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Introduction

General Introduction Peer Group Stigma Reduction

How to use the peer learning intervention package

Creating Safe Spaces





General Introduction Peer Group Stigma Reduction

This Interactive Learning Module is designed in two parts. The first is an online e-learning module which can be completed independently.

The second is a peer-to-peer learning module where a peer group is formulated for the purpose of discussion and exercises. We recommend beginning with the self-learning module which covers the basics about stigma theory.





Goal

The goal of the Intervention Package is to allow participants to explore, question, clarify and affirm their values and beliefs about 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 treatment and care. Stigma related to Drug Resistant Tuberculosis (DRTB) will often be used as an example of an infectious disease, however, stigma is prevalent in many other areas of healthcare too, and therefore what you learn about stigma can be applied to many other contexts.



Objectives

After the completion of the Intervention Package, participants should be able to:

- Appreciate their own value in the provision of healthcare
- Define and identify stigma related to infectious disease, mental health, and lifestyle choices.
- 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

This intervention package is for people who are training as healthcare professionals as well as a variety of stakeholders in public health, such as civil society organizations, policymakers, healthcare workers, managers, advocates and community members.



Participants

The intervention is appropriate for all levels and types of people who work (or study) within the health provision sector. The interactive learning module is structured in a way where a small group of peers meet on a regular basis to discuss and/or work through the exercises together. Peer discussion facilitates the application of new competencies; therefore, a team approach should be taken, and participants should support one another throughout the course.



Principles of Learning

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This Interactive Learning Module is based on adult learning principles, including individual and group work (peer discussion), hypothetical and real dilemmas, stories, case studies, and simulations (i.e., drama or role plays and visualizations). The peers will be co-facilitators in the group work, and it is important to create a safe, non-threatening space where feelings and fears can be discussed and explored openly. The tools for creating a safe space with peers will be discussed in further detail below.

You will learn through doing and by reflecting, including sharing experiences, feelings, and concerns, discussing issues, and solving problems. A participatory learning process accommodates the process of changing attitudes towards people that may be more susceptible to stigmatization. The complete Interactive Learning Module includes exercises from the below five modules, with clear instructions for preparation, individual and group work:



1. VALUES: a module on the importance, ideals, and ethos of healthcare workers.



2. HEART: a module to explore selfcompassion 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.



From each of the five modules there are recommended activities as well as additional optional activities. As a peer group you can decide which optional activities you would like to complete, based on your priorities and objectives as a group, as well as what is contextually relevant to your situation.

	Module	Recommended	Time Investment	Optional	Time Investment
	Introduction	How to use the Allies Approach peer learning intervention package	20 Minutes		
		Creating a safe space to learn, grow and change	50 Minutes		
\$ 1 m	1. Values	Keeping a journal	15-20 minutes per day, approx. 3 times per week	Is every thought you have true?	75 minutes
		River of life	60-90 Minutes	Comfort continuum	60 minutes
		Universality of Self- Stigma and Shame	90 minutes		
\square	2. Heart	My imperfection, Your imperfection	90 minutes	Our Vulnerability, Their Vulnerability	90 minutes
		Our secrets, our shame	60 minutes		
(1)	3. Head	Introduction to Stigma Theory	70 minutes	Choices – The last diagnostic test (GeneXpert Cartridge)	60 minutes
		The underlying structures of stigma	90 minutes	Four corners	60 minutes
	4. Face	Labelling	60 minutes	Safe space, safe boundaries	90 minutes
	5. Hands	Framing infectious disease	90 minutes	Creating respect and dignity messages at healthcare institutions	120 minutes
				Countering: Dealing with difficult situations	60 minutes
				Upholding the right to privacy	90 minutes





How to use the Allies Approach peer learning intervention package

The Allies Approach Intervention Package is designed for a participatory, self-organized, peer-to-peer 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 people we provide care to in the healthcare profession is successfully achieved through a participatory learning process.



For this stigma reduction course formulate a group of peers of maximum 6 people. The peer groups are self-organized, implying that you can approach people from your study institution or organization to participate in the learning group.

It is important to ensure that participants are from a similar context, in other words, a group of people still completing their studies, or a group of people working in healthcare provision, or a group of colleagues from the same organization. The purpose of this is to ensure that peers can participate equally, without feeling that some members have far more (or far less) experience than others. It also enables participants to engage in a way that is most relevant to their own context.

To ensure sufficient time for each member to participate without feeling rushed, we suggest limiting the number of people to a maximum of 6 participants.

This course could also be completed individually, as a more reflective module, rather than with peer interaction. However, this will not provide the opportunity for feedback, other perspectives, or emotional support. Therefore, we suggest formulating groups.

2. Decide on the meeting frequency, length, and location

Before beginning the course, decide as a group on the frequency of meeting, and the length of time the meeting will last. For example, a meeting once every two weeks, for 2 hours each time.

Participants can plan their individual preparatory exercises accordingly and dedicate sufficient time and energy to get full value from the course.

The meeting location is also important to agree to beforehand. For example, you could decide to meet in person each time at the study institution, workplace, or at someone's home. However, it is important to ensure that the location allows for sufficient privacy during the meetings so that all participants feel the freedom to share their thoughts and feelings openly.

3. Creating a safe space to learn, grow and change

To get full value from a peer-group, self-directed course such as this one, that could also be an emotive topic, it is imperative to discuss and agree on the creation of a safe space for all participants.

This is discussed in further detail in the next chapter.





Creating Safe Spaces



Time Investment: 50 Minutes

Creating a safe space to learn, grow and change:

To get full value from a peer-group, self-directed course such as this one, that could also be an emotive topic, it is imperative to discuss and agree on the creation of a safe space for all participants.

Creating a safe space

For a safe space to exists, it is imperative to ensure that the environment provides all participants with the opportunity to be open, to facilitate learning and growing together. This means all people need to feel that their sharing and the conversations will be kept within the group confines, and remain as confidential information, and will not be shared with others outside the group setting.

A safe space also implies that those who are listening need to feel respected. Any person that shares their experiences, thoughts or feelings need to be aware that these could have (unintended) impact on those who are listening. And therefore, people within the group can also reflect on feelings they may have had when listening to the speaker. Therefore, everyone within the group should have the opportunity to challenge things but ensuring that this is done in a respectful manner.

All group members should feel that their thoughts and feelings matter to the others in the group. For this reason, it is vital to practice active listening when a person speaks.

Active listening

Active listening is a practice of listening with the aim of fully understanding. This implies listening exclusively to what another is saying by focusing on the words they are speaking, their body posture and facial expressions, and other non-verbal cues they may be using.



Active listening can be pursued by applying several basic principles:

> Listening without interrupting:

Although you may have thoughts and emotions that rise within you when listening to someone else speak, it is imperative not to interject with these prematurely, but rather to allow the other to complete their thinking process without the threat of someone adding their own points of view or steering the conversation in a different direction. The goal is to listen to the extent that the other person has fully completed their thinking process and feels fully heard by all the team members. Following this, you could add your own thoughts or reflections.

> Set aside your own thoughts and perspectives (positive and negative) while listening:

Often when we listen to other people speaking, many thoughts and reflections come to mind – for example, whether we agree or disagree with them; reflections on our own experiences with what they may be sharing; or filling in their sentences in our own mind, etc. Although this is a natural part of how the human mind operates, it is important to quiet our wondering thoughts, as this gets in the way of fully listening to another person.

> Pay attention to the speaker's non-verbal cues:

Communication does not only involve the words that are spoken. Communication is also done in more subtle ways, such as through facial expressions; hand gestures; body posture; the speed of speaking; eye contact; etc. Paying close attention to non-verbal cues will provide more context to what someone is saying and how they are feeling. It could also influence how you respond and what type of questions to ask.

For example, if they are speaking faster than usual when sharing an experience where they were in danger, they could partially be reliving this experience and feeling an elevation in stress levels. It is important to take note of this and respond accordingly. For example, to simply brush off what they shared by saying: "that must have been scary, and it reminds me of when I was chased by a lion" would not be appropriate as the speaker may feel that what they shared is less important than your experience. A more appropriate response could be: "I am noticing that you are out of breath while you share this experience. What are you feeling now as you tell us about this experience?"

> Positive nonverbal cues while you listen:

For a person to feel that what they are saying is important, and that you are fully listening to and engaged with what they are saying, nonverbal cues are vital. These include keeping eye contact; keeping an open body posture; smiling gently or nodding; not picking up a phone to read a message, etc. Many of these prompts will be



encouraging to the speaker to continue sharing their thoughts and experiences, and they will feel that their thoughts are important to the group.

