

Supporting community action on AIDS in developing countries

Understanding and challenging HIV stigma

Toolkit for action

MODULES F & G

- Coping with stigma
- Treatment and stigma

About the International HIV/AIDS Alliance

Established in 1993, the International HIV/AIDS Alliance (the Alliance) is a global partnership of nationally based organisations working to support community action on HIV and AIDS in developing countries. Our shared mission is to reduce the spread of HIV and meet the challenges of AIDS. To date, over \$140 million has been channelled to more than 40 developing countries in support of over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to treatment.

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Understanding and challenging HIV stigma: Toolkit for action

About this toolkit

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

The toolkit evolved out of a research project on 'Understanding HIV-related stigma and resulting discrimination' that was conducted in Ethiopia, Tanzania and Zambia from 2001 to 2003. The research was implemented by the International Center for Research on Women (ICRW) in collaboration with research institutions in the three participating countries. The first edition of this toolkit was developed by the CHANGE Project AED (Academy for Educational Development) and ICRW in partnership with the research institutions and non-governmental organisations (NGOs) in these three countries who helped to design the original toolkit. It was developed and written by Ross Kidd and Sue Clay.

This edition was revised by the International HIV/AIDS Alliance country office in Zambia, building on the original toolkit, and includes experience of the Alliance's Regional Stigma Training Project, which has introduced the toolkit to many countries in Africa through a training of trainers (TOT) and networking process. The national TOT workshops and follow-up workshops conducted by members of the growing anti-stigma network have created a base of experience for revising and updating the toolkit. At a regional workshop in Zambia in August 2005, members of this network helped to review the toolkit and make changes and additions.

By the end of 2006, more than 300 anti-stigma trainers from many organisations have been trained by the Alliance using this toolkit. These include the following key partner organisations:

Burkina Faso: Initiative Privée et Communautaire Contre le VIH/SIDA au Burkina Faso (IPC)

Côte d'Ivoire: L'Alliance Nationale Contre le SIDA en Côte d'Ivoire (ANS-CI)

Ethiopia: ActionAid, Hiwot, Save Your Generation Association (SYGA)

Kenya: Regional AIDS Training Network (RATN), Network of people with HIV/AIDS in Kenya (Nephak)

Mozambique: International HIV/AIDS Alliance in Mozambique, Rede Nacional de Associações de Pessoas Vivendo Com HIV/SIDA (Rensida)

Nigeria: Network on Ethics, Human Rights, Law, HIV/AIDS Prevention, Support and Care (NELA)

Senegal: Alliance Nationale Contre le SIDA (ANCS)

Tanzania: Kimara, Muhimbili Medical College of Health Sciences (MUCHS)

Uganda: The AIDS Support Organization (TASO)

Zambia: International HIV/AIDS Alliance in Zambia, Network of Zambian People Living with HIV (NZP+)

This edition, developed and written by

Ross Kidd, Sue Clay and Chipu Chiiya

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Many ideas for the exercises came from working with staff members and partners of the ACER (ARV Community Education and Referral) Project, supported by the International HIV/AIDS Alliance in Zambia. ACER is an innovative community project, led by staff members who are open about their HIV status and who provide support and education to community members and organisations around ARVs, adherence, counselling and HIV testing.

We would also like to thank Katongo for her insight and stories about some of the challenges facing young people on treatment. At the Alliance secretariat, we would like to thank Carolyn Green for helping with the Fact Sheets, Liz Mann for her support throughout the project, and the Communications team who co-ordinated the design development and production of this toolkit.

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Contents

Module F – Coping with stigma

Introduction	
Exercises	3
F1 Strategies for coping with stigma	4
F2 Keeping quiet	5
F3 Faith healing and traditional medicine	6
F4 Disclosure – telling your family	7
F5 HIV and human rights	10
F6 Understanding assertiveness	11
F7 Paranoia and hyper-sensitivity	14
F8 Building self-esteem	15
F9 Coping with stress	18
F10 Death and dying	19
F11 Positive living	20
F12 ‘Don’t have children’	21
F13 ‘Don’t have sex’	22

Module G – Treatment and stigma

Introduction	23
Exercises	
G1 Treatment and stigma problem analysis	24
G2 Treatment and stigma in different contexts	25
G3 Treatment in the family	27
G4 The burden of secrecy	28
G5 ‘We will not tell anyone’	30
G6 Children, treatment and stigma	32
G7 Health workers, treatment and stigma	34
G8 Rumours about ARVs	37
G9 Getting treatment	38
G10 Making healthy links	40
G11 ‘Prayer is all you need!’	42
G12 Treatment journey	43

Annex 1

ARV fact sheet	44
Opportunistic infections fact sheet	45
Tuberculosis fact sheet	48

Pictures

Treatment story	49
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Other booklets in *Understanding and challenging HIV stigma: Toolkit for action* include:

Introduction

Using the toolkit

Module A

Naming the problem

Module B

More understanding, less fear

Module C

Sex, morality, shame and blame

Module D

The family and stigma

Module E

Home-based care and stigma

Module H

MSM and stigma

Module I

Children and stigma

Module J

Young people and stigma

Moving to action module

Thinking about change

Moving to action

Developing skills for advocacy

Picture booklet

General stigma pictures

Rights pictures

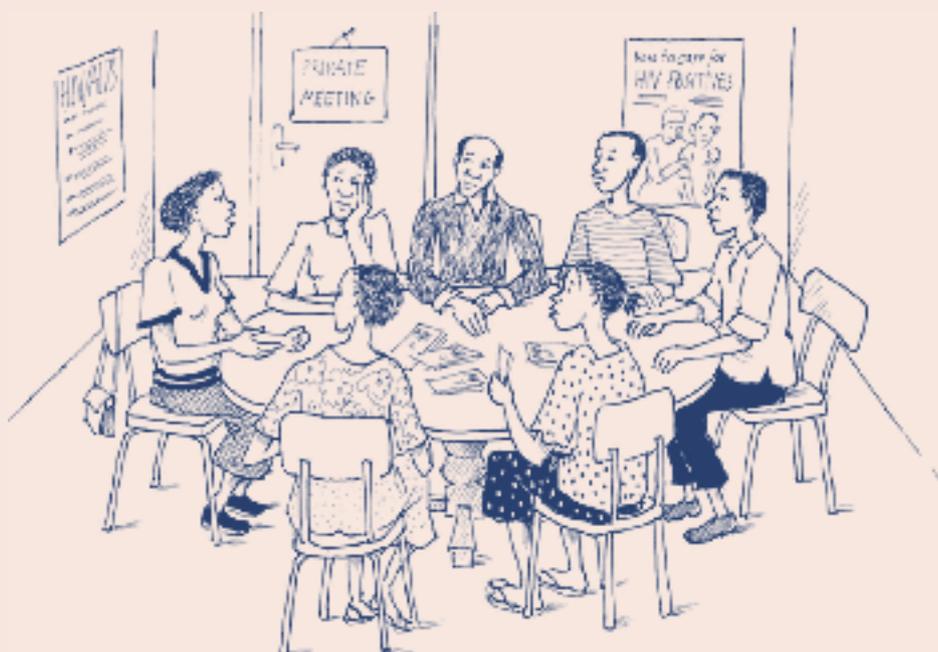
Additional booklets will be published as new modules are developed.

F module

Introduction

In any community initiative that aims to combat stigma, it is important to include strategies for supporting PLHIV to cope with the effects of stigma. PLHIV play a crucial role in helping to identify the many different types of stigma and raising community awareness about the damage and pain that stigma and discrimination bring.

This module was written with a team of PLHIV and is designed for use with PLHIV training courses and support groups. The aim is to strengthen PLHIV as individuals, in order to cope with stigma and to build up leadership ability to help and support others. The activities allow participants to share experiences and strategies, develop communication and assertiveness skills, and build self-esteem.



Exercise F1 Strategies for coping with stigma

Facilitator's notes

This is the first exercise that will ask participants to talk about their own experiences of HIV and stigma.

Objectives

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

- share experiences of being stigmatised
- assess the effects of these experiences
- begin to develop strategies for confronting stigma and discrimination.

Time

1 hour

Action ideas

Share other ideas for coping with stigma with your family and friends.

Step-by-step activity

Stigma stories¹ – individual reflection and group work

1. Ask participants to sit on their own and think about, “*An occasion when you were treated badly as a PLHIV by other people.*” Allow five minutes of quiet reflection.
2. In pairs, share your experience.
3. In the large group, ask if anyone wants to share their story.
4. Ask the group to choose one of the stories and role play it.
5. After the role play discuss:
 - *What happened? How did the person feel? How did he or she react?*
 - *Describe the power relations between stigmatiser and stigmatised.*
 - *What are the root causes of this stigma or discrimination?*

Card storm in pairs

6. Ask people to pair up again and ask them to think of the personal strategies they use to cope with stigma and discrimination. Ask, “*How do we cushion or protect ourselves against the effects of stigma and discrimination?*” Write one strategy per card. Stick cards on the wall. Ask participants to arrange cards in similar categories.
7. Ask them to form small groups, pick the three strategies that they think can work the best and explain the reasons why.
8. Ask groups to discuss, “*What are some of the ways that we cope with stigma with the help of others? How do we support each other as PLHIV?*” Write points on the flipchart.

Examples of strategies

Withdrawing. Taking ARVs and looking healthy. Ignoring stigmatisers. Avoiding situations. Joking. Answering back. Fighting back. Joining a support group. Trying to explain. Talking to stigmatisers. Going public. Denial. Talking to friends about what happened.



¹Some of this exercise is adapted from Hope and Timmel, ‘Cushions’, *Training for transformation: Handbook for community workers* (Book 4), pp.145-6.

Exercise F2 Keeping quiet

Facilitator's notes

Some people think this is a controversial strategy, but keeping quiet is one of the coping strategies identified by PLHIV. It means that in some situations we might choose not to disclose our status as a way of protecting ourselves from stigma.

Objectives

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

- recognise that keeping quiet is a coping mechanism for dealing with stigma in some situations
- understand how to choose who and when to disclose to.

Time

30 minutes

Step-by-step activity

When silence protects us – card storm

1. Hand out cards and ask participants to write one point per card on, “situations where you might choose to keep quiet about your status, about stigma, etc.”

Examples of keeping quiet

You don't want to draw attention to yourself. Stigma in front of many people. Fearing rejection from your family. Looking different from other people. Keeping quiet at work, in case you lose your job. Wanting to protect someone from our worries. It may not be safe. Choosing carefully who we talk to. Reflecting on what being positive means to us. Taking time for it to sink in. Waiting for the right moment.

Stop-start drama

2. Divide into small groups. Choose one of the situations and ask the first group to role play the situation showing someone keeping quiet. The second group role plays the same situation but with the person speaking out or challenging the situation.
3. In a large group, discuss:
 - *What happened in the role plays?*
 - *How did the strategy of keeping quiet work?*
 - *How did the strategy of speaking out work?*
 - *How do the characters feel?*
 - *Are there any other strategies you could use in this situation?*
4. Try these ideas out in the role play.

Extract from E's story, Zambia

E does not share information with her stepmother. She feels if she told her that she was HIV positive, her stepmother would stigmatise her and use the information against her.



Exercise F3 Faith healing and traditional medicine

Facilitator's notes

Some of us turn to faith healing and traditional medicine as a way of finding hope.

Objectives

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

- understand why faith healing holds hope for some people
- recognise the limitations of traditional medicine in treating HIV.

Time

1 hour

Step-by-step activity

Faith healing – story discussion

1. Ask one participant to read the story below.



Martha's story

One day, after several tests at the clinic, Martha discovered that she was HIV positive. She never told anybody her results. She went to see her priest, who prayed for her and gave her holy water, and she believed she was healed. A year later she got married. Soon after the marriage she had a baby who became sick. When she took the baby to the doctor, the baby was tested for HIV and the result was positive.

