR-TB), add to the challenge as these are especially difficult to detect and treat.
- Prevention, diagnosis, treatment and care of people with TB raise not only technical, but also important ethical issues that need to be adequately addressed. For instance, recent cases of involuntary detentions of people with TB in several parts of the world have brought up the question of how to balance individual rights and liberties against the protection of public health.
- The World Health Organization's (WHO's) End TB Strategy and the UN Sustainable Development Goals (SDGs), which target ending the TB epidemic by 2030, call for due attention to equity, human rights and ethics. "Protecting human rights, ethics and equity" is one of the four key principles of WHO's End TB Strategy. The SDGs agenda itself is inspired by a simple motto: "leave no one behind".

WHO GUIDANCE ON ETHICS TO END TB

- WHO has released new guidance on TB Ethics entitled "Ethics Guidance for the implementation of the End TB Strategy" to help ensure that the implementation of the End TB Strategy is in line with sound ethical standards.
- The goal of this guidance document is to assist those working towards ending TB by proposing practical answers to key ethical questions and enabling patients, families, civil society, health workers and policy makers to move forward and address current challenges. The document includes special sections on key populations, such as children, migrants, and prisoners, as well as on digital health technologies, screening, surveillance and research.

World Health Organization

WHY ARE ETHICS IMPORTANT

- Ethics and human rights are at the heart of a humane, patient-centred approach to TB care.
- Addressing ethical issues is crucial for winning the trust and cooperation of patients and care providers - essential for a successful TB programme. For example, engaging, educating and supporting patients are ethical responsibilities of health care workers which are directly related with a positive treatment outcome.
- TB is a disease of poverty. A focus on social justice means caring for the most vulnerable and marginalized and addressing the social determinants which underlie the TB epidemic.
- Providing health care workers with adequate protections is a key factor in having a healthy and committed work force.
- Ensuring adequate treatment for migrants is grounded in the ethical duty to care for the most vulnerable, "leaving no one behind", and also in the interest of the populations of host countries.
- As we expect most prisoners to reintegrate back into the community –adequate care and treatment for them is an ethical obligation and a public health imperative.
- Access to diagnosis and treatment for children needs to be expanded to reach all in need.

- TB research has been grossly underfunded. The international community and donors have an ethical obligation to increase investments in this area, to help save lives.

For more information please access:
WHO's website on Global Health Ethics:
http://www.who.int/ethics/en/

WHO's website on Ethics and TB:
http://www.who.int/tb/areas-of-work/treatment/ethics/en/

ETHICAL ISSUES IN TUBERCULOSIS PREVENTION, TREATMENT & CARE

World Health Organization

Governments have an ethical responsibility to implement services based on the End TB Strategy

Governments have an ethical responsibility to ensure free and universal access to diagnosis, treatment and care of TB. They also have to ensure that health care workers operate in a safe environment; patients are enabled with proper support to fulfil their responsibilities. These obligations are grounded in their duty to fulfil the human right to health. Not only does TB treatment significantly improve the health condition of individuals, stopping the spread of the disease also benefits the broader community. Governments also have the same duty to provide access to MDR-TB care, even if many countries still have to scale up treatment. In the absence of appropriate drugs, testing still can provide benefits to patients and public health.

People need to be fully informed and counselled about their TB situation

Individuals have a right to bodily autonomy, therefore people undergoing TB testing and treatment should receive complete and accurate information about the risks, benefits and alternatives available to them; and access to all means which enable informed adherence to treatment.

Health care providers have an obligation to support patients to complete therapy and offer all possible treatment options

Any tool to ensure adherence to treatment, including directly-observed therapy, should be based on a patient-centred approach, so that values and needs of patient guide the care delivered, respecting autonomy and privacy. Compassionate use and expanded access programmes are ways of ensuring that patients have access to all possible resources in treating their TB.

Health care workers have obligations to provide care, but also a right to adequate protection

Health care workers have an ethical obligation to care for their patients, even if doing so involves some degree of risk. However, they should not be expected to assume risks that result from inadequate conditions to provide care. Governments and health-care institutions must provide the necessary goods and services to allow for a safe working environment. Also, health-care workers who are at heightened risk of contracting TB themselves, such as those who are HIV positive, may be exempted from their duty to care.