> Ask open ended questions to clarify your understanding:

Open ended questions are about asking questions that can stimulate more thought or give more detail and background to what the speaker is saying. Open-ended questions also allow for clarification, or for better understanding from the listeners perspective. They usually include the words how, why, what or who.

An example of an open-ended question could be "What made you feel scared in that situation", or "How could you have responded in a way that limited the risk of stigmatizing another".

It is important to formulate your questions in a way that does not seem like you have reached a conclusion or limits the person in their response. For example, if you asked a peer the question "don't you agree with me that the patient was behaving irresponsibly when they coughed near you", you limit their ability to elaborate on their experience as this is a closed (yes-no) question, and the way the question is phrased may make your peer feel that they should answer in a way that they should agree with you. A better way to frame this question could be: "how did you feel when the person was coughing near you?"

Agree on group norms and values before beginning the course (20 minutes)

For a group to function optimally, and for all members to get full value, it is a good idea to agree on and write down several ground rules before beginning the course.

These ground rules should always be honored, by all group members. If at any point the group is in a position of disagreement, or conversations get heated, you can refer to these as a framework to navigate your way through the difficulty.

There is no limit to how the ground rules are structured, and what is included, but it is important to ensure that all members discuss and agree to the rules. A few examples of ground rules that could be included are:

- Don't interrupt when another is speaking
- Listen without judgement
- Give quieter members of the group a chance to speak up too
- Be mindful of the time available to give all members the opportunity to share their thoughts
- What is shared in the group stays in the group
- Be respectful, even when you disagree



- Be true to yourself
- Start on time, end on time
- Be open to different perspectives
- Practice curiosity
- Expect to learn new (and sometimes difficult) things, from yourself and from others

Identify a back-up support structure (20 minutes)

As was stated earlier, at times discussing and working through a module with a topic such as stigma can be emotive. It can also uncover things that we have hidden from ourselves and from others for a long time. Frequently we manage to work through difficulties and bring closure to things by ourselves, and with support from friends and family. However, there are certain topics we may find particularly difficult to discuss, or we are struggling to bring closure to. Maybe you get overwhelmed by a flood of emotions every time the topic comes up in you, or maybe you are confronted with intense flashbacks or nightmares from a particular event.

There are certain situations where we are not fully able to bring closure to an experience, and a module such as this one can uncover to the extent that you need support from a mental health professional to help you navigate this.

Therefore, before beginning this module, it is imperative to identify a support structure that you could fall back on in a situation such as this. Consider a counsellor at your tertiary education institution, or a community counsellor at a community center. It is important that everyone within the group knows who this is and how to contact them, without needing to divulge details to the group if they are not ready to do so.



Resources

Talking Points: The Resource Guide for Facilitating Stigma Conversations. https://nastad.org/stigma-toolkit/stigma-conversations/safe-spaces-and-difficult-conversations

Amplifier Giving: Group Dynamics, Safe Spaces, and Facilitation. https://www.amplifiergiving.org/resources/group-dynamics/

Adapted from:

NASTAD: Talking Points: The Resource Guide for Facilitating Stigma Conversations. https://nastad.org/stigma-toolkit/stigma-conversations/safe-spaces-and-difficult-conversations

Amplifier Giving: Group Dynamics, Safe Spaces, and Facilitation. https://www.amplifiergiving.org/resources/group-dynamics/





Values

Keeping a journal

River of Life

Universality of Self-Stigma and Shame

Is every thought you have true

Comfort continuum

Keeping a Journal as a Healthcare Professional



Time investment: 15-20 minutes per day approx. three times per week

Introduction

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 ⁱ. Often thoughts, emotions and feelings lay dormant within us, and emerge as reactions to situations, without a clear link to the emotions or feelings that trigger this. By keeping a daily journal, you will be able to bring to light and give words to the thoughts, feelings, and emotions you may have in life in general and in your journey as a healthcare professional specifically.

Since thoughts come and go at a rapid pace, taking some time to write down our thoughts and feelings allows us to slow down our thinking, and identify specific topics or themes that we need to explore further.



Objective

Journaling will help you to reflect on your daily situation and explore solutions to challenges in a personal and safe space. Keeping a journal helps develop self- reflection skills. These are critical for developing an awareness of the autopilot within us when dealing with situations, and for changing attitudes and behavior. You will be able to put stressful events in perspective and build resilience when dealing with them in the future.



Materials and preparations

You will need a blank activity journal, either with lined pages or blank pages, depending on what you prefer. You will also need a pen or pencil, and/or colored pencils, markers, crayons, etc. if you would also like to draw in your journal. Read through the article "Why you should write a letter to yourself" written by Bessel van der Kolk on page 18.







Exercise and instructions

(15-20 minutes each day approx. three times per week):

The framework for documenting your journey as a healthcare professional in your journal:

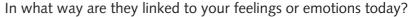
- 1. Set time aside time to write or draw in your journal each day. Make sure that you are somewhere where you can think and write properly without interruptions. Use drawings to illustrate your emotions and experiences if you prefer.
- 2. When working through the stigma reduction course with your peers you can make notes in your journal after each activity, documenting any thoughts, feelings or realizations that stood out to you while participating in these activities.
- 3. You do not have to write everything all at once. You can add or make changes as they occur to you.
- 4. Write only for yourself. Be honest with yourself. You are the only person who will read this journal, and it will be more useful to record things accurately.
- 5. Do not over-think. Write what you are thinking and feeling as it comes to mind without judgement about them.
- 6. It is advised for you to journal at least three times a week for a month or more, as this provides a good length of time to track changes and return to challenges that are not fully resolved within yourself.
- 7. Try to write in the journal for 15-20 minutes each day at least three times per week.



Topics of Reflection for Journaling:

The exercise provides questions for assessing your own assumptions and negative/positive frames and for developing stigma analysis skills. Below are questions you can ask yourself while writing in your journal. You do not need to answer all questions but notice those that stand out to you and write about them as the thoughts and emotions appear. The questions are meant to serve as a guide to your journaling process.

- 1. How are you feeling today? Can you identify triggers that have made you feel this way? If so, include them in your writing.
- 2. What is on your mind today? Are there thoughts that keep reappearing?



- 3. What are you grateful for or proud of today? These do not need to be big or important events, but can also be small, personal successes.
 - What have you noticed about yourself while reflecting on what you were grateful and proud of? What are your values that are linked to these? How could you keep practicing these values?
- 4. What happened today that you feel could have been done differently? These could include actions by someone else, or actions by you. How did these actions affect you and/or someone else?
 - How could this situation be handled differently in future by yourself and by other people present in the situation?
 - What have you noticed about yourself while reflecting on actions taken by yourself
 or someone else that could have been done differently? What are your values that
 are linked to these? And how could these values be fulfilled better in the future?
- 5. Is there anything else on your mind that you would like to document in your journal. How are these linked to your feelings, emotions, values, and experiences? Can you use lessons learnt from this in the future?

Resources: Bessel van der Kolk on journaling: Why you should write a letter to yourself (Accessed from: Why You Should Write a Letter to Yourself Tonight (thecut.com))
W. Writing to heal: a guided journal for recovering from trauma and emotional land: New Harbinger Publications; 2004





Why You Should Write a Letter to Yourself Tonight

By Bessel van der Kolk

Most of us have poured out our hearts in angry, accusatory, plaintive, or sad letters after people have betrayed or abandoned us. Doing so almost always makes us feel better, even if we never send them.

When you write to yourself, you don't have to worry about other people's judgment — you just listen to your own thoughts and let their flow take over. Later, when you reread what you wrote, you often discover surprising truths.

As functioning members of society, we're supposed to be "cool" in our day-to-day interactions and subordinate our feelings to the task at hand. When we talk with someone with whom we don't feel completely safe, our social editor jumps in on full alert and our guard is up. Writing is different. If you ask your editor to leave you alone for a while, things will come out that you had no idea were there. You are free to go into a sort of a trance state in which your pen (or keyboard) seems to channel whatever bubbles up from inside. You can connect those self-observing and narrative parts of your brain without worrying about the reception you'll get.

In the practice called free writing, you can use any object as your own personal Rorschach test for entering a stream of associations. Simply write the first thing that comes to your mind as you look at the object in front of you and then keep going without stopping, rereading, or crossing out. A wooden spoon

on the counter may trigger memories of making tomato sauce with your grandmother — or of being beaten as a child. The teapot that's been passed down for generations may take you meandering to the furthest reaches of your mind to the loved ones you've lost or family holidays that were a mix of love and conflict. Soon an image will emerge, then a memory, and then a paragraph to record it. Whatever shows up on the paper will be a manifestation of associations that are uniquely yours. As far as I'm aware, the first systematic test of the power of language to relieve trauma was done in 1986, when James Pennebaker at the University of Texas in Austin turned his introductory psychology class into an experimental laboratory. Pennebaker started off with a healthy respect for the importance of inhibition, of keeping things to yourself, which he viewed as the glue of civilization. But he also assumed that people pay a price for trying to suppress being aware of the elephant in the room.

