

SAWA SAWA POSITIVE PREVENTION

February 2017





Contact: Health Communication Capacity Collaborative Johns Hopkins Center for Communication Programs 111 Market Place, Suite 310 Baltimore, MD 21202 USA Telephone: +1-410-659-6300 Fax: +1-410-659-6266 www.healthcommcapacity.org

© 2017, Johns Hopkins University.

Table of Contents

Acknowledgements	4
Acronyms	5
Session 1 – Introduction to Sawa Sawa Positive Prevention	6
Activity 1: Introduction of Participants and Facilitators	7
Activity 2: Overview of the Sawa Sawa Positive Prevention Tool and Sessions	8
Activity 3: Expectations, Clarifications and Household Rules	9
Activity 4: Men's Health	10
Activity 5: Taking Care of Your Health	11
Activity 6: Close the Session	13
Session 2 – Disclosure	14
Activity 1: Telling Your Family	15
Activity 2: Partner Disclosure	17
Activity 3: Discordant Couples	18
Activity 4: Close the Session	19
Session 3 – Feeling Good	20
Activity 1: The Burden of Secrecy	21
Activity 2: What Makes You Feel Good about Life?	23
Activity 3: Stigma, Self-Stigma and Self-Esteem	24
Activity 4: Close the Session	25
Session 4 – Antiretroviral Treatment	26
Activity 1: ARV Treatment	27
Activity 2: Adherence	28
Activity 3: Treatment Problems – Critical Incidents	31
Activity 4: Close the Session	32
What Is ARV Treatment?	33
Session 5 – Living Positively	36
Activity 1: Living Positively	37
Activity 2: Treatment and Stigma Problem Analysis	38
Activity 3: Treatment in the Family	39
Activity 4: Close the Session	40
Session 6 – Dealing with Stigma	41
Activity 1: Self-Stigma	42
Activity 2: Strategies for Coping with Stigma	44
Activity 3: Close the Session	45

Acknowledgements

The USAID-funded Health Communication Capacity Collaborative (HC3) – based at the Johns Hopkins Center for Communication Programs (CCP) – would like to acknowledge Beth Mallalieu, Dida Pinho and Lynn Van Lith for putting together this guide. This guide is modelled after the *"Tchova Tchova – Positive Prevention"* developed by the Johns Hopkins Center for Communication Programs (CCP) under the PACTO (Prevenção Activa e Comunicação Para Todos or Active Prevention and Communication for All) project in Mozambique. The original development of Tchova Tchova was based on the Africa Transformation tool for Mozambique and was made possible thanks to the support of the United States Agency for International Development (USAID), the President's Emergency Plan for AIDS Prevention (PEPFAR) and the work of colleagues in the USAID mission in Mozambique.

The sessions in this guide related specifically to stigma were adapted from *Understanding and challenging HIV Stigma – Toolkit for Action* by Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance.

CCP is grateful to all the people who worked to develop the *Tchova Tchova* methodology which has been adopted for use in *Sawa Sawa*, especially those who agreed to tell their stories to inspire other people and families, thus contributing to the construction of a healthier society.

This guide was made possible by the support of the American People through the United States Agency for International Development (USAID). HC3 is supported by USAID's Office of Population and Reproductive Health, Bureau for Global Health, under Cooperative Agreement #AID-OAA-A-12-00058.

Acronyms

ART	Antiretroviral Treatment
ARV	Antiretroviral
CD4	Cluster of Differentiation 4 Cells
HIV	Human Immunodeficiency Virus
PLHIV	People Living with HIV
STI	Sexually Transmitted Infection
ТВ	Tuberculosis

Session 1 – Introduction to Sawa Sawa Positive Prevention

Learning Objectives

By the end of this session, participants will:

- be acquainted with the Sawa Sawa Positive Prevention tool and its objectives;
- have created an environment where there is confidentiality and all feel welcome;
- reflect on the reasons that cause men to take less care of their own health; and
- assess the importance of men taking care of their health.