World Health Organization

MAJOR ETHICAL CONSIDERATIONS WHEN ENDING THE TB EPIDEMIC

Involuntary isolation should never be a routine component of TB programmes

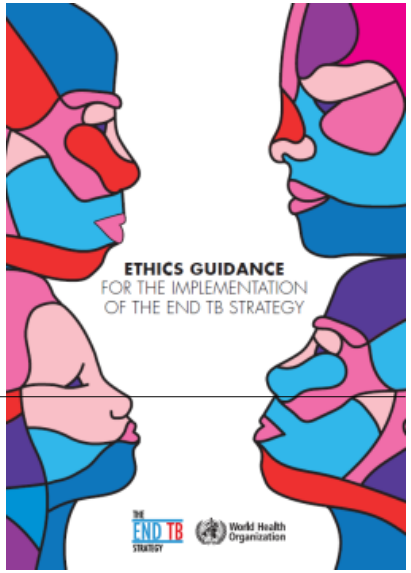
TB treatment should be provided on a voluntary basis, engaging the patient in the treatment process and respecting his/her autonomy. If a patient refuses treatment, this is likely to be due to insufficient counselling or lack of treatment support. In very rare cases, where all efforts to engage a patient to adhere treatment fail, the rights of other members of the community might justify efforts to isolate the contagious patient involuntarily. However, isolation should always be used as a very last resort and it should not include forced treatment if the patient refuses it.

Prioritizing of TB research to be conducted in an ethical manner

Continued development of an enhanced evidence base for TB diagnosis, prevention, treatment and care is urgent in order to continue improving the standards of TB care, including development of point of care tests, new drugs, and vaccines. It is imperative that research be guided by the principles articulated in the international guidelines for biomedical research involving human subjects, and that data is immediately shared without any delay for national and global policy making, so that affected populations benefit and lives are saved.

FREQUENT ETHICAL ISSUES IN TB CARE

- Should patients be diagnosed in the absence of adequate treatment?
- Should the status of people with TB be disclosed to third parties against their will?
- Do patients have the right to refuse treatment?
- Should treatment be delivered under direct-observation in the absence of a patient-centred approach?
- Is it ever legitimate to isolate contagious patients against their will?
- Should children be hospitalized just to deliver TB treatment?
- Should palliative care be offered to people with MDR-TB?
- Do health care workers have an obligation to care, even when it involves health risks?
- Should researchers retain data needed for public health policy until it is published in peer-reviewed journals?



REFERENCES

1. Uebel KE, Nash J, Avalos A. Caring for the caregivers: Models of HIV/AIDS care and treatment provision for health care workers in southern Africa. J Infect Dis n.d.:196 (SUPPL.
2. Jereb JA, Klevens RM, Privett TD, Smith PJ, Crawford JT, Sharp VL, et al. Tuberculosis in health care workers at a hospital with an outbreak of multidrug-resistant Mycobacterium tuberculosis. Arch Intern Med n.d.:155 (8) (pp 854-859), 1995.
3. Von Delft A, Dramowski A, Sifumba Z, Mosidi T, Ting TX, Von Delft D, et al. Exposed, but Not Protected: More Is Needed to Prevent Drug-Resistant Tuberculosis in Healthcare Workers and Students. Clin Infect Dis 2016;62:275–80. doi:10.1093/cid/ciw037.
4. Nathavitharana RR, Bond P, Dramowski A, Kotze K, Lederer P, Oxley I, et al. Agents of change: The role of health-care workers in the prevention of nosocomial and occupational tuberculosis. Presse Med 2017;46:e53–62. doi:10.1016/j.lpm.2017.01.014.
5. Tsofa B, Goodman C, Gilson L, Molyneux S. Devolution and its effects on health workforce and commodities management - early implementation experiences in Kilifi County, Kenya. Int J Equity Health 2017;16:169. doi:10.1186/s12939-017-0663-2.
6. Nyikuri M, Tsofa B, Barasa E, Okoth P, Molyneux S. Crises and Resilience at the Frontline-Public Health care institution Managers under Devolution in a Sub-County on the Kenyan Coast. PLoS One 2015;10:e0144768. doi:10.1371/journal.pone.0144768.
7. Honoré JG, Balan JG, Thimothé G, Diallo J, Barnhart S. Instability adversely affects HIV care in Haiti. Lancet 2017;388:1877. doi:10.1016/S0140-6736(16)31804-9.
8. Aberese-Ako M, van Dijk H, Gerrits T, Arhinful DK, Agyepong IA. "Your health our concern, our health whose concern?": perceptions of injustice in organizational relationships and processes and frontline health worker motivation in Ghana. Health Policy Plan 2014;29 Suppl 2:ii15-28. doi:10.1093/heapol/czu068.
9. Ramacciati N, Ceccagnoli A, Addey B, Lumini E, Rasero L. Violence towards emergency nurses: A narrative review of theories and frameworks. Int Emerg Nurs 2017. doi:10.1016/j.ienj.2017.08.004.
10. Hassankhani H, Parizad N, Gacki-Smith J, Rahmani A, Mohammadi E. The consequences of violence against nurses working in the emergency department: A qualitative study. Int Emerg Nurs 2017. doi:10.1016/j.ienj.2017.07.007.