2. Ask participants to discuss the following questions:

- *What happened in the story?*
- *What made Martha believe she was healed?*
- *Do you know of people who have gone for healing? What happened?*
- *What role does faith healing play in helping us cope with stigma?*
- *What else could Martha have done?*

Summary

The messages we get from faith healers help to strengthen us, and spiritual support is important to many of us. However ARVs are the best treatment available for HIV, and if we believe that prayers alone can heal us we may be deceiving ourselves.



Exercise F4 Disclosure – telling your family

Facilitator's notes

These exercises explore the issue of disclosure, especially disclosing to your family. Pick one or two depending on your group.

Objectives

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

- share experiences of telling family members about their status
- describe some basic strategies for disclosing to members of the family.

Time

1 hour

Step-by-step activities

A. Disclosing to different family members

1. Ask participants to form pairs and discuss:
 - *Who in your family have you told about being HIV positive?*
 - *How did you do it?*
 - *What happened?*

B. Deciding about disclosure – paired role play

1. This exercise is designed to give people practice in disclosing to family members. Discuss in pairs:
 - *Who would you like to tell?*
 - *What are some of your concerns about telling them?*
2. Ask each person to prioritise the people on his or her list according to:
 - important but difficult to tell – and why
 - less important but difficult to tell – and why
 - important but easy to tell
 - less important but easy to tell.

	Difficult to tell	Easy to tell
Very important	✓ mother	
Less important		✓ friend



3. Then explain that we should focus on disclosing to the 'important but difficult to tell' person.

Role play in pairs

4. Divide into pairs. Decide in each pair who is disclosing, who is being told. Practise telling the person. Then when pairs have finished, ask them to switch roles. After five minutes, ask one or two pairs to volunteer to come into the centre and show their role plays to the whole group.

Processing

5. Ask participants to discuss:
 - *How did you feel about disclosing your status?*
 - *How did you feel about being told the other person's status?*
 - *What techniques did you use to tell your story?*
 - *What advice would you give others about disclosing?*
 - *What do we learn from this?*

Exercise F4 Disclosure – telling your family

The first person E told was her cousin – her father's sister's daughter. She is a very close and understanding relative, and her response was very encouraging. Her cousin thought her so courageous to have been tested, and remarked how most people do not know their status. At this stage, E is not sure if her cousin ever told others. It really helped E to tell her cousin – it was 'one load lifted'.

Extract from E's story,
Zambia



Option: Fears about disclosure – case study and discussion

1. In small groups, ask participants to read the case study below.

Case study – Naledi's story

The funeral took place a week after her husband's death, followed by a week of being insulted by her in-laws for bewitching their only son and brother.

As she watched the coffin being lowered into the grave, she whispered to herself, *"If you had only listened to me, you would still be alive. I would not have to take so many insults from your family."*

As she tried to stand up to throw soil into the grave, she fainted. Her husband's family would say that it was her guilty conscience for killing her husband so that she could inherit the big house he had just finished building.

While she knew her husband had died of AIDS, Naledi decided to keep it to herself. Even if she told them they would never believe her. If anything, they would say she had infected him with it.

Her problem started two years earlier when she decided to go for an HIV test. Her husband refused to go with her. When her test results were positive, her husband would not accept it.

"He kept denying the fact that I had the virus and that he might also have it. He even insisted that we should not use condoms, until it reached a point where we fought over condom use. He still refused to go for a test when he started to lose weight, claiming that he was on a diet. He finally agreed on his deathbed that he could be tested for AIDS. He died knowing that he had the virus and that he was beyond redemption. But he was my husband and I will love him always. That is why I will keep his secret."

Kelebonye, Gregory (2003) 'Me Go for a Test? No Way!' *Mmegi Monitor*, Botswana, 29 April to 5 May.

2. Ask participants to discuss:

- *What happened to Naledi when she told her results to her husband?*
- *What are your own biggest fears about sharing your status with partners, family members or friends?*

Summary

Who, when and where to tell someone about your status is a personal decision. You should never be put under pressure to tell someone you do not want to. Practising telling someone can be a useful way to develop personal strategies. Avoid telling people who might use it against you. Fear of stigma and blame are the main reasons that stop people from telling others about their HIV status.

Exercise F4 Disclosure – telling your family



Examples of fears about disclosing

People may use this information against you.

Rejection.

Guilt.

Gossip.

Damage to fragile in-law relationships.

Withdrawal of material support – *“You are going to die anyway, so why should we waste our money on you?”*

Relatives neglecting you, e.g. not taking you to the hospital when sick.

Vulnerable when sick or unproductive.

Disappointment – shattered expectations.

Past sexual relationships being raised. Your role as a guardian is undermined.

Examples of disclosure practice from Ethiopia workshop

Woman telling her husband

- Selected a suitable place and time, e.g. children asleep.
- Put him in a good mood. Talked about his trip first.
- Broke the news slowly. Started off by saying she had gone to the clinic for a check-up; then said her friend had been tested for HIV; then said she decided to get tested too.
- At each point in story she stopped to check on the awareness and reaction of her partner before proceeding.

Brother telling his sister

- Best timing? In the evening after the children are asleep.
- Started with the statement, *“The reason I wanted to talk to you is because I know you can support and help me.”*
- Why select sister? She already knows about HIV. She would be sympathetic.

Son talking to father

- Best timing? Early Monday morning at home.
- Why? Want to keep it short and let him think about it.

Who is it easier to disclose to?

- Someone of the same sex.
- Sibling (same status in the family).

Strategies and approaches

- Start with relatives whom you are already close to.
- Find a time when it is easier for people to concentrate.
- Find a place where there will be no interruptions.
- Establish a good relationship and trust.
- Go slowly and at each stage see how the person is responding.
- Ask for their advice and support.
- Disclose gradually. If you get a supportive response from the first person, you can try a second; it gives you the courage to continue.
- If people respond well, you may want to tell others; if the response is poor and hurtful, you may decide not to tell others.
- Use your own status to encourage others to be careful with their lives.
- If some relatives know your status and are sick, they may come and seek advice. This will show how valuable you are (they can lean on you for help).

Exercise F5 HIV and human rights

Objectives

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

- identify some of the rights that get violated if we are living with HIV
- identify situations in which we may be denied our rights
- understand the importance of being assertive to maintain our rights.

Time

1 hour

Materials

Copies of *rights pictures* in the Picture booklet.



Facilitator's notes

This exercise is designed to help us recognise that everyone has rights regardless of HIV status, and these rights should not be denied just because we have HIV or AIDS. Rights go hand in hand with responsibilities, and these too need to be recognised in this debate. Stigma and discrimination lead to the erosion of rights, whether in a family situation, workplace or in the community.

This exercise is linked to exercise E5 that explores the use of assertiveness skills as a tool for protecting rights. E4 and E5 focus on human rights, and ideally would be part a programme of advocacy and lobbying for anti-discrimination legislation.

Step-by-step activity

Buzz and brainstorm

1. Ask participants, "What are some of the rights that may be violated if we are living with HIV?"

Examples from Kenya TOT workshop

Right to work. Right to marry. Right to worship. Right to have children. Right to health care. Right to participate in family decisions. Right to associate.

Sculptures

2. Divide into groups of three or four. The facilitator then demonstrates how to make a sculpture with some volunteers. Tell them they are the stone or clay. Arrange them in a position to illustrate a simple concept, e.g. 'Freedom' – group linking arms, raising fists, making victory signs.

Rights pictures

3. Each group picks one of the *rights pictures* and makes a sculpture to show what the right is. View the sculptures one at a time and ask groups to guess which right is being shown.
4. After each sculpture ask participants, "How does this right get violated?" Share stories and experiences.

Processing

5. To conclude, ask participants:
 - What did we learn from this exercise?
 - What are some of the ways we can protect our rights?
 - Are there other rights that other groups in the community may lose because of being stigmatised (e.g. MSM, sex workers)?

Option: Role play

Instead of sculptures, ask small groups to prepare a short role play to show the right and a situation where it may be violated.

Exercise F6 Understanding assertiveness

Facilitator's notes

Learning assertiveness skills can be one strategy to help challenge stigma and defend rights. This exercise goes well with the previous one. Find out how to say 'assertiveness' in the local language.

Objectives

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

- define and understand assertiveness
- practise some assertiveness skills.

Time

1-2 hours

Materials

Copies of *scenarios* on page 13.

Step-by-step activity

What is assertiveness? – discussion

1. Discuss in small groups:
 - *What does it mean to be assertive?*
 - *How can being assertive help us?*

What is assertiveness? From Senegal MSM workshop

Assertiveness is:

Standing up for your rights. Saying how you want things to be done. Being firm – stand up for what you believe in. Being yourself. Claiming your space by standing by your values. Deciding for yourself. Seeking recognition. Not being passive. Not being aggressive. Trying to get what you want. Being confident.

Definition of assertiveness

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



Practising assertiveness – paired role playing

2. Perform a paired role play where someone is not being assertive. Ask the group:
 - *What is happening?*
 - *How can the person be more assertive?*
 - *Does this happen to us?*
3. Show the same situation role play with the person being assertive.
4. Divide into pairs and ask pairs to stand facing each other. Ask each pair to decide their roles. Give out the *scenarios* (see page 13), one per pair.
5. Then ask all the pairs to perform at the same time. After a few minutes, shout "Stop!" and ask to see a few of the plays. After a few demonstrations stop and ask:
 - *What happened? How did you feel? Were they being assertive?*
 - *How can you assert your rights in different settings and keep control over your life?*

When people suggest solutions, ask one of the pairs to play it out. Then discuss what made a difference – voice level, language, body posture, confidence.

Broken record²

6. This is one of the assertiveness techniques you can use in order to emphasise your point. It involves repeating your request or point – gently in different ways (see example on next page).

² Some of this exercise is adapted from Gordon, Gill (1999). *Choices: A guide for young people*, London: Macmillan Education, pp. 33-35.

Exercise F6 Understanding assertiveness

! Action ideas

Try these techniques at home and report back!



- PLHIV: I want to go to see my friend.
 Family: No, you should stay in the house and rest.
 PLHIV: I'll rest when I get home. I want to go to see my friend.
 Family: The neighbours will see you.
 PLHIV: I'm not worried. What is there to see? I want to see my friend.
 Family: You don't have time for friends. You need to focus on your health.
 PLHIV: I'm getting stronger every day. This friendship is helping. So I would really like to see my friend.