Duration of the Session

• Two hours

Materials

- Tape
- Flip chart
- Markers

Topics Covered by the Session

- Sawa Sawa Positive Prevention objectives, activities and sessions
- Introduction of participants and facilitators
- Expectations and household rules
- Men's health
- Taking care of your health

Activities

- 1. Introduction of participants and facilitators
- 2. Overview of the Sawa Sawa tool and sessions
- 3. Expectations, clarifications and household rules
- 4. Taking care of your health
- 5. Taking care of your partner's health
- 6. Close the session

Key Messages of the Session

- It is a man's responsibility to take care of his own health and the health of his partner.
- It is important for men to seek health services and guide other men to do the same, in order to:
 - \circ $\:$ use condoms to avoid transmitting the human immunodeficiency virus (HIV) to their partner; and
 - when having a sign/symptom of a sexually transmitted infection (STI), preventing the disease from getting worse or transmitting it to their partner.

Activity 1: Introduction of Participants and Facilitators

What We Want Participants to Achieve:

- Feel comfortable with the facilitator
- Know each other

Duration: 15 minutes

Step 1: Introduction of the Facilitators

- Introduce yourself as a Sawa Sawa Positive Prevention facilitator (name, age, marital status and whatever you wish to add). If you are HIV positive and comfortable disclosing your status to the group, this would be a good time to do that.
- Describe what you do as facilitator. You may say something like, "I will guide our discussions; I will ask questions about the topics that we will work on; and sometimes I will pass on new information. My role is to facilitate the sessions and we will learn from each other and together we will solve the problems that arise in the group. Remember that although I will provide you some important information, my role is not the one of a teacher who will tell you everything you need to know. You already have important knowledge and experiences to share, and my role is to help to make this happen."

Step 2: Introduction of the Participants

- Ask a member of the group to introduce someone he does not know well. Give the participants a few minutes to interview each other about their:
 - o Name
 - o Age
 - Marital status (if he lives with someone)
 - o Number of children
 - o A quality (something good that he has) that he would like to share with the group
 - Something in himself or way of being that needs to improve (a shortcoming)
 - Reasons for choosing to participate in the Sawa Sawa Positive Prevention group

Step 3: Ask each participant to introduce his partner. They may also decide to talk about themselves, and the facilitator should determine the amount of time that each participant has to introduce himself or his partner.

Step 4: Close the activity by calling the attention of the group to the aspects they have in common – place of residence, age, employment, marital status, etc. Highlight some differences in the group and the importance of respecting all their differences and points of view, without discrimination and without judging each other.

FACILITATOR'S NOTE

The facilitators should start this first session in a warm, open way so that people feel welcomed. The introduction of the participants helps people to open up and feel more comfortable within the group.

- Be positive
- Invite all to talk
- Learn the names of all participants as soon as possible

Alternatively, distribute cards or tape to all participants on which they can write their name, or how they want to be called in the group.

Activity 2: Overview of the Sawa Sawa Positive Prevention Tool and Sessions

What We Want Participants to Achieve:

• Know the Sawa Sawa Positive Prevention tool, its objectives and what will be covered in each of the sessions

Duration: 15 minutes

Step 1: What Does Sawa Sawa Positive Prevention Aim to Achieve?

• Clarify that Sawa Sawa Positive Prevention is an educational tool to promote living a healthy life with HIV and providing support to men who have been diagnosed HIV positive.

Step 2: Understanding the Objectives of the Sessions

- Write the objectives on a big sheet of paper before the start of the session.
- When you start the activity, place the paper in a visible place. Introduce and discuss the following objectives with the participants:
 - Finding creative ways to live a healthier and more productive life.
 - Understand the importance of Antiretroviral (ARV) treatment (also known as ART) and the benefits that it can provide.
 - Develop and strengthen personal skills to make changes in their lives and communities.
 - o Identify best practices in the way men can care for their health and support others.
 - Encourage men to seek help from health services and the community.