He began by asking each student to identify a deeply personal experience that they'd found very stressful or traumatic. He then divided the class into three groups: One would write about what was currently going on in their lives; the second would write about the details of the traumatic or stressful event; and the third would recount the facts of the experience, their feelings and emotions about it, and what impact they thought this event had had on their lives. All of the students wrote continuously for 15 minutes on four

consecutive days while sitting alone in a small cubicle in the psychology building.

The students took the study very seriously; many revealed secrets that they had never told anyone. They often cried as they wrote, and many confided in the course assistants that they'd become preoccupied with these experiences. Of the 200 participants, 65 wrote about a childhood trauma. Although the death of a family member was the most frequent topic, 22 percent of the women and 10 percent of the men reported sexual trauma prior to the age of 17.

The researchers asked the students about their health and were surprised how often the students spontaneously reported histories of major and minor health problems: cancer, high blood pressure, ulcers, flu, headaches, and earaches. Those who reported a traumatic sexual experience in childhood had been hospitalized an average of 1.7 days in the previous year — almost twice the rate of the others.

The team then compared the number of visits to the student health center participants had made during the month prior to the study to the number in the month following it. The group that had written about both the facts and the emotions related to their trauma clearly benefited the most: They had a 50 percent drop in doctor visits compared with the other two groups. Writing about their deepest thoughts and feelings about traumas had improved their mood and resulted in a more optimistic attitude and better physical health.

When the students themselves were asked to assess the study, they focused on how it had increased their self-understanding: "It helped me think about what I felt during those times. I never realized how it affected me before." "I had to think and resolve past experiences. One result of the experiment was peace of mind.

To have to write about emotions and feelings helped me understand how I felt and why." It is now widely accepted that stressful experiences — whether divorce or final exams or loneliness—have a negative effect on immune function, but this was a highly controversial notion at the time of Pennebaker's study. Building on his protocols, a team of researchers at the Ohio State University College of Medicine compared two groups of students who wrote either about a personal trauma or about a superficial topic. Again, those who wrote about personal traumas had fewer visits to the student health center, and their improved health correlated with improved immune function, as measured by the action of T lymphocytes (natural killer cells) and other immune markers in the blood. This effect was most obvious directly after the experiment, but it could still be detected six weeks later. Numerous experiments have since replicated Pennebaker's findings. Writing experiments from around the world, with grade-school students, nursing-home residents, medical students, maximum-security prisoners, arthritis sufferers, new mothers, and rape victims, consistently show that writing about upsetting events improves physical and mental health. This shouldn't surprise us: Writing is one of the most effective ways to access an inner world of feelings that is the key to recovering from genuine trauma and everyday stress alike.

From The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma by Bessel van der Kolk, MD. Reprinted by arrangement with Viking, a member of Penguin Group (USA) LLC, A Penguin Random House Company. Copyright © Bessel van der Kolk MD, 2014.*

*as accessed on https://www.thecut.com/2014/10/why-you-should-write-yourself-a-letter-tonight.html. 13 December 2022





Valuing Ourselves and Our Work – "River of Life"



Time Investment: 60 - 90 Minutes

Introduction

Many people enter health care professions to be able to help others in their communities. What is your motivation to become a healthcare professional? What are your ideals and intentions? This exercise will provide you with the opportunity to reflect on these questions and discuss with your peers.

Objective



The exercise will help you to reflect on your own motivation to become a healthcare professional and know the motivation of others, as well as to provide a foundation for your commitment to healthcare when you work through topics related to stigma.

Materials

For this exercise you will need a flipchart or big sized paper and some colored pens and markers. We advise you to do this exercise on paper and not to do this on your computer.

Your journal from activity 1.



Individual Activity (30 Minutes)

Close your eyes, relax and think about a river. The water in it flows slower and sometimes faster. There may also be obstacles that change the flow of the river. You can see the river as a symbol of life.

Open your eyes and make a drawing of a river and imagine it is your life. What are important events in your life that influenced your choice to become a health care professional? Why did you become a health care professional? What were the opportunities, roadblocks, unexpected things/experiences that moved you toward this direction? What are your expectations and wishes? Feel free to add some words and quotes to your drawing. Take your drawing with you when you meet with your peer group. You can write some notes about this exercise in your journal.



Peer Group Discussion (30 - 60 minutes)

- Place all the drawings next to one another and take a moment to look at each person's drawing
- Give each participant the opportunity to tell the story of their 'river of life', followed by questions that group members may have about each 'river of life'.
- What do they have in common and what are differences?
- Spend some time evaluating the exercise by discussing
- What it was like for you to reflect on what life circumstances led you to the healthcare profession.
- What it was like for you to make this painting/drawing?
- What it was like for you to tell your story to the peer group?
- What it was like for you to hear others' stories?
- What surprised you?
- What insights have you gained about the group and about yourself?





Universality of Self-Stigma and Shame



Time Investment: 90 Minutes

Introduction

Self-stigma and shame are experienced by all people and have an impact on how we view ourselves and on how we behave. By recognizing that we have stigmatizing or shaming thoughts about ourselves we can intercept them and identify the root of these thoughts, with the aim of reducing their impact on our lives and our behaviour.

Self-stigma is the result of complex interactions between social, contextual, and self-factors. Edwin Cameron (2012) defined internalized stigma (or self-stigma) as the "self-disabling inner feelings of contamination, self-rejection, and self- loathing... even when there is no objective reason to fear rejection..., and even when there is good objective reason to believe that they will receive external support, protection, treatment, and acceptance."



Objective

To identify the feeling of self-stigma and shame within ourselves, and to recognize that it is universal to all people.

To understand how it affects people's feelings, perceptions of themselves, motives, and actions.



Preparation (15 minutes)

In preparation watch the following two TED talks:

Edwin Cameron: Dealing with Internalised Stigma | TEDxEuston:

https://youtu.be/6YOkIGYktlU

Brene Brown: The need to talk about shame:

https://youtu.be/5C6UELitWkw





Materials

During your peer group discussion have two blank sheets of paper labelled: "Feelings of self-stigma and shame" and "Effects of self-stigma and shame" and a marker available.

Use your journal (from exercise 1) for the self-reflection exercise.



Instructions:

Self-reflection (15 minutes)

- Close your eyes and spend a few moments focusing on what you feel
 the breath entering and leaving your body; the feeling of the chair beneath you; the sounds around you.
- Picture a situation where you had the thought: 'I am not good enough'.

When you picture this situation, be as specific as you can – where were you; who were you with; what time of day was it; did something happen before this situation that contributed to the thought?

- Notice thoughts that come up about:
- How this felt
- How it limited you or made you feel inferior
- How this separated you from people around you
- Comparisons you were making about yourself in relation to other people
- In your journal you can write down any thoughts, feelings or reflections that come up from this self-reflection exercise.



Peer group discussion (60 minutes)

Gather in your peer group where you will each have the opportunity to share these experiences:

- Spend a few minutes to share the situation you pictured in the selfreflection activity and express how it made you feel; impacted your actions or consequences you experienced.
- On the page labelled: "Feelings of self-stigma and shame" write down the feelings or emotions attached to situations where you do not feel good enough (for example, fear of rejection, judgement). Let each person in the group have the opportunity to add their own feelings to the list.



- On the page labelled: "Effects of self-stigma and shame", write down the effects that thoughts of not feeling good enough have had on you in the past, or could have on you in the future (for example, things you cannot do or won't do when you believe you are not good enough). Let each person in the group have the opportunity to add their own effects to the list.

As a group spend some time looking at the two pages side by side. Notice similarities and differences in the experiences, emotions, and effects that other group members shared.

Spend time discussing:

- What it was like for you to share your own and hear other people's moments of self-stigma.
- Reflections on the similarities and differences you see between yourself and other members in the group about self-stigma and shame.
- Reflections on how stigma and shame influence us daily.
- Identify social, contextual, and self-factors that influence the level of self-stigma we experience and discuss where you see the effects of these within your own life.
- How we can intercept thoughts of shame and stigma and how we can reduce their impact on our lives.