Summary

Assertiveness techniques

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

Exercise F6 Understanding assertiveness

Scenarios

<p>1. You are staying with your auntie. You have been sick but are now feeling better. You are helping with the housework. Your auntie returns and orders you, "Go into your room. You shouldn't be doing that. Go!"</p>	<p>9. You have been out with your friends playing pool. It is the first time you have had a drink since you got sick. Your cousin tells you, "If you are going to start drinking alcohol again, I will not be looking after you."</p>
<p>2. You are invited to your brother's house for lunch. While the other adults are talking together, you go outside to play football with your nephew. Your brother comes out and says to you, "You are too sick to be running around. You need to rest! Come inside."</p>	<p>10. Last year you were quite sick but since you have been taking ARVs you have been feeling good. Today you have come to tell your sister that you are expecting your first baby. Your sister is shocked and upset and says, "How can you be so irresponsible!"</p>
<p>3. You have been visiting some friends in another compound. A friend gives you a lift home. When you arrive, your mother says, "You should not be going out at night and mixing with those people. I forbid you to see them again!"</p>	<p>11. You found out two months ago that you are HIV positive. You have not told anyone yet but you have now discovered that the counsellor you talked to has been telling other people, including a member of your family. You go to confront the counsellor.</p>
<p>4. You bring your new girlfriend home to meet your uncle and auntie. Later when your girlfriend has left, your uncle says to you, "You really shouldn't be seeing girls any more. You need all your strength to get better."</p>	<p>12. You have been having some stomach pains and diarrhoea. You go to the clinic where you are well known. You want to see a doctor but the nurse tells you, "You should just go home and rest, there is nothing more we can do for you."</p>
<p>5. You have been sick recently and do not seem to be getting better. The nurse comes to your house and sits discussing your health with your wife and sister. When you join them, they stop talking.</p>	<p>13. You are just recovering after being sick. You have started taking ARVs and do not feel like eating big meals. When you ask for just a little food, your mother says, "If you don't eat you will get sick again, and you will have only yourself to blame."</p>
<p>6. After being off sick for a while, you return to work. Your boss says, "You really shouldn't be here. Why don't you look for a job that is less tiring?"</p>	<p>14. You have just come back to your football team after being sick for a while. When you score a fantastic goal you overhear a team mate saying, "Be careful about hugging him, you shouldn't get too close to him."</p>
<p>7. You have applied to go on a two-week training course. Your boss tells you, "I wish you could go, but I think you should stay close to home in case you get sick again."</p>	<p>15. You go to the clinic to find out the results of your CD4 count. This is the third time that you have come. When you ask a nurse if the results are ready, she tells you, "I am so busy. We just can't find your results. I think you will have to come back next week."</p>
<p>8. You decide that you are feeling better and go to join your wife and brother in the field. Your wife says, "You should really be inside. It's not good to be in the sun when you are sick."</p>	

Exercise F7 Paranoia and hyper-sensitivity



Facilitator's notes

This exercise explores how self-stigma can develop. It is important to explain that identifying self-stigma is not a reason to blame someone for feeling self-conscious or isolating themselves. Self-stigma happens because of the climate of stigma. It is a reaction to, or fear of, being stigmatised.



Objectives

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

- identify the symptoms and causes of paranoia and hyper-sensitivity rooted in stigma
- gain insight into their own way of responding to people who stigmatise them.



Time

1 hour



Materials

Props for the role play, e.g. a poster, a cup.

Step-by-step activity

Paranoia – story role play

1. Ask a participant to read aloud the story below, or prepare beforehand for some participants to act out the story as it is read aloud. One of the trainers can play the role of Sam. Stop at intervals to listen in to some of Sam's thoughts (say them out loud).

Three weeks ago, Sam took an HIV test and tested positive. At first he seemed to be okay and felt quite calm, but for the last few days he has been feeling that everyone is watching him and talking about him.

He gets the bus to work and overhears two women talking about someone who is sick and very thin. He looks at his own body and is sure that he is losing weight and beginning to look thin. He wonders if they are talking about him.

At work he notices a new poster about ARV treatments. Sam has not told anyone at work about being positive, yet he thinks that someone has guessed and put the poster up as a way of telling others about him.

When his boss asks him how he is feeling, he thinks she is asking him about being positive. He wonders if he is looking sick. He starts to sweat and feels the beginning of a headache. He thinks that he should have stayed at home today. His boss tells him that he will be working on a new programme from next week, and although this is an opportunity he has looked forward to, now he thinks she is trying to get rid of him from her department.

The final straw comes when his workmate brings him a cup of tea in a brand new mug. Now he is sure everyone is talking about the fact that he is HIV positive.

2. Ask participants to discuss:

- *What happened in the story?*
- *Have you had similar experiences?*
- *What can we do to reduce these feelings of being looked at or judged?*

Summary

- Learn to recognise that we will face stigma in society, but if you are prepared you won't let it destroy you.
- Don't always assume that you are stigmatised in every situation. Ask why.
- Discuss your experiences of being stigmatised with other PLHIV and try to distinguish between stigmatising behaviours and those that were simply normal reactions.
- Encourage family members to stop 'killing you with kindness' – help them see that over-sympathy also hurts.
- Gain control over your feelings and emotions.
- Use humour as a way to cope with stigma, especially among others in the same situation.

Exercise F8 Building self-esteem

Facilitator's notes

This is a series of exercises³ on self-esteem. Choose one or two, or do them all over a period of time. If you use the visualisation technique, think about whether it would be better to translate it into a local language.

Objectives

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

- build up their self-esteem so that they can cope with stigma
- be more aware of their personal coping strategies and strengths.

Time

Varies per exercise

Materials

Exercise A – copies of the *word list* or make your own.

Exercise E – ball of string.



³ Some of these exercises were adapted from Gordon, Gill (1999). *Choices: A guide for young people*, London: Macmillan Education, p. 29

Step-by-step activities

A. What kind of a person am I? – Word list

1. Hand out the word lists and ask each participant to draw circles around the words that best describe her or him. Tell them they can add new words to the list.

Sample word list

Short, tall, funny, serious, clumsy, attractive, slow, fast, generous, kind, strict, proud, friendly, warm, aggressive, hard-working, shy, stubborn, humorous, cheerful, playful.

2. Ask participants to discuss:

- *How did you feel during the exercise?*
- *Did you recognise anything new about yourself?*
- *Were there any words that you wanted to choose but felt that they were not you?*

B. Seeking comfort – visualisation exercise

1. Ask participants to find their own space to sit or lie on the floor. Put on soft music. Once they are relaxed and comfortable, read out the exercise below. Read very slowly and pause between sentences. The exercise should take at least 15 minutes.

Close your eyes, get comfortable and focus on your breathing for a few moments (pause). Take some deep breaths and feel your body relax (pause). Now imagine a place you would like to be where you feel totally comfortable with yourself (pause).

It could be somewhere you know or a place in your imagination (long pause). How does it look? Look all around you. What do you see? Do you notice the weather? (pause) Any colours? (pause) The atmosphere?

Now imagine that you can bring anyone you want to meet you in this place. It could be a friend, someone in your family, a stranger (pause). Take time to get a sense of who you want this person to be (pause).

You may want to talk to this person about your life, or you may want to share the silence (pause). You might want to ask questions, tell them about yourself, maybe ask them for help (pause). Take some time to be with this person (long pause).

Now it is time to leave (pause). Take a look around you (pause). Remember your beautiful place (pause). And slowly, when you are ready, come back to the room.

Exercise F8 Building self-esteem

Debriefing

- Let participants share their experiences if they wish. (Often participants may remain in a quiet space and not wish to share straight away.) Emphasise that if they found a peaceful place to be in the exercise, then that place will always be there for them. When they are feeling low or full of self-pity, they can remember that place in their mind as a place of rest, free from judgements.

Note: In any group there may be one or two people who will not like visualisation exercises. In the debriefing, let these participants talk about what happened for them during the exercise or why they were not able to find their 'place'. Everyone will have his or her own experience.

C. A message to you!

This exercise works best in a group who have known each other for a while.

- Give participants a piece of paper and ask them to write their name at the top. Now stick or pin their paper onto their back.
- Ask participants to write down something that they really appreciate about that person on their piece of paper. Allow enough time for everyone to write on each other's paper.
- Participants then read their messages out aloud or to themselves.

D. Walkabout

- Give the following instructions in the form of a story. Talk slowly and pause between sentences.

Close your eyes and imagine it is five o'clock in the morning. Feel the freshness and coolness of the morning before the heat of the day comes. Now open your eyes. Start walking in any direction you feel like, making sure not to bump into anyone else. Focus on your own thoughts and actions. It is still early in the morning and you are feeling strong and fresh. Show how good you are feeling in the way you walk (pause). Now imagine you have been walking for a long time and you are beginning to feel tired. The path is getting steeper – in fact, it is going straight up a mountain! Reach out to grab hold of trees and pull yourself up. You have to work hard now to get to the top. Pull yourself up. Pull! Pull! You've made it! Stop and take a break. Look down the mountain. Can you see where you started? Now start walking again. Show the tiredness in your body. You come to a river. Cross it carefully. The water is up to your waist. When you reach the other side, you come to an area full of tall grass. Be careful where you walk – watch out for snakes! You finally come to a road and start to walk along it. All of a sudden you see an old friend. Rush to him or her and tell them about your journey.

Optional debriefing

- Ask participants to discuss how they felt at different times during the journey.



Exercise F8 Building self-esteem

“When spider webs unite,
they can tie up a lion.”

Ethiopian proverb



E. Building community – web of string

1. Ask the group to sit in a circle and give one person in the group a ball of string. Ask him or her to say one quality that they have for helping others and then throw the ball to someone else, holding on to the end of the string. Repeat until everyone has caught the ball and said a helping quality.
2. Ask participants:
 - *What does the web represent (togetherness, unity, links between us, etc.)?*
 - *What would happen if someone did not participate?*

F. Building self-esteem – individual reflection

1. Ask participants to sit on their own and answer the following questions:
 - *What things make you proud of yourself and your achievements? Make a list.*
 - *How do other people see you? How do you want other people to see you?*
 - *What do they expect you to do?*
 - *How do these expectations and the way people see you affect how you feel about yourself?*
2. Then ask participants to pair off and share what they have written.

G. Body self-esteem – mime in circle

1. Ask participants to think of three things that they like about themselves, e.g. appearance, mannerisms, thinking, relationships, spirituality, etc.
2. Go around the circle asking each person to say, “*One thing I like about myself is...*” and then make a gesture to show what it is he or she likes (e.g. if you like your hair, you might shake your head; if it is your body, you might wiggle your hips).
3. After each mime, ask the group to guess what it is the person likes about himself or herself. Make sure the group guesses what it is. Continue going around until everyone has had three turns.

Summary

Our family and friends sometimes forget to praise us, they only criticise us. If they also stigmatise us, this affects our self-identity and lowers our self-esteem, which in turn affects our ability to take action to improve things.

We can change the way we feel about ourselves and develop confidence and self-esteem in the following ways:

- Encourage people to praise us by praising them. Tell others what they have done well, the things we like about them, their strengths.
- Give ourselves positive messages. Sometimes we say good things about ourselves and sometimes bad. Sometimes our conscience tells us we have done wrong. Sometimes we are too hard on ourselves.
- We all make mistakes – that’s how we learn. But we don’t need to feel bad every time we make a mistake.
- Being good at something helps us gain confidence, so focus on your strengths. Then when you are feeling bad, say to yourself, “*Yes, but I’m very good at...*”

Exercise F9 Coping with stress



Objectives

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

- recognise some of the factors that cause stress, including stigma
- develop skills and strategies for dealing with stress.



Time

1 hour



Materials

Copies of *Penina's story* (see right).

Tips for relaxation

Close your eyes and breathe slowly, focusing on the breath going in and out of your body.

Start with your left foot and relax all the bones and muscles in it. Move up to your calf muscle and then continue all around your body ending with the right foot. By then your whole body will be relaxed.

Step-by-step activity⁴

What is stress? – story discussion

1. In small groups, ask a participant to read the story below. Then discuss,
 - *What is happening to Penina? Why is she behaving this way?*

Card storm in small groups

1. Ask participants, “*What are the things that cause you stress?*” Write each point on a card. Then put the cards into two piles: (a) what you can change and (b) what you are stuck with.
2. Select a few of the most important causes of stress and discuss what you might be able to do to reduce these causes.
3. Tell the group that you cannot change some of these causes, but you might be able to reduce the stress produced by them. Ask, “*What can you do to reduce stress?*”

Penina's story

Penina's husband is away in the city. Penina has been having lots of diarrhoea lately and thinks she may have HIV. It is the farming season and Penina has to work alone in the fields because all her children are in school. The weeds are growing fast and she cannot keep up with them.

The maize stored from last year is almost finished, the price of food is going up and the children are often hungry. Normally Penina would discuss this with her neighbours, but recently they have not been speaking to her. The rains have brought malaria and her youngest daughter has a fever. Penina worries she may get it too. She has not paid the school fees, and whenever the head teacher sees her in the village he shouts at her. Her friend told her that he was spreading rumours about her illness.