Step 3:

- Ask participants to explain how they perceive the Sawa Sawa Positive Prevention sessions in their own words.
- Ask participants to discuss for five minutes in pairs ("whisper") about what they would like to get out of attending the sessions.

Step 4:

- Explain that, in order to achieve its objectives, the Sawa Sawa Positive Prevention tool will be conducted in six sessions, and each session will be two hours long.
 - Session 1: Introduction and Men's Health
 - Session 2: Disclosure and Discordance
 - Session 3: Feeling good
 - Session 4: Lifelong Antiretroviral Treatment (ART)
 - Session 5: Living Positively
 - Session 6: Dealing with Stigma

Activity 3: Expectations, Clarifications and Household Rules

What We Want Participants to Achieve:

- Know and harmonise their expectations regarding the sessions
- Facilitate agreement on the group rules and how the group will function

Duration: 15 minutes

Step 1: Explaining the Expectations

- Make sure that everyone has a very clear understanding of what they should and should not expect from the Sawa Sawa Positive Prevention sessions, so that no one is disappointed at the end.
- Start the activities by asking: "Considering the topics that we will be discussing and the objectives of Sawa Sawa Positive Prevention, what do you expect to learn, or what do you expect from the community dialogue sessions?"
- On a big sheet of paper, list all EXPECTATIONS of the group.

Step 2: The Importance of Participating

- Clarify that everyone should participate and share their ideas during the discussions.
- Highlight that it is important to be present in all meetings, to achieve and meet the various expectations that were presented, and to promote the changes that we wish to create in our lives and communities.

Step 3: Household Rules

- Ask the group to think about the rules they should follow so that they can have a good experience in the sessions and get along together in the group in the best possible way.
- Write the ideas on a big sheet of paper.
- Use key symbols or ideas so that everyone can understand them.
- Clarify to participants that the rules are made by them and that everyone is responsible for their implementation, and therefore they should be well thought out and discussed.
- Keep the list visible during each session so that the group remembers the rules.

Make sure the rules include:

- Listen to what each person has to say everyone has the right to express his opinion.
- Do not interrupt while someone is speaking.
- Do not judge all opinions are valid and can be discussed.
- How cell phones will be used during the sessions.
- No one should share the personal information of other people outside the group.
- If someone disrespects these rules, the measures to be taken can be agreed by the group.
- The day of the week and time of the meetings.

All other aspects related to the functioning of the group can be agreed upon at this stage and may be reviewed whenever necessary.

FACILITATOR'S NOTE

This is also when you should learn the schedules of the people in the group and the community; ensure you have chosen the most appropriate day/time for the meetings; set the number of times the group will meet during a week (preferably once a week); and inform the group that at least six meetings will be needed, and each meeting will be two hours long.

Do not forget to book the next meeting and to ask a group participant to help remind all participants of the day and time of the meeting.

Activity 4: Men's Health

What We Want Participants to Achieve:

- Recognise that men often are not supported in taking care of their health in the community
- Recognise that men can do a better job of taking care of their health
- Come up with ideas on how to better support men in taking care of their health

Duration: 40 minutes

Step 1: Divide the group into three even groups. Explain that each group will be discussing different questions for 10 minutes. After the 10 minutes are over, all but one person from the group should rotate to the next group. When you get to the next group the one person who remained will provide a brief recap of what was previously discussed and then the new group will discuss the question. After 10 minutes the group will move on to the final topic with the same person remaining behind to provide a summary to the next group.

Step 2:

- Assign each group one of the following questions for discussion:
 - What is the hardest issue for a man in your community? Specifically, what makes it hard for a man to take care of his health?
 - What do you wish women and the community better understood about men, especially men living with HIV?
 - What are the things you wish others would never say about people living with HIV?
- Give the men time to think about it and answer freely, encourage debate among the men but clarify that there is no one right answer to any of the questions.