Resources:

Brene Brown: I Thought it Was Just Me reading guide:

https://brenebrown.com/resources/itiwjm-making-the-journey-from-what-will-people-think-to-i-am-enough/

How we internalise stigma and shame by Edwin Cameron:

https://www.groundup.org.za/article/how-we-internalise-stigma-and-shame/

Stigma Topics: Internalized Stigma | NASTAD

NASTAD Stigma Series: Internalized Stigma: https://youtu.be/W3YSVrIU 64

Adapted from:

From the Inside Out: Universality, Self-Stigma and, Shame:

https://www.kncvtbc.org/uploaded/2018/10/From-the-Inside-out-stigma-compressed.pdf





Is every thought you have true?



Time Investment: 75 Minutes

Introduction

This exercise will help people understand the powerful effect believing negative thoughts and judgements have on their lives. We all have many negative self-judgements and judgements about other people. We must see the power our thinking has on our lives first and then take steps to break these patterns.

Often, we believe the thoughts we have, and we integrate them fully into ourselves, rather than noticing the thoughts without allowing them to impact us negatively.

"A stressful thought is one perspective of reality - and when it's believed it prevents us from seeing the whole picture. Negative thoughts limit our ability to work with what's happening from an empowered state and hold us back from experiencing openness, creativity, and joy - even in the midst of very challenging circumstances." – Beyond Stigma.

Objective



To understand and to be mindful about the impact beliefs have on our lives.



Preparation

2 x printouts of the belief tree.





Instructions:

Self-reflection (15 minutes)

Spend some time thinking about your current or future work in healthcare – bring to mind some of the views you or society has about working with people who are ill. Get specific about various disease types - how do you feel about providing healthcare to people who have TB, HIV/AIDS, diabetes, high cholesterol levels, asthma, COVID-19, etc. How does society respond to people that provide healthcare to the different disease types?

Now spend some time bringing to mind what it will mean for you to work in healthcare – what are some of the fears or stressors you have when you imagine yourself providing healthcare to them. Visualize yourself in these situations and notice the emotions that arise within you.

Group work (60 minutes)

- 1. Once you have your list, highlight the two items that you believe will cause you the most stress, and spend some time sharing this with your peer group.
- 2. As a group select two items that you commonly agree which you anticipate will cause the most stress in your journey as healthcare providers. On the stem of the 'belief tree' write down one of these. For example, a stress could be: "I will infect my family".
- 3. Now as a group name the causes of this belief (including personal and societal causes). For example, fear of rejection by your family; misinformation in society, etc. Write each of the causes on the root of the tree.
- 4. As a group name the consequences of believing this thought and write each of these on a branch of the belief tree. For example, a consequence could be limited interpersonal interactions, shame, etc.
- 5. Now look at the stressor you wrote down at the center of the tree again. Imagine what you would feel like without believing this thought. Who would you be without this belief?

Maybe you would feel confident when interreacting with acquaintances? Maybe you would become more solution oriented? For example, you notice the thought "I will infect my family", but instead of



fear, shame, etc. dictating how you behave, you would have brain space for a more productive way of being. You could realize that you run the risk of becoming infected when you treat people withTB, but you could then explore solutions where your risk is reduced, for example, keeping a good airflow though the healthcare facility by opening windows.

Write down the effects of not believing your negative thoughts as rays from the sun shining down on the tree – solution oriented; peaceful; confident; hopeful; etc.

- 6. Try to think of examples and share them with the group where what you believe was not true. For example: "I did not infect my family", when I cared for my grandmother who had TB.
- 7. You can repeat the activity from step 2 about a second element you believe you will cause you stress and create a second belief tree.

Group reflection

- Are there instances in your own life where you realized that a belief you held was not true?
- How have certain beliefs impacted the way you behave towards yourself and other people?
- What are some beliefs you hold currently about your future as a healthcare professional that you would like to investigate further/change?
- What have you learnt about yourself from this activity that you would like to share with the group?



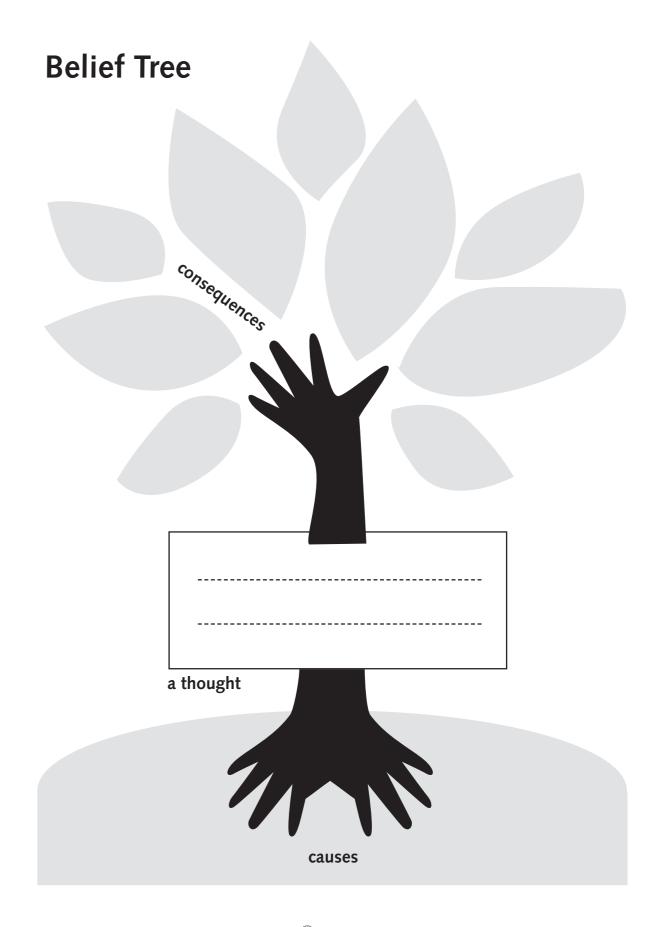
Resources:

https://thework.com/wp-content/uploads/2019/02/English LB.pdf https://www.beyondstigma.org/ibsr-the-work https://thework.com/instruction-the-work-byron-katie/

Adapted from:

From the Inside Out: Universality, Self-Stigma and, Shame: https://www.kncvtbc.org/uploaded/2018/10/From-the-Inside-out-stigma-compressed.pdf







Comfort continuum



Time Investment: 60 Minutes

Introduction

Every person has different levels of personal comfort. Your personality, life experiences, and different contexts influence this. This exercise will help you to reflect on how comfortable you are with certain situations and to reflect on this with your peers.



Objective

Reflect how varying personal comfort levels and life experiences impact the treatment and care you will provide as health care professional.



Preparation

This exercise does not require special preparations. You can print the statements and your answers or copy them in a notebook for discussion with your peers later.



Individual Exercise (10 minutes)

Mark which statement applies to you by rating it: "a little", "a lot" or "not at all"."

You may want to write reflections about this exercise in your journal. Take your answers with you when you have a discussion with your peer group.



Statement	A little	A lot	Not at all	Reflection / Notes
How comfortable are you to work in infectious disease service provision?				
How much disapproval would you expect to feel from your family and friends if you told them that you provide services to people with infectious diseases?				
How supportive do you expect your family or friends to be if you were diagnosed with an infectious disease?				
How much would you expect your relationship with your family or friends to change if you infected them with an infectious disease?				
How much does your comfort level change if you wear an N95 mask when you provide treatment to a person with an infectious disease?				
To what extent do you think stigma, fear, or distrust of patients influences your actions towards them?				
How scared are you of contracting an infectious disease?				
How scared are you of infecting family members with a disease you picked up during your work?				
How scared are you of dying from an infectious disease?				
			: : : : :	





Peer Group Discussion (50 minutes)

- Share your responses with your peers and give your peers the opportunity to ask open ended questions related to your responses.
- What are the differences between people's responses? What could reasons be for these differences?
- What can you say in general about the group's overall level of comfort?
- What did you learn about your own comfort level?
- What surprised you in the responses of others?
- How do you think your support network (family; friends) influences your comfort level?
- What could you do to increase your level of comfort when you provide care to a person with an infectious disease?
- What might decrease your level of comfort when you provide care to a person with an infectious disease?



Heart

My imperfection your imperfection

Our vulnerability their vulnerability

Our secrets our shame





My imperfection, Your imperfection



Time Investment: 90 Minutes

Introduction

We all do things that we know we should not do, even though we know the consequences. All the exercises in the module "Heart" are about exploring self-compassion and compassion for persons with an illness. This exercise is a self-reflection on your own behavior and has a component to discuss with your peers.



Objective

- 1. To reflect on the fact that no human being is perfect and that we may judge negatively on behaviors, identities, habits, histories, or diagnosis of our patients.
- 2. To practice observation without evaluation, judgement, and labeling.