Penina has problems sleeping. She wakes up each night and sits for hours thinking about her problems. Her heart beats fast, she shakes and she sometimes has nightmares. She finds herself shouting at the children and slapping them. They are shocked. Why is their mother behaving like this?

Ways to reduce stress

- Don't carry all your problems on your shoulders. Try to see how others, such as family members, can help you in your home and outside.
- Use prayer to share your load so you worry less about your problems.
- Talk about your problems with someone you trust.
- Have a good cry – it can relieve stress and sadness.
- If your friends and neighbours have similar problems, meet together and share worries and feelings. Look for solutions that you can work on together.
- Put your problems in order of importance and set goals to solve the most important.
- Try a relaxation exercise (see left).
- Play some music that makes you feel relaxed.
- Do something that you enjoy (e.g. singing or reading) at least once a day.

⁴ Adapted from Gordon, Gill (1999). *Choices: A guide for young people*, London: Macmillan Education, pp.33-35.

Exercise F10 Death and dying

Facilitator's notes

In many communities it is difficult to talk about death. People believe that the minute you start to talk about death, you will make death a reality. This exercise provides a safe space and hopefully less fearful way of getting people to talk about death.

However, this is another exercise tackling a difficult subject. Strong emotions may come up and you should be prepared to manage the feelings. It may be worth trying the exercise yourself first. Ask for support from a counsellor colleague.

Objectives

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

- understand their own feelings and fears about death and dying
- talk to others about this topic.

Time

2 hours

Materials

Tape recorder and soft music.

Step-by-step activity

Talking about death – brainstorm

1. Ask participants, "How do we feel talking about death?"

'My funeral' – visualisation

2. Ask participants to sit comfortably or lie on their backs on the floor, and put on some soft music. Ask them to close their eyes and breathe deeply. Once they are relaxed and comfortable, read out the visualisation exercise below very slowly.

Imagine you have died. You are watching your own funeral or your own burial. How would you like your funeral to be? Where is it being held? Is there any music playing? Who are the mourners? Is there anyone missing? Who is lowering the coffin? Are there flowers?

Do you have a sense of whether there is life after death? Any sense of heaven or something else? How does it feel to watch what is going on?

3. Allow some time and then ask participants slowly to come back to the room. Then ask participants to discuss:
 - How was it?
 - What role can you play in your funeral?
 - Is there any preparation that you wish to do before you die?

Summary

Death is a difficult topic to talk about. We often avoid discussing it. Yet we may be thinking about death even if we are not talking about it. Sharing some of our fears and worries can help to give us support. There are preparations we can make that may make things easier for us and for the people we leave behind.



Exercise F11 Positive living

Facilitator's notes

There are many written materials about different aspects of positive living that can help us to lead healthy and productive lives – and live longer! In this way we put a stop to the belief that HIV means we are dying. This exercise is a way of sharing what we already know.

Objectives

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

- understand how positive living can help us to combat stigma
- identify some of the main features of positive living in order to support us.

Time

1 hour

Step-by-step activity

Positive living – card storm and presentations

1. In pairs, ask the group to write on cards all the different things they know are involved in positive living – one per card.
2. Cluster the cards according to categories.
3. Assign each category to a group of participants to research.
4. Ask groups to prepare a short (five minute) presentation on their topic. Tell them to try to present new information that the group may not know about.

Possible topics on positive living

- Taking ARVs (and adherence)
- Food
- Hygiene
- Spiritual support
- Support from family and friends
- Safe sex
- Emotional well-being
- Exercise
- Early medical care
- Treating opportunistic infections
- Limiting alcohol intake



Exercise F12 'Don't have children'

Facilitator's notes

When we tell family members and friends that we are living with HIV, they often start to give advice about what we should and should not do, e.g. don't drink, don't go out so much, don't stay up late, don't work too hard. This exercise explores one of the most powerful 'don'ts': 'don't have children'.

Objectives

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

- discuss the stigma that is used against us if we choose to have children
- explore the conflicting stigmas faced by women who are HIV positive.

Time

1 hour



Step-by-step activity

Popular beliefs about having children – brainstorming

1. Ask participants to brainstorm things people say about women and men living with HIV to try to stop them having children.

Examples of things people say

- If a woman is HIV positive, she cannot bear children.
- If she is HIV positive, she will miscarry or the baby will be stillborn.
- If a woman is HIV positive and gets pregnant, it is a big strain on the immune system and she will die much quicker.
- People living with HIV who have children are being selfish.
- It's not fair on the children.
- Children will be orphans when the parents die.

2. In pairs discuss:

- *How do these things make you feel?*
- *What can we do to cope with these attitudes?*

Women having children versus not having children – card storm

3. As women living with HIV, we are caught between two stigmas: of being judged if we choose to have children and the stigma of being childless, which in many cultures is great. The choices are not easy. In pairs, write on cards some of the things people say if we do not have children.

Examples of the stigma of not having children

- Society does not see me as a woman.
- There is no one to look after me when I am ill or old.
- People keep asking me, "Why don't you have kids?" Or they say I am useless because I have no children.
- If you have no children, your partner leaves you.
- Pressure from relatives to have children.
- My name is not used to name a relative's child for fear that my situation (childlessness) will be passed on.
- Fear of looking and behaving different, (i.e. not having children).

4. In small groups, share experiences and discuss:

- *How do these things make us feel?*
- *What can we do to cope with these attitudes?*

Summary

Having children brings difficult decisions for those of us who live with HIV. Most of us think carefully before planning a child. Women face double stigmas and a no-win situation. The pressure on us all – men and women – to have children is great, and for many of us children bring great joy and help us to live longer.

Exercise F13 ‘Don’t have sex’

Facilitator’s notes

There are lots of assumptions and stereotypes about us and our sexual performance. Many people assume that once we are diagnosed, we have no sexual feelings. This exercise is aimed at bringing these comments out into the open and reaffirming that it is normal to have sexual desires whatever your status.

Objectives

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

- analyse and deal with stigma that says that they should not have sex
- reaffirm that they also have sexual feelings and can ‘do it!’
- review what is involved in safe sex.

Time

45 minutes

Step-by-step activity

Listing ‘don’ts’ about sex – brainstorming

1. Work in gender groups (women together, men together). Ask participants to make a list of negative things that people say about sex and PLHIV, especially in relation to sexual performance.
2. Share the points in the large group.
3. Discuss some of the strategies we use in dealing with these comments.

What people say

What people say about sex and PLHIV

Flat battery. No fire. The penis can’t wake up. You will be barren. You can’t ejaculate. You no longer need to have sex. You can only do one round a week. No one wants you now.

Dealing with the comments

Ignore them. Laugh and make a joke about it. Dance like you haven’t heard them! Make a point of talking about it with your partner.

Option: Safe sex – small group discussion

1. Divide into small groups and discuss:
 - *What is safe sex?*
 - *How can you minimise the risk for you and your partner of re-infection?*
2. Share safe sex tips, fears and joys.

“ One man told us how his wife goes to see a counsellor every month for support. Every month the counsellor asks her how often she is having sex with her husband, whether they are using condoms and how his sexual performance is! ”

Summary

There is so much stigma around being sexually active if you are HIV positive. You can’t win. When people know that you are HIV positive, they assume you are going to die soon and ignore your feelings. As one man said, other people have already “buried your feelings in the cemetery”. They feel this gives them a licence to say anything about you, no matter how much it hurts.

You can’t win:

- If you do have sex, you are irresponsible.
- If you don’t have sex, then you are ‘not a man’ or you are ‘barren’.
- If you use condoms even they can be stigmatising.

It is up to us to be responsible and have fun!

G e n d r e m o d u l e

Introduction

As ARVs become more widely available across Africa, there is hope that treatment will reduce HIV stigma: PLHIV will be able to live longer and healthier lives; the virus will be less associated with death; and treatment will ensure that many of the signs and symptoms of AIDS are less common.

However, it has been recognised that HIV stigma can be a barrier to accessing treatment, and fears around disclosure, exposure and judgements all fuel this stigma. Many people still only get tested for HIV when they become very sick. Others are scared to disclose their HIV status to their partners for fear of the consequences. Many professionals, particularly in the health field, fear stigma and judgements from colleagues and loss of social status. In these circumstances, if people are able to access treatment it is often kept a secret. The treatment itself becomes a means of public disclosure and so it is hidden and taboo.

Rumours about the side effects and efficacy of ARVs also create doubts and fear. Some extreme religious groups even challenge the taking of medicines and preach that only prayer and a 'holy life' can 'cure' AIDS.

Adherence (sticking to a treatment regime of taking daily doses at the same time each day) is a crucial part of ARV treatment: poor adherence causes drug resistance and less effective viral control. Stigma is also being cited as a barrier to good adherence. Studies – and good practice – have shown that where there is openness and acceptance, (i.e. the opposite of stigma) both access and adherence to treatment are easier to achieve.

Models of community engagement and treatment literacy lead to populations who feel freer to discuss HIV, test for HIV and seek treatment, and who receive both family and community support to continue successfully with that treatment.

This module contains exercises that try to disentangle and explore some of the ways in which stigma is a barrier to effective ARV treatment. It was developed with the support of ACER¹ project staff, Carolyn Green and Katongo.

¹*Antiretroviral community education and referral project (ACER)* is based in Alliance Zambia and works on principles of community engagement and involvement of PLHIV in treatment support.

Exercise G1 Treatment and stigma problem analysis

Facilitator's notes

This is a good starter exercise if you are focusing on treatment and stigma. You may wish to share your own experiences of accessing ARV treatment if it seems appropriate.

Objectives

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

- begin to understand how HIV stigma can affect access and adherence to ARV treatment
- share ideas and experiences of stigma related to ARVs.

Time

30 minutes

Materials

Selection of *general stigma pictures* from the Picture booklet and *treatment story pictures* (see page 49).

Step-by-step activity

Buzz and card storm

1. Distribute cards and markers. Ask participants to buzz with the person next to them some of the ways in which stigma affects effective ARV treatment. Write one point per card.
2. Stick cards up and ask some participants to help cluster similar points.
3. Divide into small groups and give each group one of the clusters to analyse further. Share stories and experiences to try to understand the problems more.

Report back

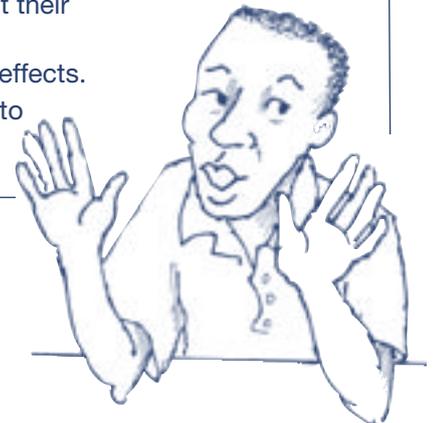
4. Groups present summaries of their discussions in any way they choose, e.g. flipchart, story, role play.

Processing

5. Ask participants:
 - *What do we learn from this?*
 - *What are some initial ideas about how we could change things?*

Examples of treatment and stigma from ACER partners

- Disclosure – you don't tell your family and keep your ARVs hidden.
- Secrecy – your colleagues don't know you are taking ARVs.
- The church teaches that you need to pray instead of taking medicine.
- Health workers don't take time to tell you about adherence, especially if you look dirty or poor.
- Health workers fear colleagues finding out their HIV status.
- There are myths and rumours about side effects.
- The family doesn't want to spend money to support your treatment.



Exercise G2 Treatment and stigma in different contexts

Facilitator's notes

You may consider grouping participants strategically, e.g. religious leaders, teachers, health workers.