Step 3:

- After each group has rotated through each question, bring everyone back together to discuss as a larger group. Allow about 15 minutes for this discussion.
- If the following topics are not addressed, bring them up and ask the participants what their thoughts are.
 - Why do men dislike going to health centres?
 - How can the community support and encourage men to go to health centres?
 - What are some ways you think men could better take care of their health?
 - Why do men choose not to get tested for HIV?

Activity 5: Taking Care of Your Health

What We Want Participants to Achieve:

- Recognise ways they may be harming their health
- Recognise steps they can take to better care for themselves and their families

Duration: 35 minutes

Step 1: Ask the participants:

- What behaviours and health problems may be harmful to men themselves, their partners or their families?
- Why are these behaviours harmful?
- Record the points that participants are making on the left side of a piece of flip chart paper (draw a line down the middle from top to bottom so the paper is divided in columns).

Step 2: Ask participants the following two questions:

- What are the actions that you as men can take to protect your own health and the health of your partners?
- $\circ~$ How do you think they can act to reduce you and your partners' health risks (HIV, other STIs or other problems cited)?
- Make sure the group brings up things that can be done to prevent both men and women from having poor health.
- Write these answers down on the right side of the flip chart paper.
 - For each behaviour they come up with, ask what it takes to prevent this from happening.

How Men's Behaviour Affects Their Health and Their Partner's Health	How to Care for You and Your Partner's Health	
 Make sure that following issues were mentioned: They do not always take care of their own reproductive and sexual health by avoiding going the health centre or bringing up health issues they may have. Sometimes they do not treat their STIs. They may sometimes have more than one sexual partner. They sometimes do not use condoms. Some men force women to have sex. Sometimes they drink a lot and can be violent at home (i.e., beat their wives or children). They do not test for HIV until they are sick. Some men know they have HIV and hide it from their partners. Some men do not support their wife following antenatal care (ANC) or the Prevention of Mother-to-child Transmission (PMTCT) Programme when they are HIV positive and pregnant. Some expel their wives from the house, accusing them of being responsible for bringing HIV home. 	 Make sure that actions such as the following were mentioned: Go to the health facility when you suspect having a health problem. Do not let the situation get worse or self-medicate. Use condoms to prevent STIs. If you have an STI, get treatment immediately. Reduce your number of sexual partners. Never force a woman to have sex when she does not want to or when she is sick. Never use money to convince a woman to have sex (i.e., exchange money for sexual favours). Never beat your partner. Discuss issues related to your health and wellbeing with your wife or partner. Disclose your HIV status to your wife or partner. Support your spouse or partner to follow ANC and the PMTCT Programme when she is pregnant. It is especially important to go to the clinic as soon as she knows she is pregnant. If your partner is also positive, help them to adhere to her ART, especially if she is pregnant. Attend ANC appointments with your partner. 	

FACILITATOR'S NOTE

- Attention: If the points in the right column are not raised in the discussion, for each behaviour that harms women's health, ask *"what can men do?"*
- Remind participants that times have changed.
- Many of the behaviours that our parents/grandparents practiced no longer serve us today.
 - As we have seen in past sessions, this is because many of the needs men and women have now are different. Today, more women work outside the home and are heads of households, and more men do housework and care for the children.
 - When we talk about HIV, we know treatment is available that greatly improves the quality of life for people living with HIV (PLHIV). However, HIV has no cure, and some people do not access treatment. So we need to encourage everyone to know their status, disclose to their partners and enrol in treatment.
- Some attitudes and behaviours that are more in line with being a respectful man who listens to his partner, and who takes care that she is always physically and emotionally well, are:
 - o discussing these issues with your wife or partner;
 - remembering that being HIV positive is not anyone's fault and there should be no placing of blame or guilt in the relationship;
 - looking for a health facility when they suspect having some health problem, and not letting the situation get worse or medicating on their own;
 - o preventing and treating STIs;
 - using condoms during sexual intercourse;
 - reducing their number of sexual partners;
 - o disclosing your HIV status to your wife or partner, and seeking their support;
 - encouraging your wife or partner to also get tested for HIV;
 - o not forcing a woman to have sex when she does not want to or is sick;
 - not abusing their position of wealth or power to convince a woman to have sex (i.e., exchange money for sexual favours);
 - not drinking excessively;
 - o controlling anger and feelings/not assaulting their partner.
 - looking for the health services and guiding other men you know to go to the health services, and to:
 - follow health providers instructions for staying in care;
 - start treatment as directed by their provider;
 - if on treatment, adhere to their treatment daily; and
 - use a condom to avoid transmitting HIV and other STIs to their partner.
 - When having a sign/symptom of an STI, seeking health care. This will prevent the disease from becoming more severe and reduces the risk of transmitting the infection to your partner.