Preparations

A pen and four squares of paper per person with enough space to write one or two sentences on.



Self-reflection (10 minutes)

- Reflect on things you do (or have done in the past) that you know are not good for you, e.g., eating unhealthy food, not doing enough exercise, having unprotected sex, smoking, etc.
- Select two of these behaviors and write one down per piece of paper (don't write your name on the papers)
- Now think about two people you have judged negatively. Write down your judgmental thought (one per paper), even if you have kept these thoughts to yourself and later regretted thinking such things (do not put your name on the paper).





Peer Group Activity (20 minutes)

- All papers should be folded and put into a box.
- Each person should pick out two folded papers and read to the group what is written on the paper they selected (it can be a behavior or a judgmental thought).
- If you read a behavior, identify what a reason for such a behavior could be.
- If you read a judgmental thought, try to make a distinction between a judgement on the behavior, and the behavior itself. Identify why you might judge the behavior.

Peer Group Discussion (60 minutes)

Discuss the following questions:

- Why do people choose unhealthy behaviours?
- Why do we judge ourselves and other people's unhealthy behaviours?
- How can we feel our feelings without letting our judgements harm others?
- How do we learn to note behaviours 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?
- Do you notice similarities in the judgements you place on yourself, and the way you judge other people, and if so, what similarities do you notice?
- What did you learn from doing this exercise?



Closing remarks after the discussion

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 professionals 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.



Vulnerability, Their Vulnerability



Time Investment: 90 Minutes

Introduction

People are all different, and yet we share many commonalities, including the feeling of vulnerability at certain moments in our life. In moments when we need to ask for help, or to rely on someone else to meet our needs, the feeling of vulnerability may emerge.

The reasons for this depend on the person, and the situation. They could include not feeling 100% in control of our lives; or showing 'gaps' to the outside world about our internal functioning. Maybe it reveals a secret that we have been keeping from the outside world, or it makes us feel weak or inferior to the person we are seeking out for help.

In the healthcare profession you will encounter many people who need help but may be experiencing feelings of vulnerability or shame when seeking care. Recognizing these feelings in ourselves, and other people, is vital in providing compassionate care.



Objective

To appreciate how self-stigma and shame operates in the context of a power differential, and that there is the potential for shameful feelings when we are vulnerable.

To develop empathy for people that are affected by TB or other illnesses.



Materials and resources

Your journal from exercise 1





Activity

Self-reflection (20 minutes)

Think of a time where you had a problem or needed help, but where you found it particularly hard to ask for help. Specifically reflect on moments where you may have needed to ask for help from someone that was not a friend or family member (for example, an employer, a teacher, someone with a specialized skill).

Reflect on the following:

- Why was it hard to ask for help / why were you hesitant to ask for help?
- Did you experience the feeling of shame / vulnerability etc.? And if yes, what caused these feelings?
- How did it feel in the moment that you asked for help?
- How did the person respond to your request? What was helpful, and not helpful in their response?
- Has the experience you have been reflecting on impacted the way you ask for help in the future, and if yes, how?

You can make use of the journal you began with in the first exercise to make any notes that come to mind during the reflection exercise. You can include writing down sensations and feelings that rise-up within you as you remember and reflect.



Group work (70 minutes)

As a group give the chance to each person to share their memory and reflections – allow them the opportunity to complete their story without interrupting with questions / your own reflections.

Based on this, as a group spend some time discussing common themes from each of the group members stories:

- What makes people feel vulnerable when they ask for help?
- What generates the feeling of shame in people when they ask for help?
- How can you identify whether a person who is asking for help is feeling vulnerable or ashamed?
- In what ways can you be helpful in a situation where someone may be feeling vulnerable and needs help? And what are unhelpful responses / mannerisms in these situations?



- What are important points to remember when you interact with someone who needs help / is in a crisis?
- How can you apply what you have learnt from these stories when you interact with patients in the future?

As a group write down three principles you would like to practice in your daily life when you interact with your fellow human (and of course people you will provide care to) based on what you have discussed above. Check in with one another over the space of a few weeks to share successes and challenges and to encourage one another to keep up with the practice of these three principles.

You can also write down your successes and challenges in your journal.





The Allies Approach: Peer Learning Intervention Package

Our secrets, our shame



Time Investment: 60 Minutes

Introduction

We all hear secrets from others and have secrets ourselves. In this exercise we reflect on this topic and explore how this can be related to anticipated stigma.



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.



Materials and resources

Your journal from activity 1.

Draw two columns on a piece of paper. The heading of the first column is "feelings", and the heading of the second column is "consequences".



Individual Exercises

1. Revealing secrets (10 minutes)

Think of a secret you know about another person that only a few people know. In your journal write down one or more reasons why you might reveal the person's secret to someone you trust.

There are different reasons why you may want to reveal a secret. It is natural/tempting to tell your friend/best friend/spouse everything. Below are some common reasons people have for revealing other people's secrets. You can compare it with the answers you wrote down.

- 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.

2. Feelings and consequences of revealing secrets (20 minutes)

- How would you feel if you confided your secret to someone and that person told the secret to someone else without your permission? List your responses under the column labeled "feelings".
- What might the consequences be of someone telling their secrets to other people without their permission?

 List responses under the column labeled "consequences".

Health care workers often need to ask persons with infectious diseases sensitive questions about who they 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.

- How might a client feel if sensitive information about their situation was revealed to another person who did not need to know the information? Write these in the column labelled "feelings".
- What could the consequences of this be for the patient? Write these in the column labelled "consequences"



Peer Group Discussion (30 minutes)

Discuss the exercise with your peers and compare your individual lists under the feelings and consequences columns.

In what ways can you ensure people's right to privacy is upheld?

- How should you as a healthcare provider act if you have personal information about a person that you are providing care to?
- What should you do if a colleague/friend/family member is telling you personal information about someone?



Closing remarks after the discussion

Revealing private information about a person to someone else without the authorization is a violation of the person's rights. A person is entitled to privacy, and to have the reassurance that a healthcare provider is not allowed to give any information to anyone else without written permission (except for other health care workers directly involved in care).



References:

<u>Declaration of rights</u> of people affected by tuberculosis.



Head

Introduction to Stigma Theory

The underlying structures of stigma

Choices: The last diagnostic test

Four corners

Introduction to Stigma Theory



Time Investment: 70 Minutes

Introduction (10 minutes)

Understanding the way that stigma is constructed is important for measuring and reducing it. Most theorists see stigma as a maladaptive social structure. TB stigma is neither a natural nor inevitable part of having an infectious disease. Stigma requires an enabling environment.

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.). 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.

In this exercise you read an exchange between doctors illustrating the mechanisms by which stigma can be created, normalized, and ultimately institutionalized in policy. We use the example of a person with type II diabetes, a chronic disease that carries some stigma. Like infectious diseases, it has a complex set of conditions that foster it, including both genetic and lifestyle factors. Carefully read the interaction on 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.



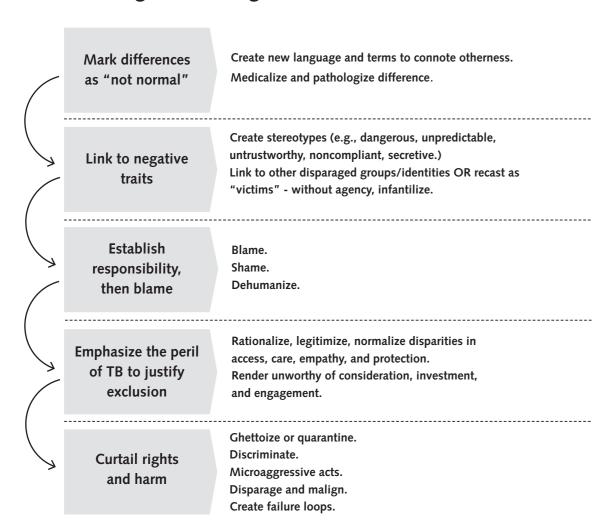
The building blocks of stigma include:

- 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.

The stigma-building cascades illustrates these steps:

Classical stigma-building cascade







Objective

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



Preparations

This exercise does not require special preparations. You only need a notebook and pen.



Individual Exercise (30 minutes)

Think of a secret you know about another person that only a few people Read the dialogue between the doctors and write in your note book any overt naming, blaming or shaming. What did you observe looking at the stigma-building cascade?

Re-write how the dialogue could have been if there was no stigma and the person with type II diabetes was approached with compassion and kindness.

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 Bliss, 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 Comino and I am a TB doctor with 12 years of experience.



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 hypoglycaemic 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.

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 hypoglycaemic 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.