Objective

By the end of this session, participants will be able to identify how stigma in different contexts (e.g. clinic, workplace, church, family/home) becomes a barrier to getting treatment.

Time

1 hour

Materials

Context cards from Module A booklet.

Preparation

Put up context title cards in different stations around the room or outside, e.g. clinic, workplace, church, family/home, school.

Step-by-step activity

Identifying forms of stigma – rotational card storm

1. Divide into pairs and hand out cards. Ask, “*What types of stigma do people face in these places when it is known they are taking ARVs?*” Pairs move around the stations and place cards under the relevant context title card.
2. When everyone has been to each station, ask groups at that station to cluster common forms of stigma together and summarise each context.

Examples from Livingstone regional trainers meeting

Church

- Blame and judging – church links AIDS to sin.
- Judging – HIV was acquired through prostitution or adultery.
- Gossiping when a church member is discovered or suspected of being on treatment.
- Disbelief – some don't believe in medical treatment.
- Saying you can only be healed by prayer; no need for medicine.
- Misinformation – claiming prayer heals HIV; if you are not healed by prayers, then you are a sinner.
- Prayer for HIV positive people only.
- Selling holy water as a cure – telling you to throw away ARVs.

Workplace

- Gossip – colleagues talk behind your back.
- Name-calling – ‘air time top-up’ – life has expired so you need to top-up/refuel.
- Finger-pointing if they catch you taking medicines.
- No confidentiality.
- Intimidation by fellow workers – not allowed to contribute ideas.
- Firing, demotion or no promotion once suspected of taking treatment.
- Sent on enforced leave – people don't disclose treatment for fear of losing job.

Clinic

- Isolation – ARV clinics often isolated from other wards.
- Name-calling and finger-pointing.
- Labelling of medical cards and medical jargon to inform other staff of patient's status.
- State of the disease – need only palliative care.
- Excessive protection – some staff overprotect themselves when handling patients.
- Health workers' poor communication skills and lack of counselling skills.
- Conditional disclosure when applying for ARVs.
- Less time spent with you if you look poor, more time with those who are educated.
- Lack of caring.

Family

- Name-calling by siblings.
- Don't want to ‘waste resources’ getting you to the clinic.
- Blaming.
- Tell you that you can't drink, stay up late, do physical sports.
- You keep it secret for fear of rejection.

Exercise G2 Treatment and stigma in different contexts

Examples from Livingtone regional trainers meeting (cont.)



School

- You don't know who to tell.
- Name-calling if someone finds out.
- Teachers can be cruel.
- If you go to boarding school, everyone will see your medicine.
- Missing classes to go to the clinic, no permission to go for routine checks.

Personal sharing around the circle – standing circle

3. Ask participants to take one of the cards and give examples from their own experience or things they have seen or heard in the community: *“What is the story or incident behind the issue in each card? What kind of experience have you had about treatment?”* For example, *“My cousin who is on treatment heard this...”*
4. Do this personal sharing exercise in a standing circle – people don't talk for too long when they are standing.

Option 1: In small groups, each take a context to work on. Ask, *“What did we learn from this list of forms of stigma? What can we do to challenge forms of stigma which are hindering treatment?”*

Report back to large group.

Option 2: In small groups, perform role plays to show the stigma in each of the above contexts. Select one scenario and use stop-start drama to discuss, *“What could change things and turn it around?”*

Examples of contexts

Church: Preacher says, *“God will heal you if you pray, unless you are a sinner. So you should stop using this medicine.”*

Clinic: A nurse is worried about facing stigma from her colleagues, so she self-administers ARV drugs in secret with no one seeing her.

Workplace: A worker is not chosen for a training course because his boss thinks he will have problems with treatment, i.e. not getting tablets.

Fishing camp: Other workers gossip about a woman who was not tested which put her off getting tested and starting treatment.

Community: Name-calling and gossiping in church.

Summary

The stigma facing people on ARVs happens in many places, resulting in layers of stigma; you face it at work, at church, in the home and so on. It is important to address this stigma. Those taking ARVs can be prepared through counselling and community support so that the stigma does not hamper their treatment. Stigma in different places may need specific approaches to suit the context.



Exercise G3 Treatment in the family

Objectives

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

- analyse how stigma in the family affects treatment
- explore strategies that can help a family support someone on treatment.

Time

1 hour

Materials

Two role play scenarios written on cards.

Action ideas

Try this out in your community group, church group or anti-AIDS club – explore solutions together.

Step-by-step activity

Stigma in the family – role playing

1. Split into two groups. Ask each group to perform one of the two role plays below. Ask participants to discuss and record points on cards:
 - *What did you see in each play?*
 - *What are the similarities and differences?*
 - *What is preventing Family A from being more accepting?*
 - *What might be the effects of these different situations on adherence?*

Family A: Tumaini is a 27-year-old journalist. Her father is a teacher and her family are well respected in the community. Tumaini is HIV positive. She has not disclosed her status to her family. She is taking ARVs secretly and hides them in her bedroom. Her family often boasts that there is no HIV in the family. They say that if anyone gets HIV they will be kicked out of the house.

Family B: Mulenga is 28 years old and works as a newspaper seller. He stays with his aunt, uncle and cousins. Mulenga is HIV positive. He has disclosed his status to family members. He is taking ARVs. Mulenga's family gives him lots of support around taking his treatment.

Examples from regional workshop

Family A: Family's own fears about HIV. Moralising judgements. Climate of secrecy. Relationships within the family. Their status and fears about what others (e.g. neighbours) will say.

Family B: Openness. Family support. Reminding him about taking medicine. Accompanying him to the clinic. High self-esteem.

Problem solving – topic groups

2. Divide into small groups and ask each group to select one of the examples. Ask, "What could happen to change the attitudes of Family A members, to make them more accepting/supportive?" Devise a role play to try out a suggestion.

Prevention	Possible solutions
Family's own fears about HIV	Young family member returns from attending anti-AIDS club. Sees something on TV which prompts him to talk about HIV to give the family more information. Trusted family member comes in and tells them he has just gone for an HIV test at the clinic.
Secrecy	A friend talks to Tumaini about how to disclose to one family member, or she joins a support group where she learns how to do this. Tumaini's counsellor offers to talk to the family on her behalf. Tumaini meets Mulenga and they share experiences!

Report back

3. Test the realism of the solutions through drama. Ask the reporting group to role play their solution, and use stop-start drama to explore it further.

Exercise G4 The burden of secrecy



Objectives

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

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



Time

1 hour



Materials

Copies of *case study*.



Step-by-step activity

Case study

1. Give out copies of the case study. Ask one or two participants to read it aloud to the group.
2. Tell the group you are going to make a drama to show the situation. There are three scenes. You will ask for volunteers for each scene. After each scene the group will discuss the key issues that have been shown.
3. Write each of the events over a single day on a flipchart. Read them out one by one, asking actors to help improvise each scene.
4. Ask volunteers to act out the scenes.
5. After each scene ask the volunteer playing Lawrence, “*How are you feeling?*”
6. Write up key observations on a flipchart.

Case study

Lawrence is 31, single and working in an engineering company. He is on ARVs and takes them each morning at 7am before going to work, and at 7pm when he returns. His HIV status and the ARV treatment is a secret. He always remembers his HIV counsellor telling him that everything is confidential.

One day his older brother phones and says he will meet him after work so they can go to his uncle’s place for funeral prayers. He quickly agrees, but after his brother has rung off remembers that the medicine is at home. He will not have time to get it. He worries the whole afternoon. To add to his worries, his boss asks him to make a presentation the following day at 9am – the time he had booked to go for his six-monthly CD4 check. He tries to get out of this presentation, but his boss insists.

When his brother arrives at 4.30pm, he goes with him. At his uncle’s place there is a lot of talk about how the uncle died – people say he was “misbehaving” and that he had started “using these ARV drugs”. Someone says, “Maybe it is the drugs which killed him”.

Lawrence reaches home at 10pm, very hungry. He only had tea at the funeral. There is no food in the house. He takes the medicine without any food and has trouble sleeping because of his worries. Will the family find out about his status? Will the treatment taken without food bother him? Does it matter that he took it three hours late? What is he going to say at his presentation – he has not prepared.

Scene 1: Brother phoning him to go to the prayers/boss asking him to give a presentation.

Scene 2: Uncle’s house – people gossiping about his uncle’s death.

Scene 3: Going home late at night to take the ARVs without food.

Exercise G4 The burden of secrecy

Follow-up discussion

7. Ask participants:

- *How does the secrecy impact on Lawrence's life and ARV treatment?*
- *Why is it important to break the secrecy and tell someone?*
- *Who should he tell to lighten his burden of secrecy?*
- *What could really help him in different places (home, extended family, workplace) to manage his treatment more effectively?*

Option: Choose one scene to replay, imagining that Lawrence is open about his HIV status and treatment.



Exercise G5 'We will not tell anyone'



Facilitator's notes

This exercise could be a good one to use with counsellors and other health care workers to help them explore how discussing disclosure strategies with clients can support adherence.



Objectives

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

- explore how emphasising confidentiality can hamper disclosure
- look at how secrecy can create problems around treatment and adherence
- look at ways we can support each other to find strategies for disclosing our status.



Time

1 hour



Materials

Copies of *case studies* on page 31.

Step-by-step activity

Case studies

1. Divide into small groups and read through a case study together (see page 31).
2. Discuss what would be the benefits/advantages of the person disclosing their status.
3. Develop five top tips that you would give to the person in the case study, on how to disclose. Write them on a flipchart.

Report back

4. Groups come back into plenary, read the case studies and present their top tips.

Option: Role play the disclosure based on trying out your top tips.

Examples of top tips

- Choose the right time and place.
- Practise what you will say with a friend, or on your own.
- Ask a friend or other family member to be with you.
- Ask others who are in the same position as you for ideas.
- Ask your counsellor to help you to tell someone close to you.



Summary

- When counsellors or other health workers focus so much on confidentiality, it can discourage us from thinking about telling people about our status.
- We can feel that disclosing is a difficult thing to do, but with support from friends and family it becomes easier.
- Sharing strategies with others in a similar position can help us to be more open.
- Once we have disclosed we are less vulnerable to stigma.
- Being open helps us to talk about our health, taking ARVs and sticking to adherence.
- Gender and power differences make disclosing to some people more difficult.

Exercise G5 'We will not tell anyone'



Disclosure case studies

Case study 1: Natasha is 18 years old, single and living with her parents in an urban compound. She is taking ARVs with the knowledge of her parents, but they have agreed that this treatment should be kept secret from the neighbours and extended family. Natasha would really like to tell her best friend at school, whom she is very close to.

Case study 2: Kabalika, who knows he is positive, has not yet disclosed to his family. One day he goes to the clinic to get some advice about telling his mother from Emmanuel, the treatment support worker. Emmanuel is very impatient – he is overburdened with work – and tells Kabalika that he should consider how much it will upset his mother.

Case study 3: John is already on ARV treatment, but he has not told his wife about the treatment or his HIV status. He takes the drugs while he is at work. One day the maid sees John hiding the tablets in his briefcase. He decides that it is time to tell his wife before someone else does.

Case study 4: Rudo is a school teacher at a primary school in town. She stays alone with her niece in one of the shanties. She has a good friend at school, a fellow teacher whom she would love to talk to about her HIV status. She suspects her friend might also be living with HIV, as she saw some ARV bottles in her bag.

Case study 5: Martha found out that she was HIV positive when she went to the antenatal clinic. The nurse has told her she should tell her husband, but she is scared of how he will react. She has started taking ARVs and keeps them at her sister's house nearby.



Exercise G6 Children, treatment and stigma

Facilitator's notes

This exercise is especially helpful for guardians and parents of children who are living with HIV.