Activity 6: Close the Session

Duration: 10 minutes

Step 1: Session Evaluation

• Evaluate the session orally with participants, asking "What did we learn in today's session?"

Step 2: Summary of the Key Points

• Repeat the session's learning objectives and their relationship to the key points raised in the discussion, using the ideas brought by the participants to summarise the session's main topics.

Step 3: Preparation of Next Meeting

• Remind participants of the date and time of the next meeting.

Close the session by thanking everyone for their participation.

Session 2 – Disclosure

Learning Objectives

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

- provide essential information and skills to address the topic of disclosure of HIV status, considering the family and social barriers and ways to overcome them;
- understand the social and cultural determinants that hinder disclosing the HIV status and partner testing, particularly for women;
- understand the importance of disclosing one's HIV status;
- share experiences of telling family members about their status; and
- describe some basic strategies for disclosing to members of the family.

Duration of the Session

• Two hours

Preparatory Activities

• Familiarise yourself with the concepts that you will present.

Materials

- Handouts
- Flip chart
- Markers

Topics Covered by the Session

- Disclosing an HIV positive status
- How to talk to your partner about your test results
- Discordant couples

Activities

- 1. Telling your family
- 2. Partner disclosure
- 3. Discordant couples
- 4. Close the session

Key Messages of the Session

- 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 disclosure strategies.
- Fear of stigma and blame are the main reasons that stop people from telling others about their HIV status.
- Share your experiences with others who are HIV positive and/or participate in self-help and community support groups

Activity 1: Telling Your Family¹

What We Want Participants to Achieve:

- Feel comfortable disclosing their status to family members
- Share experiences about disclosing their status

Duration: 40 minutes

Step 1: Disclosing to Different Family Members

- 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?
 - If you have not disclosed your status to anyone, we will spend time practising disclosing in order to build your comfort level to do so when you are ready.

Step 2: Deciding about Disclosure

- Have participants discuss in pairs:
 - Who (else) would you like to tell about your status in your family? Why?
 - What are some of your concerns about telling them?

Step 3: Tips for Disclosure

- Bring the group back together
- Ask the group to share some of the things they feel helped when they disclosed or any tips they have to share with the group.
- Write these tips on a flip chart for everyone
- Share the tips below if they do not come up in discussion.

Tips for Disclosure

- Think about who, what, when, where and why all of these elements play a role in your disclosure experience. Who do you want to tell? What do you want to tell them about your diagnosis? When do you want to tell them? Where do you feel most comfortable talking to them? Why are you choosing to tell that person?
- Choose a quiet time to get the attention of the person you chose to talk about your status with.
- Once you have told the person, be patient. It may take time for them to process what you have told them and become okay with your status. Remember it may have taken you time to accept and understand your status, and the people you tell may need this too.
- After disclosing to one person, you may want to ask them for help and support in disclosing to others. You can talk it over with them and develop a way forward together for disclosing to others.
- Trust your instincts and do not give in to your fear. Each time you disclose, it will be difficult and may have different endings, and that is okay.
- Be selective in who you tell at first. Disclosing your status does not mean every person who knows you needs to know. You can choose to tell those closest to you, who you feel you will be most supported by. As you become more comfortable, you can choose to disclose to more people.
- Even if it does not go the way you had hoped, that is okay. Do not let it stop you from living your life and disclosing to others.
- Remember, you are not alone; millions of others have also done this. If you do not feel comfortable
 disclosing to friends or family, find another person living with HIV in your community and talk about
 your fears of disclosing with them.