11. Al-Shamlan NA, Jayaseeli N, Al-Shawi MM, Al-Joudi AS. Are nurses verbally abused? A cross-sectional study of nurses at a university hospital, Eastern Province, Saudi Arabia. J Family Community Med 2017;24:173–80. doi:10.4103/jfcm.JFCM_45_17.

12. Zhou C, Mou H, Xu W, Li Z, Liu X, Shi L, et al. Study on factors inducing workplace violence in Chinese hospitals based on the broken window theory: a cross-sectional study. BMJ Open 2017;7:e016290. doi:10.1136/bmjopen-2017-016290.

13. Cheung T, Lee PH, Yip PSF. Workplace Violence toward Physicians and Nurses: Prevalence and Correlates in Macau. Int J Environ Res Public Health 2017;14. doi:10.3390/ijerph14080879.

14. Li L, Lin C, Guan J, Wu Z. Implementing a stigma reduction intervention in healthcare settings 2013;16:1–8.

15. Rogers EM. Diffusion of Innovations. 4th ed. New York: Free Press; 1995.

16. Ashforth BE, Kreiner GE. 'How can you do it?': Dirty work and the challenge of constructing a positive identity. Acad Manag Rev 1999:413–434.

17. Pennebaker JW. Writing to heal: a guided journal for recovering from trauma and emotional upheavel. Oakland: New Harbinger Publications; 2004.

18. Smith RA, Smith RA. Segmenting an Audience into the Own , the Wise , and Normals : A Latent Class Analysis of Stigma-Related Categories Segmenting an Audience into the Own , the Wise , and Normals : A Latent Class Analysis of Stigma-Related Categories 2017. doi:10.1080/08824096.2012.704599.

19. Major B, Brien LTO. THE SOCIAL PSYCHOLOGYOF STIGMA. Annu Rev Psychol 2005:393–421. doi:10.1146/annurev.psych.56.091103.070137.

20. Link BG, Phelan JC. Conceptualizing Stigma. Annu Rev Sociol 2001;27:363–85.

21. Parker R, Aggeleton P. HIV / AIDS-related Stigma and Discrimination : A Conceptual Framework and an Agenda for Action. Soc Sci Med 2003;57:1–28.

22. Smith RA. Testing the Model of Stigma Communication with a Factorial Experiment in an Interpersonal Context Communication with a Factorial Experiment in an Interpersonal Context 2014. doi:10.1080/10510974.2013.851095.

23. Fairclough N. Critical discourse analysis: The critical study of language. 2nd edition ed. New York: Routledge; 2010.

24. Stop TB Partnership, UNOPS. The Paradigm Shift 2016-2020: Global plan to end TB. Geneva: 2015. doi:22 August 2016.

25. Lafrance A. The Danger of Ignoring Tuberculosis Despite its reputation as an illness of the past, the deadly disease is as much of a threat to people in America as Ebola and Zika. 2016. https://www.theatlantic.com/health/archive/2016/08/tuberculosis-doomsday-scenario/494108/ (accessed July 11, 2018).

26. Centers for Disease Control and Prevention. What You Need To Know About Tuberculosis Infection. 2015. doi:10.1097/01.NURSE.0000426621.59131.e5.