Objective

By the end of the session, participants will have a clear idea about why and how to inform children about their HIV status and ARV treatment.

Time

1 hour 30 minutes

Preparation

Ensure you have enough space to carry this out – a place for the reflection and for paired role plays.



Step-by-step activity

Introduction – brainstorm

1. Ask participants to think about some of the questions that parents might have around telling (or not telling) their child about their (the child's) status and why they are taking ARVs.

Examples of talking about treatment for children

- If a child is on ARV treatment, should you tell him or her what they are taking?
- Are you protecting your child by just treating it as normal medicine, rather than giving him or her more information about ARVs and how they can manage it better?
- Is there a right age to be told you are HIV positive?
- What about a child's right to know or understand his or her status and the medication?
- How can a child be supported when he or she is told?
- How does this issue overlap with the confidentiality issue?
- What happens to the family if the child tells everyone?
- Will the child be stigmatised at school?

Remembering being 12 years old – reflection

2. Ask participants to sit on their own and close their eyes. Say:

“Imagine you are a 12-year-old. What is it like? What is important in your life? What do you like doing? Who are you close to? Who do you talk to about things? What do you worry about? (Wait a while to let people imagine.) Now imagine that you have been taking medicine for a while and you have asked your aunt what it is for. She tells you that you are living with HIV. How do you react? How do you feel? How will this affect you?”

Discussion

3. In pairs discuss, “*How did the reflection go?*”
4. Return to plenary and ask, “*At what age and how do we tell a child about their HIV status and ARV treatment?*”

Telling the child – paired role playing and stop-start drama

5. Divide into pairs again and find an empty space. Within each pair agree on who is the child and who is the parent.
6. Brief the person playing the child. Say, “*Your role is to ask your mother or father some of the following questions.*”
 - *What is this medicine?*
 - *Why do I have to take it?*
 - *Why are my brothers not taking it?*
 - *When can I stop? You keep saying I will have to take it for my whole life.*
 - *What have I got? Is it AIDS?*



7. Let each pair work out how to role play this situation. When they finish, invite one pair to perform their role play. When they finish, ask:

- *Do you agree or disagree with this approach? Why?*
- *If you disagree, how would you respond to your child?*
- *What other approach might be used?*

If others have different ideas, ask them to volunteer to try it out. Use stop-start drama to show a range of approaches.

Debriefing

8. Ask participants:

- *How did it feel being the child? Being the parent?*
- *How would you tell your child about his or her status?*
- *What kind of support do you need as a family?*

Summary

- Children have a right to know about their HIV status so long as this is done in a sensitive way.
- Talk to other parents who are in the same situation.
- If a child starts asking questions it is probably the right time for the answers.
- You can also share your own HIV status with the child as a way of supporting them.
- Discuss different coping strategies with your children for who they should tell and how.
- Ensure that your child understands about the importance of adherence and help him or her to work out the best way to achieve it.
- Try to find out if there are any leaflets or books that your child can read about children in the same position.



Exercise G7 Health workers, treatment and stigma

Objectives

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

- explore some of the particular stigma issues facing health workers
- discuss ideas on how to reduce stigma in clinics and increase uptake of ARVs among health workers living with HIV.



Time
1 hour



Materials

Copies of *health worker case studies* (see pages 34-36).

“ If you go for a test, you have to disguise yourself, go somewhere else, don't look like a nurse, wear tropicals, don't be seen! ”

Nurse, Kitwe, Zambia

Facilitator's notes

This exercise explores the stigma that often exists among health workers. Health workers frequently report that they are scared to go for an HIV test in a place where they are known – they fear the judgements of their colleagues and patients. There is often a suggestion that ‘as a nurse you should know better’. Some nurses and doctors fear that their HIV status may put their jobs at risk. In many health institutions health workers are dying because of this kind of stigma – they are not even accessing the ARVs that are available in their own clinics.

Step-by-step activity

Introduce the topic – brainstorm and case studies

1. Ask, “*What are some of the examples of stigma facing health workers?*”
2. Break into small groups. Give each group a case study. Read through together and discuss the questions. Write answers on a flipchart.

Report back

3. Take turns to share the case studies and discussions. Record action ideas on a flipchart.

Examples from Copperbelt nurses workshop

Name-calling (‘you should know better’). Gossiping. Exclusion. Separation of cups in staff room. Loss of respect from juniors. Teasing. Excluded from hand-over meetings. Hiding medicine so no one knows. Judgements by patients.

Health worker case study – Mrs Mulenga

Mrs Mulenga is 47 years old and is the Sister-in-charge at the clinic. She has four children who are all grown up, and she is well respected in the community. Mrs Mulenga is HIV positive and gets ARVs from a private clinic. She spends a lot of her salary on the treatment.

Recently when she went to the clinic to collect her monthly prescription, she met a colleague from her workplace. The colleague guessed that she was HIV positive and told others at work.

Mrs Mulenga is aware that there is a lot of gossiping about her, especially among junior colleagues and she has started to hate going to work.

Questions

- *Why do you think Mrs Mulenga went to the private clinic for her treatment?*
- *Why do you think colleagues are gossiping about her at work?*
- *What can you do to support someone like Mrs Mulenga and address the problem of stigma in the clinic?*



Health worker case study – Viola Malambo

Viola Malambo is a voluntary counselling and testing counsellor at the local clinic. She is 27 years old and is engaged to be married. She has a good reputation as a hard worker and gets on well with her colleagues.

Viola tested herself last year and found out that she was HIV positive. She knows about ARVs but does not know whether she wants to start treatment yet. She feels well but has begun to lose weight. She has overheard some colleagues talking about her, saying that they suspect she has HIV and that “she should know better”.

She has not talked to anyone at work about her situation.

Questions

- *Why do you think Viola has not talked to anyone at work yet?*
- *Why do you think colleagues are gossiping about her at work?*
- *What can you do to support someone like Viola and address the problem of stigma in the clinic?*

Health worker case study – Gilbert

Gilbert is a male nurse on the surgical ward. He is 30 years old and married with two children. Gilbert is HIV positive and was getting his ARVs from a clinic in Kabwe, outside of town. He did not want anyone at work to know about his status. Last month his clinic ran out of his medication, so he went to the clinic at the hospital. Since then, nearly all his colleagues have avoided him, they whisper names and have stopped asking him to come for a drink after work.

Gilbert feels depressed and has begun taking sick leave as he cannot face the situation at work.

Questions

- *Why do you think Gilbert was going to Kabwe to get his ARVs?*
- *Why do you think colleagues are treating him like this at work?*
- *What can you do to support someone like Gilbert and address the problem of stigma in the hospital?*

Exercise G7 Health workers, treatment and stigma



Health worker case study – Dr Arnando

Dr Arnando is 40 years old and works in the hospital. He has a good reputation and is well respected. His wife died two years ago and he has four children. Dr Arnando has known he is HIV positive for the last two years and has been taking ARVs, which he obtains secretly from the hospital. Sometimes the supply of ARVs does not come through and he has to buy them at a private clinic where his friend works. Dr Arnando has not told anyone at work about his status and he lives in fear of anyone finding out.

Questions

- *Why do you think Dr Arnando does not want people to know his status?*
- *What can you do to support somebody like Dr Arnando and address the problem of stigma in the hospital?*

Health worker case study – Mrs Godia

Mrs Godia is a home-based carer in one of the compounds outside of town. She got involved in volunteering through her church and looks after a lot of people who have AIDS-related illnesses. Mrs Godia also helps community members set up support groups for PLHIV.

Mrs Godia is HIV positive herself, but travels to the clinic in town to get her ARVs so that no one will see her. She has told her family, but they have asked her not to tell anyone else, especially people in the home-based care team. Recently her husband lost his job and there is a shortage of money. Her family are putting pressure on her to access the free ARVs at the local clinic nearby.

Questions

- *Why do you think Mrs Godia has been getting her ARVs in town?*
- *Why do you think her family do not want her to tell others about her status?*
- *What can you do to support someone like Mrs Godia and address the problem of stigma in the home-based care team?*

Summary

- As health workers, we can all take responsibility for trying to reduce stigma in the clinics.
- We can use monthly meetings to talk about stigma.
- We can change our personal attitudes and behaviour and stop gossiping.
- We can go for an HIV test together with our colleagues.
- We can challenge others if they stigmatise.
- We can use hand-over meetings to emphasise the importance of teamwork and support.
- We can lobby our clinic for an anti-stigma policy.

Exercise G8 Rumours about ARVs



Facilitator's notes

In most communities where ARVs are becoming available, there are different rumours being spread about these medicines. In each country or community the rumours will vary. Sometimes these rumours will discourage people from getting or taking ARVs. The importance of this exercise is to help people to disentangle the facts from the rumours.



Objectives

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

- explore some of the rumours in their community about ARVs
- identify how rumours can hamper access to treatment
- understand how we can combat these rumours.



Time

45 minutes



Materials

Markers

Step-by-step activity

Buzz in partners

1. Participants stand in two lines facing each other. Ask them to buzz for two minutes with the partner opposite, on something negative that they have heard people say about ARVs.

Passing the rumour

2. First, explain the rules. If you want to start a rumour, you should have a marker in your hand. (Have three markers for a group of 20.) You must pass the rumour to the person opposite you by whispering in their ear. They then pass it to the person diagonally opposite them. The rumour is passed zigzag up the line. When it gets back to you, write it on a card, then pass the marker to someone else. There can be three rumours being passed at the same time.
3. Stick all the cards on the wall, clustering similar rumours.
4. Divide into small groups. Each group takes a card and discusses the following questions:
 - *What is behind this rumour?*
 - *Who believes it?*
 - *How can we challenge this rumour?*

Examples of rumours from Ng'ombe ACER staff

ARVs will 'solidify your pregnancy' – create an anthill inside you. You will never give birth. They kill libido. They give you an abnormal appetite. You can never have children. You will go blind. You are taking more viruses. They are toxic. Free ARVs are not as powerful as the ones you can buy, they make you feel more sick and the side effects are too much.

Summary

Some people do have problems when they take ARVs (this can be how rumours start), and it is important to acknowledge these experiences. However, we need to find ways to show that for the majority of people, ARVs are working and keeping people alive!

Health workers, treatment support workers and adherence counsellors are all key players in helping to increase treatment literacy and understanding in the community.

If you know someone who is having problems with ARVs, encourage them to go and talk to their doctor or support worker. We can all take responsibility for finding out more about ARVs and help to challenge the harmful rumours.

Exercise G9 Getting treatment

Facilitator's notes

This exercise offers a brief look at opportunistic infections and ARVs. Invite a medical expert (someone who knows about ARV treatment) to help you explain the issues and answer participants' questions. You are not expected to be clinical experts.

Objectives

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

- recognise that many opportunistic infections are curable
- identify how to prevent and minimise opportunistic infections
- explain some of the basic facts of ARVs.

Time

2 hours

Materials

Copies of the *fact sheets* on pages 44 to 48.

Preparation

Write the questions (see start of exercise) on flipcharts – one to a sheet – and pin them up in different parts of the room.

Step-by-step activities

A. Opportunistic infections – rotational brainstorm

1. Write a different question at the top of each sheet and stick them up around the room.
 - *What are some common opportunistic infections (OIs)?*
 - *What are some of the symptoms of TB?*
 - *What can we do if we are living with HIV, to prevent OIs?*
 - *How do infections affect the attitudes of others?*
 - *What kind of stigma do we face as a result of OIs?*
2. Divide participants into small groups (the same number of groups as flipcharts). Assign each group to a flipchart.
3. Ask groups to write down any responses to the question on the flipchart. Start some singing or music to move the groups clockwise around the room to the next flipchart, where they begin answering the next question. Repeat until groups are back at their original flipchart.
4. Do a gallery report back by walking around with participants to each flipchart and get original groups to report back. Ask the group to clarify or explain any questions.