You wrote in your notebook the naming, blaming, or shaming that occurred in this conversation and how this fit in the stigma-building cascade. Keep your notes for your discussion with your peers.



Peer Group Discussion (30 minutes)

- Use time to discuss the stigma-building cascade.
- Do you have examples of your own you would like to share with the group?
- Compare your answers on the conversation between Sugar,
 Huda and Farma and read out loud to the group how you re-wrote the interaction.



Closing remarks after the discussion

The words we use may reflect our thoughts. We need to be conscious about the words we use and the assumptions and stereotypes we create about other people. Without making the same "mistake" of blaming, shaming and dehumanizing we can make a choice to do it differently and support our peers in a kind way to make this change.





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Words matter language guide Stop TB Partnership 2022





The Underlying Structures of Stigma



Time Investment: 90 Minutes

Introduction

When we consider stigma, we can look at it in the framework of a structure, with certain layers supporting others.

A spider's web, for example, is a type of structure, with many threads connected to one another. It is made by small connections over time, maintained by supporting structures. Its purpose is to function as a trap for the benefit of the spider.

Stigma, similarly, can be viewed as a trap. It traps people who are stigmatized, limiting their freedom, movements, actions, etc. Stigma around the world takes on many different shapes, but all stigma is built on related core ideas and actions. At times it serves as a benefit for its instigators.

By utilizing the framework of a spider's web, we can learn to appreciate how the stigma we see, and experience, forms a part of an interrelated web. We are also able to identify the core drivers of stigma, and adjust our actions, thoughts, and treatment of others to ensure we limit perpetuation and ultimate effects of stigma.



Objective

By learning to identify the structure of stigma, we can look more objectively at the drivers and ultimately change behaviors within ourselves that may perpetuate stigmatization of other people.





Individual Preparation (20 minutes)

In preparation, watch the following two videos:

- Soka Moses, a Liberian healthcare professional, discussing the topic: "For survivors of Ebola, the crisis isn't over". https://youtu.be/tl-3r8Gid90
- Leprosy patient Ajay dreams of a better future for his son: https://youtu.be/PZY5qEdD6fQ



Materials:

3 blank sheets of paper.

On the first page write the title: 'Experiences of stigma' (this will be list 1 referred to in the group activity)

On the second page write the title: 'Reasons for stigmatizing behavior' (this will be list 2 referred to in the group activity)

On the third page draw a circle in the center of a page and write stigma in the center of the circle (this will be the stigma web referred to in the group activity).



Group Activity (30 minutes)

- 1. Take a look at the list of stigmatized conditions, identities and behaviors below and select one to structure the following activities discussion around:
- a. Tuberculosis
- b. Leprosy
- c. Mental illness
- d. Physical deformity
- e. HIV
- f. Obesity
- g. Sex works
- h. Homosexuality
- i. Addiction
- j. Criminal history
- k. Smoking
- I. Homelessness



- 2. From the perspective of a person experiencing stigma, discuss what people experience when they are being stigmatized. For example, isolation, exclusion, labeling, etc. Think as broadly as possible. Write down keywords related to these experiences on the page titled 'Experiences of Stigma' (list 1).
- 3. Taking a step back now, looking from the perspective of the stigma perpetrator (person who is stigmatizing someone else), discuss why the perpetrator might behave in this way? For example, fear, societal influence, etc. Write down as many keywords you can think of related to these actions on the page titled 'Reasons for Stigmatizing Behavior' (list 2).
- 4. On the third page (stigma web), draw lines from the circle and write down all the reasons a perpetrator may behave in that way (from list 2 created above).
- 5. And now, looking at the list you created from the person experiencing stigma (from list 1), are there links you notice for the reasons for stigmatizing behavior? For example, a person with TB who experiences being isolated from
- a friendship group (*experience of stigma*) may stem from society reinforcing the message that a person with TB is 'dirty' (*reason for stigmatizing behavior*). Try to link as many experiences from list 1 to as many reasons from list 2. Write the experiences from list 1 down on the page 'stigma web' and draw a connecting line to the reasons you have already written down on the stigma web.
- 6. It may be that multiple experiences fit multiple reasons in this case, draw connecting lines between all the interlinking parts. Eventually you should end up with a diagram that looks very similar to a spider's web, with many connected and interlinked parts.
- 7. If you would like to, you can create another stigma web from a different stigmatized condition, identity, or behavior.



Discussion and reflection (30 minutes)

As a group, look at your web(s) of stigma, and spend some time discussing and reflecting on the following:

- Can you identify who the 'spider' might be in this web of stigma? Is there a person, or a group of people, that benefit from perpetuating stigma?





- In what way does this 'web of stigma' impact your view on how stigma is generated and continues to exist?
- Have you ever been a perpetrator of stigma? Would you like to share this with the group?
- Have you ever experienced being stigmatized? Would you like to share this with the group?
- How can you implement what you have learnt in this activity in your future interactions with people?



Resources (10 minutes)

For further information on the causes of stigma, you can have a look at the following web link that provides numerous reasons for stigma being generated. https://www.infontd.org/toolkits/stigma-guides/guide-1-what-are-health-related-stigma-and-mental-0

Choices – The last diagnostic test (GeneXpert Cartridge)



Time Investment: 30 Minutes

Introduction

In some countries there are legal, policy, financial, and other restrictions on diagnostic and treatment services that impede access to and quality of treatment. In this exercise there is a (fictitious) situation, only three more diagnostic tests for TB can be performed. You can read the situation that describes a large group of people who have been in the same room for several hours with a symptomatic person (pulmonary (X/DR-) TB). Everyone has been screened, and some need to be tested, but the cartridges must be rationed. Imagine you are the one that needs to decide who should receive testing.



Objective

- 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 priorities.



Materials

Your journal from activity 1



Individual activity

Read the scenario. Only spend 5 minutes to choose the three people you will be granted the test and write down your rationale for choosing these three people.





The scenario (10 minutes)

You are living on a remote island. 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)

In total there are 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 people will need to wait for the next shipment of 2 cartridges to the island, which may take six to eight weeks to arrive.

Choose the three people who should use the last diagnostic tests and write down your rationale for choosing them, and the rationale for why the other seven people need to wait until the next shipment arrives.



Individual reflection (20 minutes)

Reflect on the following questions and write them in your journal:

- How do you feel about rationing diagnostics?
- Were your choices influenced in some way?
- What influences, biases or assumptions may have played a role in your decision?
- How did these influence your decision?

Take your notebook to the peer group discussion.





Peer Group Discussion (30 minutes)

Share with each other the choices you made and the rationale behind it. It is important to practice staying neutral during this discussion and to reduce the impulse to judge.

Listen to each other without making comments or making alternative suggestions, and only ask clarifying questions. You can appoint a facilitator who facilitates the discussion and tries to maintain neutrality.

Discuss the following:

- Is this scenario related to any situation you have come across in the past?
- Who has the right to make judgments for another human being?
- When access to care is restricted, you may come across these difficult choices. How could you act in these situations?
- Are there ways in which these decisions can be made easier? And if so, how?
- What did you learn from this exercise?





59 The Allies Approach: Peer Learning Intervention Package

Four corners



Time Investment: 60 Minutes

Introduction

Often within the context of a group many people hold differing views and values about certain topics, creating diversity among members. Of course, diversity is important as it allows a group to look at multiple facets of a topic.

In the case of policy development or change, it is important to recognize that stakeholders will have different values and feelings about patient support and stigma. It is equally important to acknowledge that feelings do not need to (or will not) be acted on, and neither does it imply that attitudes or values invariably lead to stigmatizing behaviors. However, individual feelings and values will influence the prioritization of certain topics in policy change.



Objective

To explore individual's values and feelings towards people with stigmatized conditions, identities, or behaviors, and to observe how that impacts prioritization of certain topics.



Preparation and materials

Enough sheets of paper for each member of the group to have 5 sheets (i.e. 4 group members x 5 sheets= 20 sheets of paper) – they can be A6 sized. These will be used to make response cards.