27. Getahun T, Yimer S. Actual practice of healthcare providers towards prevention and control of Multidrug-resistant tuberculosis (MDR-TB) at Borumeda Hospital, Ethiopia. African J Pharm Pharmacol 2017;11:152–60. doi:10.5897/AJPP2015.4402.

28. Pommier EA. The compassion scale. Diss Abstr Int Sect A Humanit Soc Sci 2010:262. doi:10.1037/t10177-000.

29. Neff K. The development and validation of a scale to measure self-compassion. Self Identity 2003;2:223–50. doi:10.1080/15298860390209035.

30. Corrigan PW, Powell KJ, Michaels PJ. Brief battery for measurement of stigmatizing versus affirming attitudes about mental illness. Psychiatry Res 2014;215:466–70. doi:10.1016/j.psychres.2013.12.006.

31. Wouters E, Rau A, Engelbrecht M, Uebel K, Siegel J, Masquillier C, et al. The Development and Piloting of Parallel Scales Measuring External and Internal HIV and Tuberculosis Stigma Among Healthcare Workers in the Free State Province, South Africa. Clin Infect Dis 2016;62:S244–54. doi:10.1093/cid/civ1185.

32. Wouters E, Masquillier C, Sommerland N, Engelbrecht M, Rensburg AJ Van, Kigozi G. Measuring HIV- and TB-related stigma among health care workers in South Africa : a validation and reliability study 2017;00:1–11.

33. Sommerland N, Wouters E, Masquillier C, Engelbrecht M, Rau A, Kigozi G, et al. Stigma as a barrier to the use of occupational health units for TB services in South Africa. Int J Tuberc Lung Dis 2017;Supplement.

34. Maslach C, Jackson S. The measurement of experienced Burnout. J Occup Behav 1981;2:99–113. doi:10.1002/job.4030020205.

35. Eisenberger R, Cummings J, Armeli S, Lynch P. Perceived Organizational Support , Discretionary Treatment , and Job Satisfaction 1997;82:812–20.

36. Barrows HS. An overview of the uses of standardized patients for teaching and evaluating clinical skills. AAMC. Acad Med 1993;68:443–51. doi:10.1097/00001888-199306000-00002.

37. Mitchell EMH, Pérez-then E, Orejel-juarez I, Baez J, Gonzáles F, Morrobel AL, et al. Effectiveness of Interventions to Increase Referral of Clients Exhibiting TB Symptoms by Pharmacies and Corner Stores in Santo Domingo , Dominican Republic. Open Infect Dis Journal, 2013:47–53.

38. Mesquita AR, Lyra DPJ, Brito GC, Balisa-Rocha BJ, Aguiar PM, de Almeida Neto AC. Developing communication skills in pharmacy: a systematic review of the use of simulated patient methods. Patient Educ Couns 2010;78:143–8. doi:10.1016/j.pec.2009.07.012.

39. Finlay, Alyssa; Lancaster, Joey; Holtz, Timothy H.; Weyer, Karin; Miranda, Abe; van der Walt M, Finlay A, Lancaster J, Holtz TH, Weyer K, Miranda A, et al. Patient- and provider-level risk factors associated with default from tuberculosis treatment, South Africa, 2002: a case-control study. BMC Public Health 2012;12:56. doi:10.1186/1471-2458-12-56.

40. Luck J, Glassman P, Dresselhaus TR, Lee M. Comparison of Vignettes , Standardized Patients , and Chart Abstraction 2000;283:1715–22.

41. Banerjee A, Sharma B V, Ray A, Kannuri NK, Venkateswarlu T V. Acceptability of traditional healers as directly observed treatment providers in tuberculosis control in a tribal area of Andhra Pradesh, India. Int J Tuberc Lung Dis 2004;8:1260–5.

42. Uwimana J, Jackson D. Integration of tuberculosis and prevention of mother-to-child transmission of HIV programmes in South Africa. Int J Tuberc Lung Dis 2013;17:1285–90. doi:10.5588/ijtld.12.0068.

43. Montagu D, Sudhinaraset M, Lwin T, Onozaki I, Win Z, Aung T. Equity and the Sun Quality Health Private Provider Social Franchise: comparative analysis of patient survey data and a nationally representative TB prevalence survey. Int J Equity Health 2013;12:5. doi:10.1186/1475-9276-12-5.