Examples from stigma workshop

What are some common OIs faced by PLHIV?

TB, diarrhoea, pneumonia, bowel infection, fungal infection, skin cancer, Kaposi's Sarcoma, candidiasis, herpes zoster, meningitis.

What are some of the symptoms of TB?

Weight loss. Persistent cough. Sharp chest pains. Night sweats. Poor appetite. Decline in immune status.

How can PLHIV prevent OIs?

Regular medical check-up. Go to clinic when we start to get sick. Look after ourselves. Good food and nutrition. Good hygiene. Cut down on alcohol and smoking. Get enough rest. TB prevention therapy. Avoid milk to minimise diarrhoea. Avoid sugar to stop fungal infection.

How do infections affect the attitudes of others?

Stigma increases because of the visibility of infections like sores. Worry about what neighbours will say. Want to hide PLHIV. PLHIV gets discouraged and becomes more fearful of symptoms.

What kind of stigma do we face as a result of OIs?

No one wants to take you to the toilet. People look angry if you cough. No one wants to sit next to you. People think it is your fault. You are not looking after yourself. Now ARVs are here, people think you shouldn't get sick any more. People think you are starting to get AIDS and will die soon.

B. ARV treatment – card storming and discussion

1. Hand out cards. Ask, "*What do you know about ARV treatment?*" Ask participants to write one point on each card and tape on the wall.

Exercise G9 Getting treatment



Processing

2. Cluster common points, then review each point by asking:

- *Do you agree with this point?*
- *Any corrections or additions?*

3. Go through the *ARV fact sheet* with the group, making sure the following issues are covered:

Combination therapy. Different types of drugs. When to start treatment. CD4 and viral load tests. Adherence (right time of day, right number of pills, every day). Adverse side effects. Toxicity. Where to get the pills from. Do they cost? Drug resistance (use people's own knowledge of resistance in other situations to explain resistance, e.g. chloroquine or pesticides that insects get used to). Length of treatment.

C. Treatment problems – critical incidents

1. Divide into small groups and give each group one of the problems listed below. Ask them to role play the situation and try to find solutions.

Problems

- A.** A man says to his nephew, *"I'm really sorry. We no longer have money to buy medicine."* Privately he tells his brother, *"Why should we waste money on him? He is only going to die! And anyway, he brought these problems on himself."*
- B.** A family goes into debt trying to find a cure for their relative living with HIV, moving back and forth between private doctors and traditional healers.
- C.** A family member on ARVs approaches you and says, *"This modern medicine is not working. Let's go to see the traditional healer."*
- D.** An auntie tells her nephew he might as well stop taking his ARV drugs because he goes out drinking too much and is not taking care of himself.
- E.** A family member goes to the clinic to get ARVs with their brother and quarrels with the health staff because of the way they treat him.

Processing

2. Ask participants:

- *What happened in the role plays?*
- *What did we learn?*
- *How can we overcome some of the obstacles we might face on our treatment journey?*

Summary

Many families do not have enough information about opportunistic infections. This can lead to stigmatising beliefs, such as that HIV means you just get sick and die. ARVs are becoming more available in many countries and provide hope for the future. Even when ARVs are accessible, we may still face problems linked to stigma. Family and community support can help us overcome this. It is helpful if families know about treatments and different options to support someone on ARVs.

Exercise G10 Making healthy links

Facilitator's notes

This exercise is based on work done with traditional healers in Zambia through the ACER project. Once traditional healers are given more information about ARVs, they tend to be very supportive of the treatment, including enrolling for treatment themselves in some cases. They feel relieved that they can refer their clients to clinics for ARVs. Before, they were losing credibility because they could not provide any treatment or answers.

This exercise looks at how traditional healers and clinics can work together.

Objectives

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

- explore the role that traditional healers play in a community
- examine the importance of traditional healers and clinics working together in promoting ARV literacy and adherence.

Materials

General stigma picture 24 of a couple visiting a traditional healer, in the Picture booklet. Context card 3 in the Module A booklet of a woman visiting a clinic. Stick them on opposite walls.

Step-by-step activity

Where to go for different health problems – continuum exercise

1. Read out one of the health problems below and ask participants to walk to the institution (clinic or traditional healer) where they would go to solve the problem. Now ask, “*Why would you go there?*”
2. Tell participants the results of the visit. Either a) the problem has been solved, or b) the problem is getting worse. Ask, “*Now where would you go?*”
3. Continue this process with each of the health problems.

Health problems

1. You have had a bad cough recently and it hasn't gone away.
 2. You get a rash on your 'private parts'.
 3. Your husband has been losing weight and he has lost his appetite.
 4. Your child is sick and has had diarrhoea for the last three days.
 5. You have had a severe headache for four days.
4. After all the problems have been introduced, ask, “*What are the advantages and disadvantages of each institution?*”

Examples of advantages and disadvantages

Institution	Advantages	Disadvantages
Clinic	Benefits offered by ARVs Fees less expensive than traditional healer Dosages of medicine are clear Admission services (residential)	Sometimes there is blame and harsh treatment by health staff who fear contact Sometimes no medicines Shortage of staff
Traditional healer	Friendly, respectful, and welcoming Good listeners – psychosocial support No judging, blame, shame or stigma Blame shifted to person who is bewitching Lives in community – close to people's lives Private services, so no stigmatising by others	Fees more expensive, e.g. a cow Unclear dosage of treatments

Exercise G10 Making healthy links



Sharing knowledge – role play

5. Ask for two volunteers to be in the role play. One is the traditional healer, the other is a nurse or doctor from the clinic. Ask them to walk from opposite ends of the room and come together to talk.

Role plays

Traditional healer

You have had several patients coming in with problems of weight loss, diarrhoea and headaches. None of your remedies are working and the patients are not getting any better. You have heard about ARVs and want to know more. You can ask the nurse three questions.

Nurse

You have a patient who has just started taking ARVs and is suffering from severe side effects. You want to know whether the traditional healer can help. You can ask the traditional healer three questions.

Processing

6. Ask participants:

- *What can we do to build on the advantages and overcome the disadvantages of going to the clinic or traditional healer?*
- *How can we help traditional healers to know more about ARVs?*
- *How can we build closer collaboration between the clinics and traditional healers to support ARV treatment?*

Summary

- Many people go to a traditional healer when they first get sick, or if they are scared to go to the clinic or if the clinic is far away.
- Traditional healers need to know the value of ARVs and the importance of their role in promoting treatment literacy, including adherence knowledge.
- Clinic staff need to recognise the value and importance of traditional healers in building acceptance and support for ARVs.
- There needs to be mutual respect between clinics and traditional healers.
- Before ARVs, there was limited collaboration between clinics and traditional healers. ARVs provide a new context for looking at collaboration.



Exercise G11 ‘Prayer is all you need!’

Facilitator’s notes

This exercise is very useful for working with faith-based groups. However, in every group there will be church members who could influence policies and thinking within their places of worship.

Objectives

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

- recognise how religion-shaped stigma affects treatment
- recognise the importance of adherence.

Time

1 hour

Materials

Copies of the case study or written on a flipchart sheet and displayed on the wall.

“ Acceptance is part of healing. Accepting your status and accepting that ARVs will help is all part of healing. And we should never stop praying. ”

Treatment support worker,
Zambia

Step-by-step activity

Introduction – buzz groups

1. Ask the group to buzz in pairs, “How do some churches fuel stigma against ARVs?”

Examples of church stigma and ARVs

Some churches do not believe in the efficacy of medical treatment. They say that a person can only be healed by prayer. However, some qualify this, saying that a person will not be healed if he or she is a sinner. If a person with HIV does not get better through prayer, then he or she is further isolated or stigmatised. Some churches sell holy water as a cure.

2. Ask participants to read or act out the case study below.

Case study: Solomon, a university graduate, is HIV positive and takes ARVs. He goes to church every Sunday. One Sunday morning the pastor tells him to pray and start fasting. Solomon agrees. When his health improves he gives a testimony in church that prayer and fasting have improved his health. He then stops taking ARVs. Then his health begins to get worse.

3. Ask participants:
 - *What happened in the story? Why?*
 - *Does this happen in your community? Give some examples.*
 - *What do you think might happen next?*
 - *What is our responsibility as community and religious leaders to support people’s access to ARV treatment?*
 - *What might happen next?*

Option: Use stop-start drama to see what could happen next.

Examples from stigma workshop

What might happen next?

He would find it difficult to go back to the clinic where he was getting ARVs – it would be harder to start treatment again.

Responsibilities as community and religious leaders

To know what treatment is available, what ARV treatment is, the importance of starting early (not leaving it until it is too late) and the importance of adherence.

Summary

Religious leaders are key people in building community treatment literacy. They have a huge influence on those who come to worship, and play a major role in running care programmes and helping families to access treatment. Spiritual healing and prayer can provide important support for people on ARVs.

Exercise G12 Treatment journey

Facilitator's notes

This exercise uses the *treatment story pictures* (see pages 49-54) in order to explore some of the events that may happen during the process of getting tested for HIV and accessing treatment.

Objectives

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

- explore some of the challenges that we may encounter when testing for HIV and going for treatment
- identify some of the ways we can overcome these challenges.

Time

1 hour

Materials

Copied sets of *treatment story pictures* (see pages 49-54) according to the number of small groups.

Step-by-step activity

Picture story

1. Divide participants into small groups (four or five people per group). Give each group a selection of the *treatment story pictures*. Give groups different pictures (approximately seven or eight pictures) but make sure all groups have the 'going to get tested' picture.
2. Ask the groups to use the pictures to make a story about someone who tests positive for HIV. Include positive and negative things that happen to the person. Arrange the pictures and stick them onto a flipchart.
3. Each group take turns to tell their story, ensuring that each member of the group speaks, describing what is happening through the pictures.

Processing

4. Ask participants to discuss:
 - *What were some of the challenges that came up in the stories?*
 - *What were some of the ways that these challenges were overcome?*
 - *How can we help to support each other to face these challenges?*

Examples of ways we can support each other to face challenges

- Be open about our own experiences.
- Talk to our families.
- Seek spiritual help to strengthen us.
- Build each other's self-esteem and assertiveness skills.
- Ensure that counsellors are able to talk about stigma.



'Going to get tested' picture (see page 49)

Annex 1 ARV fact sheet

ARV treatment

What are ARVs?

ARV drugs help reduce the level of HIV in your body and slow down the speed with which the virus attacks your immune system. When you start taking ARVs you won't fall sick so often and will feel better. ARVs are usually a combination of medicines.

People who start taking ARVs have already tested positive for HIV and in most cases are given a CD4 test.

CD4 test

A CD4 test measures the amount of white blood (CD4) cells in your blood. When you have HIV it attacks your CD4 cells, which makes your immune system weak. The CD4 cells are the ones that fight diseases. Once you start taking ARVs, you may be given a CD4 test every so often to see if your immune system is responding to the ARVs.

Viral load test

A viral load test measures the amount of HIV in the blood.

Adherence

When you take ARVs it is very important that you take the drugs at the same time every day without ever missing a dose. This is called adherence.

Many of us have different strategies for adhering to our drugs. Some people have a 'treatment buddy' who helps them to remember (a friend or family member). Others use the alarm on their cellphone twice a day. Others take their drugs at the same time as doing something else that they always do – brushing their teeth or drinking tea. You can keep a diary where you mark every time you take your dose.

Stopping and restarting, or missing tablets, stops the ARVs from working well and you can develop drug resistance.

Drug resistance

Drug resistance means that the drugs you were taking don't work any more for you. You have developed a type of HIV that cannot be attacked by the ARVs you are taking. Your doctor will need to find new drugs and this may be difficult and expensive. Avoid drug resistance by maintaining adherence as much as you can.