Group Activity (15 minutes)

- Each person in the group needs to write down the following responses on a sheet of paper (one response per page): Strongly agree; Agree; Don't know/Neutral; Disagree; Strongly disagree
- Let a participant from the group read out one value at a time from the below list:
- People can be educated and empowered to avoid infectious diseases
- All people know what support services they need when being treated for an infectious disease
- Healthcare workers providing care to people for infectious diseases should be screened at work to ensure they do not spread disease
- All people with infectious diseases are innocent victims
- People with infectious diseases who do not complete their treatment are selfish
- People with infectious diseases need to be actively observed and managed to ensure they complete their treatment
- All people with infectious diseases are aware of the risk of infecting others
- If a friend had an infectious disease, I would still visit him/her at his/her house
- A person seeking treatment for an infectious disease should be isolated from others in the waiting area
- When the value is read out, select the response you feel resonates
 with your feelings and values most closely, without showing other
 group members. For example, the value "people can be educated
 and empowered to avoid infectious diseases" is read out. You strongly
 agree with this statement, therefore select this response from your
 response cards.
- On the count of three, hold your response card out in front of you for others to see. Give each member the chance to view your response silently.
- Continue this until all the value statements listed above have been read out and responded to.
- In this section of the exercise, don't ask any questions, or justify your answer/enter a debate. It is merely intended to observe what people's responses are, and how they differ from other group members.
- Notice similarities and differences, and notice patterns in the responses.







Discussion (45 minutes)

Following this activity, you can enter discussions as a group based on what you observed.

- What surprised you about seeing other group members responses?
- Did you feel that you needed to justify your position when other people's responses were different to your own, and if so, why?
- Did you feel that you needed to change someone's mind about their response when your response was different to theirs, and if so, why?
- How do you think individual differences could impact how an organization makes decisions about policy change?
- In the context of the values read out during the above activity, and the related responses, what topics may be prioritized if you were participating as a group in discussions about policy change?
- What should you be aware of regarding the impact your personal feelings and values have when participating in decision making within an organization?



Self-reflection

If you have reflections about this activity, you could write those down in your journal.



Face

Labelling

Safe space, safe boundaries





Labelling



Time Investment: 60 Minutes

Introduction

In our interpersonal communication we are often not aware of the influence of information that we receive from other people. We also may have assumptions that we have never checked or base our conclusions on incomplete information.



Objective

To identify labels used to stigmatize persons with infectious diseases.



Preparation (15 minutes)

Watch the video on "<u>labels</u>, <u>stigma & shifting perceptions</u> in Mental Health with Shannon Jaccard".



Individual reflection (20 minutes)

Reflect on the following questions and write down these reflections in your journal

- What have you learned from this video?
- The video was about mental health and a plead to talk about mental wellness instead of mental disease. If you translate the content to labeling persons with infectious diseases, what labels do they get?
- What role can you play as health care professional to stop labeling?



Peer Group Discussion (25 minutes)

- Discuss with each other what you learned from the video and what role you would like to play as a health care professional in avoiding attaching labels to people?
- Exchange examples with each other where you have been influenced by labels given to someone you know, in a negative or in a positive way?
- Discuss the power of labels and how they impact a working environment.
- What did you learn from this exercise?



Closing remarks after the discussion

Be aware of the labels you are using and the impact they can have. A label can be interpreted from a positive or negative view. We may not always perceive what is positive or negative so we will need to check it in our communication.



References

Handbook of social and clinical psychology – Beatrice A. Wright, 1991, chapter 23 labeling: the need for greater person-environment individuation.





Safe space, safe boundaries



Time Investment: 90 Minutes

Introduction

All people have different needs for personal space. This depends from person to person and also from situation to situation. As healthcare workers you will often have people in your personal space, and need to enter other people's personal space. At times you will need to treat a person with an infectious disease - this can influence your need for personal space and impact your comfort levels.



Objective

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



Materials

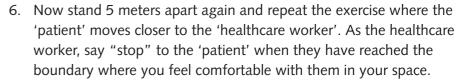
None needed.



Group Activity (20 minutes)

- 1. Break into pairs of two
- 2. Stand approximately 5 meters apart from your partner
- 3. Imagine that one of you is a patient with an infectious disease, and the other is a healthcare worker.
- 4. As the 'patient' take one step at a time towards the 'healthcare worker'. Stop when you feel that you have reached your comfort level in terms of proximity to the healthcare worker in other words, when do you feel that you should not get any closer?
- 5. As a group, notice where each 'patient' stops, and the difference between each person's level of comfort.





- 7. Notice as a group where each 'healthcare worker' asked the 'patient' to stop, and the difference between each 'healthcare workers' level of comfort.
- 8. Also notice the difference between the boundary of the healthcare worker and the boundary of the patient in terms of the need for social distance.
- 9. Switch roles and repeat the exercise.
- 10. Repeat the exercise, but instead of having a patient with an infectious disease and a healthcare worker, do the activity as two friends meeting up in a public place.



Discussion (60 minutes)

- What do you notice about different people's need for personal space?
- How does your comfort zone change, depending on whether you are a 'patient' or a 'healthcare worker'?
- How does your comfort zone change when the situation was between two friends, instead of between a patient and a healthcare worker?
- Was there a pattern in how much space a healthcare worker needed, vs. how much personal space a 'patient' needed/or offered, and if so, what was the pattern?
- How does your need for personal space as a healthcare provider differ from one care giving situation to another?
- How could the need for personal space in different situations impact the care you provide?
- What are the possibilities in maintaining personal space in real-work situations?
- As healthcare providers how could you express your boundaries to patients without being hurtful or making them feel stigmatized?
- As a healthcare provider how could you be mindful of a patients need for personal space and how can you respect that?





Final thoughts (10 minutes)

The need for personal space is highly variable and is influenced by personal preference as well as the situational context, as you will have seen in the above activity and accompanying discussion with your peer group.

As a person who is entering the healthcare profession it is important to be mindful of your own boundaries as well as those of the people you will be providing care to. It may be that when you provide care to a person with an infectious disease you require more social distancing than what you would require if you were providing care to a person with cancer, for example. Although it is acceptable to be clear about your boundaries with people who you will be treating, it is imperative to be cognizant of how you express your need for boundaries (how you deliver this message to people you are providing care to). For example, you may be more aware of the risk associated with transmitting an infectious disease, and therefore naturally want greater distance. Whereas a person you are providing care to may not be actively thinking about the amount of space to keep between themselves and you, as their mind may be on other things, such as treatment duration; financial implications; etc.

Therefore, it is important to identify your boundaries up front, and clearly express those if the need arises, in a sensitive and caring manner to the person you are treating, to ensure they feel respected, and do not feel stigmatized.

Similarly, a person you are treating may have a greater need for distance. As a healthcare provider it is imperative to construct a sensitive approach when entering a patient's personal space, so they feel respected, dignified, and empowered. A person receiving treatment may already feel 'on edge', and therefore will need more space, or warning when you enter their space, especially in situations where the person receiving treatment may be feeling a power differential.



Hands

Framing infectious disease

Creating respect and dignity messages at healthcare institutions

Countering: Dealing with difficult situations

Upholding the right to privacy





Framing infectious diseases



Time Investment: 90 Minutes

Introduction

Discourse analysists examine text and language and what the implications are for assigning responsibilities and solutions.

In the example of TB as an infectious disease, 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 legitimizationsⁱ.

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.



Objective

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

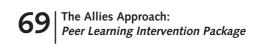


Preparations

Print out a copy of each situation example text – enough for each group member.

Read "Words Matter: suggested language and usage for tuberculosis communications" published by StopTBPartnership.







Activity (30 minutes)

- 1. Select a situation you will analyze together from the three example texts below
- 2. Read the text silently on your own and try to identify what parts of the text could stimulate stigma
- 3. As a group, discuss what parts of the text could add to the risk of stigma, and how the text might be revised to reduce stigmatizing language.
- 4. Spend time collaborating as a group on the revision of the text to ensure it reduces the risk of stigma. Agree as a group on the final text.

Situation examples 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 ...

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.

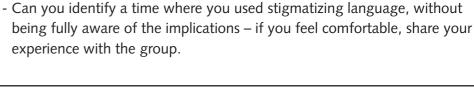
"For the United States, the challenge is probably people coming in from immigrant populations who are already stigmatized," said Glenda Gray, the president of the South African Medical Research Council and an expert on tuberculosis and HIV. "You need an environment that's not going to be punitive [to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



Discussion (1 hour)

- How could you adapt your own language usage when you communicate with people, verbally, or in the written form?
- Do you notice blind spots in your own language usage that adds to the risk of stigma?





- Have you ever been on the receiving end of stigmatizing language, and if

Resources:

Words Matter Language Guide | Stop TB Partnership

so, how did this impact you?

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

<u>Critical Discourse Analysis | The Critical Study of Language | Norman (taylorfrancis.com)</u>

ii Stop TB Partnership, UNOPS. The Paradigm Shift 2016-2020:

Global plan to end TB. Geneva: 2015. doi:22 August 2016. globalplantoendtb theparadigmshift 2016-2020 stoptbpartnership.pdf

iii 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).