44. Kigozi NG, Heunis JC, Chikobvu P, van den Berg H, van Rensburg HCJ, Wouters E. Predictors of uptake of human immunodeficiency virus testing by tuberculosis patients in Free State Province, South Africa. Int J Tuberc Lung Dis 2010;14:399–405.

45. Rood E, Mergenthaler C, Bakker MI, Redwood L, Ellen MH. Using 15 DHS surveys to study epidemiologic correlates of TB courtesy stigma and health seeking behavior . 2017;21:1–19.

46. Sheferaw ED, Mengesha TZ, Wase SB. Development of a tool to measure women's perception of respectful maternity care in public health facilities. BMC Pregnancy Childbirth 2016;16:67. doi:10.1186/s12884-016-0848-5.

47. Buregyeya E, Kasasa S, Mitchell EMH. Tuberculosis infection control knowledge and attitudes among health workers in Uganda: a cross-sectional study n.d. doi:10.1186/s12879-016-1740-7.

48. Sagbakken M, Bjune GA, Frich JC. Experiences of being diagnosed with tuberculosis among immigrants in Norway - Factors associated with diagnostic delay: A qualitative study. Scand J Public Health 2010;38:283–90. doi:10.1177/1403494809357101.

49. Buregyeya E, Mitchell EMH, Criel B, Kiguli J, Nuwaha F. Acceptability of masking and patient separation to control nosocomial Tuberculosis in Uganda : a qualitative study 2012:599–606. doi:10.1007/s10389-012-0503-1.

50. Mask Culture in Japan. Nippon 2016.

51. Li TC. Mask appeal: The addiction of surgical masks in Japan. Straits Times n.d.

52. Egli J. How surgical masks became a fashion statement. Dazed 2015.

53. Buregyeya E, Nuwaha F, Verver S, Criel B, Colebunders R, Wanyenze R, et al. Implementation of tuberculosis infection control in health facilities in Mukono and Wakiso districts, Uganda. BMC Infect Dis 2013;13:360. doi:10.1186/1471-2334-13-360.

54. Buregyeya E, Kulane a, Colebunders R, Wajja a, Kiguli J, Mayanja H, et al. Tuberculosis knowledge, attitudes and health-seeking behaviour in rural Uganda. Int J Tuberc Lung Dis 2011;15:938–42. doi:10.5588/ijtld.10.0211.

55. Buregyeya E, Nuwaha F, Wanyenze RK, Mitchell EMH, Criel B, Verver S, et al. Utilization of HIV and Tuberculosis Services by Health Care Workers in Uganda: Implications for Occupational Health Policies and Implementation. PLoS One 2012;7:e46069. doi:10.1371/journal.pone.0046069.

56. Gaviria M, Henao H, Martínez T, Bernal E. Papel del personal de salud en el y Elisa Bernal Marta Beatriz Gaviria, diagnóstico tardío de la tuberculosis pulmonar en adultos de Medellín, Colombia. Rev Panam Salud Pública 2010;27:83–92. doi:10.1590/S1020-49892010000200001.

57. Angermeyer MC, Schulze B, Dietrich S. Courtesy stigma. Soc Psychiatry Psychiatr Epidemiol 2003;38:593–602. doi:10.1007/s00127-003-0680-x.

58. Ashforth BE, Kreiner GE. Dirty Work and Dirtier Work: Differences in Countering Physical, Social, and Moral Stigma. Manag Organ Rev 2014;10:81–108. doi:10.1111/more.12044.

59. Kreiner GE, Ashforth BE, Sluss DM. Identity Dynamics in Occupational Dirty Work: Integrating Social Identity and System Justification Perspectives. Organ Sci 2006;17:619–36. doi:10.1287/orsc.1060.0208.

60. Corrigan PW, Druss BG, Perlick DA. The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care. Psychol Sci Public Interes 2014;15:37–70. doi:10.1177/1529100614531398.

61. NASEM. Ending Discrimination Against People with Mental and Substance Use Disorders. Washington, D.C.: National Academies Press; 2016. doi:10.17226/23442.

62. Hatzenbuehler M, Link B. Introduction to the special issue on structural stigma and health. Soc Sci Med 2014;Feb:1–6.

WWW.KNCVTBC.ORG

@KNCVTBC