Opportunistic infections

What are opportunistic infections?

Opportunistic infections are HIV and AIDS-related illnesses caused by bacteria, fungi and viruses. These infections take advantage of the 'opportunity' offered by an immune system that is weakened by HIV. By this stage the HIV virus has damaged the CD4 cells, which can no longer do their job of keeping the body healthy. Germs then take advantage of the weakened immune system and attack the body. These infections would not cause illness in a healthy person, but in the body of an HIV-infected person whose immune system has been weakened, they do cause illness.

There are over 20 opportunistic diseases associated with AIDS, including TB, diarrhoea, pneumonia, bowel infection, Kaposi's Sarcoma, candidiasis, skin cancer and meningitis. An individual with an AIDS diagnosis may have two or more diseases at the same time.

Most of these infections can be prevented or treated with medication, and this can help to improve the quality of life and delay the onset of AIDS. Encourage PLHIV to be proactive in preventing and treating opportunistic infections.

When AIDS first appeared in the mid-80s, many PLHIV died rapidly from opportunistic infections because their doctors did not know how to treat and prevent these diseases in people with damaged immune systems. But as doctors learned how to prevent opportunistic infections with medication and how to recognise and treat these infections more effectively, PLHIV began to live longer.

Different types of opportunistic infections

TB is a disease of the lungs and other parts of the body that affects many people with HIV. It is preventable and curable. Read the TB fact sheet on page 48 for more details.

Candidiasis is a fungal infection, commonly known as 'thrush'. It appears as white, sometimes painful patches on the tongue and as ulcers in the mouth that make it difficult to swallow. This fungal infection can also affect the vagina, causing vaginal candidiasis. This shows up as a thick, curd-like vaginal discharge, redness of the vaginal wall and can make intercourse painful.

Kaposi's sarcoma is a commonly diagnosed cancer found in PLHIV. Its symptoms are darkish lesions or nodules on the skin on different parts of the body. It

commonly affects the skin, lymph nodes and the mouth. Lesions can also be found in the stomach and the lungs, causing severe breathing problems.

Pneumocystic Carinii Pneumonia (PCP) is an infection of the lungs that can cause severe pneumonia and result in difficult breathing, fever and a dry cough. PCP is the leading cause of death of infants with AIDS in India.

Other common symptoms of AIDS and what to do

The most common symptoms of AIDS include weight loss, fevers, breathing problems, digestive problems and infections of the mouth, skin and genital areas. Some of these conditions can be treated at home, with support from the health care provider.

Nausea and vomiting

AIDS patients often feel nauseous. Get them to keep their mouth clean by frequently rinsing with clean water and using a toothbrush to brush the teeth and tongue. Cooking smells can make them feel nauseous and vomit, making them unable to eat. If the patient is vomiting, they should:

- avoid fatty foods and not eat or drink fluids for one or two hours, then
- gradually increase their intake of fluids.

Tiredness and weakness

PLHIV often feel very tired. Encourage them to rest often. Help them do simple exercises, e.g. moving their arms and legs. If the patient is bedridden, encourage him or her to move their arms and legs often. Turn the patient every now and then. Keep them involved in daily home activities, but help them with their daily needs, such as bathing and going to the toilet.

Sore mouth and throat

This is a common problem for PLHIV. You should:

- allow the patient to rinse his or her mouth with warm, clean water mixed with a pinch of salt
- give the patient a lemon to suck for white patches in the mouth – although sometimes this may be too painful
- apply gentian violet solution to the sores on the lips
- use soothing local remedies to help the patient.

Annex 1 Opportunistic infections fact sheet

Pain

To help with pain relief, give the patient two aspirin or paracetamol tablets every four hours. When giving aspirin, make sure the patient does not have an empty stomach.

Swelling

Raise the legs or the swollen part of the body on pillows, and massage the sore muscles, using some oil or soothing cream. Help the patient change position often.

Fever

Check for fever by putting the back of your hand on the patient's forehead and the back of your other hand on your own forehead. You will feel the difference if there is a fever. To deal with fever:

- Lower the fever by removing unnecessary clothing and blankets.
- Wipe the patient down with a wet cloth, or use a cold compress.
- Get the patient to drink lots of water or other liquids.
- Use aspirin or paracetamol (two tablets every four hours).

If the patient is too hot and the fever continues for a long time, or is accompanied by stiffness, severe pain, confusion, yellow colour in the eyes, sudden diarrhoea or convulsions, seek medical assistance immediately. The fever may be caused by malaria.

Diarrhoea

Diarrhoea is very common in AIDS patients. The stools are very watery and sometimes contain blood. Patients suffering from diarrhoea often get dehydrated. Treat as follows:

- Keep the skin clean and dry. Wash with clean water after each bowel movement.
- Treat dehydration with an oral rehydration drink – add half a flat teaspoon of salt and eight flat teaspoons of sugar to one litre of cooled boiled water. Make a fresh mixture every day. If the diarrhoea continues, get help from a health worker.
- Give the patient solid or starchy foods such as rice water.
- Don't give foods containing a lot of sugar as they can worsen the diarrhoea.

Skin problems

Skin problems include rashes, itching, painful sores, skin dryness, slow healing wounds, boils and abscesses. Each problem may need a different treatment:

Cleanliness: Clean skin frequently with soap and water. Keep patient's nails short to avoid them scratching themselves roughly and causing more injury to the skin.

Itching: Keep cooling the skin with water. Apply lotions such as calamine. Keep the skin dry.

Wounds: Clean the wounded area with boiled, clean water. Cover with a bandage or cloth wrapped loosely around the wound. Put a warm compress of weak salt water on the wound four times a day (a teaspoonful of salt to one litre of clean water). If the wound is on the foot or leg, raise the affected area as high as possible and as often as possible. During sleep, it should rest on a pillow. During the day, try to raise the foot for five minutes every 30 minutes. Walking helps the circulation of the blood. Standing or sitting with the affected foot down for long periods is harmful. When wounds are infected, seek medical attention immediately.

Bed sores: Bed sores are caused by pressure on parts of the patient's back – a result of lying in the same position for long periods. They often occur on the buttocks, elbows, hips, back and feet. You need to do the following:

- Get the patient out of bed as much as possible.
- Change the patient's position often – at least every two hours.
- Use soft bed sheets and padding, which should be hung to air daily. Change when soiled with urine, vomit or sweat.
- Straighten the bedding, as lying on wrinkled bedding can hurt the skin.
- Put a cushion under the patient to support bony parts.
- Encourage the patient to eat well. Extra vitamins help to heal the sores.

Boils and abscesses: These are painful, raised, red lumps on the skin. They are common on the groin, buttock, armpits and upper parts of the legs.

You need to:

- Wash boil/abscess with salt water (one teaspoonful of salt in a cup of clean water).
- Put a hot compress over the wound for 20 minutes four times a day. Be careful not to burn the patient.
- If the boil continues to grow, seek medical help.

Shingles: Shingles is a rash, blisters or sores that develop on the chest or back. It is very painful and itchy. You need to do the following:

- Apply calamine lotion twice a day to relieve pain and itching.
- Keep sores dry and do not let clothing rub against them.
- Let the patient wear clean, loose-fitting clothing.
- Relieve pain with aspirin or paracetamol.
- Bathe sores with clean water three times a day, or apply gentian violet solution.
- Watch for signs of infected sores, such as redness or pus.

Difficulties in breathing

PLHIV often have infections in the lungs and experience chronic coughing and difficulties in breathing. You can help by:

- Making the patient lie with pillows under their head, or with the head of the bed raised on blocks.
- Making the patient sit forward with his or her elbows on their knees or on a low table.
- Make sure someone is there to watch over the patient as not being able to breathe could make him or her very frightened.

Coughing

If pain is felt in the chest or ribs during coughing, a pillow or hand should be held tightly over the area that hurts. This makes the cough less painful. Where possible, encourage the patient to keep walking, turning around in bed or simply sitting up. This helps the lungs to drain. Give the patient a clean cloth to cover the mouth when coughing.

Medicines used for treating opportunistic infections

- **Fluconazole** is used to treat severe oral thrush infections. Thrush causes painful little white sores in the mouth.
- **Acyclovir** is used to treat herpes, which are painful blisters on the lips or genitals.
- **Cotrimoxazole** is an antibiotic that is given to PLHIV whose CD4 count is below 200. This medicine helps to prevent PCP, a severe lung infection that kills many PLHIV.

Annex 1 Tuberculosis fact sheet

Tuberculosis

What is TB?

TB is an infection of the lungs and other parts of the body. The body tries to stop the infection by making a hard wall around the germs. This means that small, hard lumps develop and damage the organs where the TB germs are.

Most people have TB in the lungs; however, because TB can travel through the blood it can also attack any other part of the body, like the glands, brain, spine, hip, intestines.

After causing the first infection, the TB germs can remain quietly in the body for a long time. Then, if a person becomes unable to fight it, TB becomes active again – it is reactivated.

How can you get TB?

Without treatment, TB germs travel from the lungs of an infected person through the drops of moisture sent out when coughing, sneezing, spitting or breathing. A nearby person can then take in the drops of moisture so that the TB germs enter the lungs.

After two to three weeks of TB treatment, there will be no more TB germs in the drops of moisture, so there is no further risk to other people.

A healthy person is less likely to get TB than a person who is weak or ill. The risk is worse if a person also lives in crowded conditions.

TB is not transmitted by touch, food, water, insects, sexual activity or blood contact.

How do you know if you have TB?

Some signs of active TB include an ongoing cough, coughing up blood, loss of appetite, sweating at night, feeling tired and weak, pain in the chest.

If you suspect that you have TB, you should go to your nearest clinic for some tests and treatment.

TB can be cured

The treatment for TB involves taking some tablets every day for six months to one year.

It is very important that you remember to take your treatment every day and you complete the whole treatment, even if you feel better.

DANGER! If you do not finish your treatment, the TB germs can get stronger and they can resist the medicine. Drug-resistant TB can kill you.

Do TB patients need to be isolated?

NO! Two weeks after you have started taking your treatments you are no longer infectious. This means you can eat, sleep and work together as normal. You do not need special utensils or separate bedding. Just remember to keep taking the treatments daily until the full course is finished.

TB and HIV

Having TB is not the same as having HIV. They are two different diseases. TB can be cured. When a person with HIV shows signs of TB, it is usually because the TB is already in the body. The TB is reactivated because HIV has made the immune (defence) system weak.

If you are HIV positive, you can take treatment that will prevent you from getting active TB. In many places this treatment is freely available.

If you are living with HIV and you do get TB, you can still cure the TB by taking the treatment.

TB and ARVs

If a person already has active TB when starting ARV treatment, TB treatment is usually given first. ARV treatment starts later when the person is stronger. Sometimes when the TB is cured, a person with HIV becomes so much better that ARV treatment does not need to start right away.

If a person with HIV is already very ill (at the AIDS stage), ARV treatment must start immediately. Some weeks after this, when the immune system starts to recover, the body might show symptoms of other infections like TB. Then, it is essential to continue the ARV treatment and to start treatment for TB. If the ARV treatment is stopped, the immune system can break down again and the person might die.















Booklets in *Understanding and challenging HIV stigma: Toolkit for action* include:

Introduction

Using the toolkit

Module A

Naming the problem

Module B

More understanding, less fear

Module C

Sex, morality, shame and blame

Module D

The family and stigma

Module E

Home-based care and stigma

Module F

Coping with stigma

Module G

Treatment and stigma

Module H

MSM and stigma

Module I

Children and stigma

Module J

Young people and stigma

Moving to action module

Thinking about change

Moving to action

Developing skills for advocacy

Picture booklet

General stigma pictures

Rights pictures

Additional booklets will be published as new modules are developed.