The Danger of Ignoring Tuberculosis - The Atlantic



Creating respect and dignity messages at healthcare institutions



Time Investment: 2 hours

Introduction

The goal of health literacy is that healthcare provider's offer a clear understanding to persons they are providing treatment to about what, how, and why to improve health. Basic standards of health literacy include using lay language and culturally appropriate visuals for the target audience. It is important that the intended user is identified, and the number of key messages is about three (with a maximum of five) messages. 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 an 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.



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.





Materials:

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

A computer/laptop/tablet to access the <u>CDC Communication Index Score Sheet</u> (or a printout of the score sheet).



Preparations

As individuals read through the following two documents developed by the CDC:

- 1. "Simply Put: A guide for creating easy to understand materials".
- 2. <u>CDC Clear Communication Index: A Tool for Developing and Assessing</u>
 Public Communication Products



Activities:

Activity: Key messages within your community (1 hour)

- 1. As a group spend some time discussing your views on the necessity of the information and education of staff, patients, and families, etc. within healthcare.
- 2. Take a moment as individuals to think about the health messaging around you and write down one health message that comes to mind that educates people on infectious diseases.
- 3. Once everyone has written down their key message, pass your papers clockwise.
- 4. Now simplify the message that was passed to you by using simpler language.
- 5. Give each participant the opportunity to share the original message and the rewritten message with the group. Also describe the reasons why you adapted the language in the way that you did outline for the others in the group what your thinking process was when you adapted the message.
- 6. Then as a group, spend some time discussing with one another:
- a. Are the messages as simplified as possible?
- b. Do the messages carry any subtle undertones of stigma?
- c. How would you adapt the messages even further to ensure they are respectful, and dignity messages?
- d. Are there other messages within your community that come to mind that need adapting to be more respectful to the intended audience?
- e. How could you go about adapting some of these messages within your community how could you participate in the change?



Activity: Developing communication materials (1 hour)

- 1. Take a moment to think about the health messages within your community and develop a poster with text and visuals on one of the following topics:
- a. Protecting oneself from TB infection by following standard procedures
- b. People with TB deserve the same quality health care services as like everybody else (patient provider relationship)
- c. People with TB have rights
- 2. Once completed, give each group member the opportunity to share their poster. Others should assess if:
- a. The intended target audience can be identified
- b. The number of messages are limited to three, with a maximum of five.
- c. The language is simple.
- d. The focus of the poster is on behavior
- e. Visuals (if used) should be supplementary and culturally appropriate
- f. Potential stigmatizing language and visuals
- 3. Once all the posters have been presented, spend some time providing one another with constructive criticism for each poster. Include elements from the <u>CDC Communication Index Score Sheet</u> to develop and evaluate health messages.
- 4. Once everyone has presented their poster, spend time as a group to redesign one or two posters according to the feedback provided. Ensure the visuals are complimentary to the text; understandable without text; culturally appropriate; and aimed at behavior change. Use the various CDC resources listed above in the preparations section to guide the redesign.
- 5. Based on this activity, discuss:
- a. What have you learnt about critically assessing health messages?
- b. Are there posters or communication materials that come to mind that may perpetuate stigma related to infectious diseases if so, share this with the group.
- c. How would you implement these learnings in the future in your career as a healthcare professional?



Resources:

https://www.cdc.gov/healthliteracy/pdf/simply_put.pdf

CDC Clear Communication Index: A Tool for Developing and Assessing CDC Public Communication Products—User Guide

CDC Clear Communication Index Score Sheet





Countering: Dealing with difficult situations



Time Investment: 60 minutes

Introduction

In your work you may have come across situations that you would like to discuss with your peers. In this exercise you will discuss some difficult situations with your peers and discuss with each other how you can solve the situation or if it is already in the past, what you can do differently next time. It will help you create an enabling environment in which you can do your work with compassion and care.



Objective

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



Materials:

2-3 pieces of paper (approximately A5 sized) per person Your journal from activity 1



Individual reflection (10 minutes)

Reflect on difficult situations you have experienced and how you have dealt with them in the past or can deal with them in the future. Choose some situations you would like to discuss further in your peer group. Write two to three situations on different pieces of paper – try to keep it short, providing high level detail. Also include a question you would like to pose to the group about this situation.





Peer Group Exercise (50 minutes)

For the peer group exercise, we will use an exercise called the "gossip InterVision method". It is a fun and interesting way to discuss difficult situations.

Gossip method

- 1. Introduction
- 2. Problem identification
- 3. Gossip round
- 4. Reaction participant
- 5. Evaluation

1. Introduction of the question by participant

All peers sit in a circle. The participant (person who brings in the situation/question) briefly describes the situation and the question to be discussed in the peer group.

2. Problem identification

This step is to get clarity on the situation or question the participant describes. All peers get the opportunity to ask 3 open questions to get a clearer picture on the situation and the question asked by the participant. The participant answers the questions without elaborating on the content.

3. Gossip round

The participant steps out of the circle and sits with the back to the peers. The participant does not intervene and only listens to the peers while making notes in the journal. The peers are talking to each other as if the participant is not in the room (gossiping with each other) and they discuss the question and situation of the participant, possible background and causes of the problem and the solutions. The participant makes notes on what is surprising, helpful, etc.



4. Reaction participant

The participant joins the group again. The participant tells the peers what has touched him, what was the most surprising part, and which new insights were learned from the "gossip".

5. Evaluation

Discuss with each other what you have learned from this session? Insights, new ideas, etc. What will the participant put in practice in the future? If there is time you can do another round with another problem or plan an extra session.



Closing remarks after the discussion

Discussing situations and problems with each other can be a very valuable exercise. There are different methodologies you can use and the "gossip method" is just one of them.





Upholding the right to privacy



Time Investment: 90 minutes

Introduction

Upholding privacy and confidentiality of the persons that are entrusted to your care as a health care professional is very important. In this situation we talk about the patient-provider confidentiality. In this exercise you will reflect on current practices and a fictitious situation. There will also be an exercise you can do together with your peers.



Objective

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



Materials:

Your journal from activity 1



Individual reflection (30 minutes)

Reflect on the questions in this exercise and write your answers in a notebook. You can use them later in your discussion with your peers.

- 1. How can supervisors/managers ensure privacy and confidentiality in their health settings?
- 2. How can supervisors/managers help staff protect the privacy and confidentiality of patients?
- 3. How can supervisors/managers ensure that health center staff are protecting a client's privacy and confidentiality?



4. What do you think the role of supervisors/managers should be in handling breaches of privacy and confidentiality?

- 5. How are intentional and unintentional violations handled? Write down some examples you have witnessed.
- 6. Who determines the consequences for privacy and confidentiality breaches?
- 7. How are the following situations handled in the health centers you have worked in or if you have not yet worked in a health center how should it be handled?
- Disclosing a patients' infectious disease status to other family members.
- Disclosing a patients' infectious disease status 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 (or other airborne infectious disease) status while identifying and screening contacts during a contact investigation.
- Finding confidential patient records easily accessibly where other staff members can easily find or view them.
- Hearing a receptionist ask a patient a personal question in the presence of others.
- 8. What current policies are there in your workplace for handling the situations mentioned in #7 above.
- 9. Are there differences, if any, which exist between policies and actual practice?

It is important to keep in mind that some providers are unaware of the privacy and confidentiality laws and assume they are required to notify family members. Others apply their own cultural or religious standards when serving patients.

- 10. How should supervisors/managers deal with it when discrepancies exist between policy and practice? For example, rules may exist to protect privacy and confidentiality, but health staff do not actually behave according to the rules.
- 11. How can health care institution staff be made more aware of privacy and confidentiality policies and how can these policies be better enforced?

Read the job aid related to people with tuberculosis: "Supporting client privacy and confidentiality: a checklist for supervisors and managers". Note your questions and remarks for discussion with your peers on this job aid.



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.

Individual Exercise (30 minutes)

Read the situation and answer the questions. You can take your answers with you for further discussion with your peers.



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.





Questions:

How could this incident have been avoided?

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



Peer Group Discussion (30 minutes)

The objective of the exercise was to develop our competencies to uphold patient-provider confidentiality.

Discuss with each other the main take home message you have learned from your individual work, as well as your responses to some of the questions posed above.

Compare you answers on how it could have been avoided that Esme left the clinic without seeing a doctor.

Re-write the last paragraph together as a group if Esme was treated with compassion and care and her privacy was respected and confidentiality was maintained.

Discuss any outstanding question or reflections.



This course was written by Ineke Huitema and Inez de Kruijf-Carter, and adapted from the original Allies Approach developed in 2018 by Sarah van de Berg, Ieva Leimane and Ellen M.H. Mitchell.

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KNCV TB|PLUS

The Allies
Approach:
Peer Learning
Intervention
Package