¹ Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action*, 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Step 4:

- Ask each person to prioritise the people among his family and friends according to the following categories:
 - Important but difficult to tell (and why)
 - Less important but difficult to tell (and why)
 - Important but easy to tell
 - o Less important but easy to tell
- Explain that they should focus on disclosing to an "important but difficult to tell" person in this activity.

Step 5:

- Divide into pairs.
- Decide (in each pair) who is disclosing and who is being told.
- Practice telling the person.
- When the 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.

Step 6: Ask participants to discuss the following questions:

- 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 did we learn from this role play?

Activity 2: Partner Disclosure²

What We Want Participants to Achieve:

- Recognise how stigma has affected them
- Understand the benefits of disclosing their status to their partner(s)

Duration: 40 minutes

Step 1: Lead a discussion about how stigma has affected participants' lives. Ask them to share stories or (if they do not want to share personal stories) ways in which they have seen stigma affect other people's lives.

- Use the information below to deepen the discussion on how stigma affects PLHIV.
 - Causes worry, sadness, guilt, shame and loss of hope.
 - Hinders adherence to treatment for fear that partners, family or friends will know their HIV status (taking the medication at home, at work or at leisure sites).
 - Contributes to not protecting their partner (e.g., not using condoms).
 - A person with HIV may be isolated from family, friends and the community. This results in the loss of support for treatment.
 - Without appropriate care, the person living with HIV will get sick more quickly and his body will not resist opportunistic infections.

Step 2: Conduct a "brainstorming" on the factors that hinder the disclosure of HIV status to partners.

- Ensure that aspects related to the following issues are mentioned:
 - $\circ \quad \text{Stigma and discrimination} \quad$
 - $\circ \quad \text{Gender norms}$
- Have participants reflect on the previous discussion and how that may influence a person's choice to disclose their status.

Step 3:

•

- Lead a discussion on the information below:
 - Is it easier to tell a partner or a family member? Why?
 - Have you disclosed to you partner?
 - How did it go?
 - What are some things that made it easier for you?
 - What are some things that made it difficult?
 - If you have not already disclosed your status to your partner, what are some of the skills you used in Activity 1 that could be used to do so?
 - \circ $\;$ Gender norms that hinder the disclosure of HIV status $\;$
 - Men feel they should not have to explain their personal lives to their wives.
 - Husbands do not accept being questioned by women.
 - \circ What do men fear?
 - Being abandoned by women and children.
 - Demonstrating weakness, undermining their image and role in the family.
 - Ask the men, "what are some ways you think you could overcome these fears?" or "what support do you need from the community to help break down these barriers?"

² Adapted from *Positive Prevention*, 2013, Johns Hopkins Center for Communication Programs Mozambique PACTO programme

Activity 3: Discordant Couples³

What We Want Participants to Achieve:

- Have an understanding of what a discordant couple is
- Recognise how to protect their partner in a discordant couple

Duration: 30 minutes

Step 1:

- Investigate whether or not participants understand the concept of discordance. It is possible that some participants do not to have clarity on this term.
- Use the information below to lead this discussion

Discordant Couples

When both partners are tested for HIV and the test results show that one partner is HIV positive (HIV+) and the other is HIV negative (HIV-).



Step 2:

- Conduct a "brainstorming" about the advantages of disclosing your HIV status and HIV testing of sexual partners. Write down the group's ideas on a flip chart.
- Use the information below to highlight any points that were not already discussed.
 - Disclosing your HIV status to your partner(s) facilitates:
 - Encouraging the partner to get tested
 - Negotiating condom use
 - Planning the future together, including the decision to have children
 - Getting support to adhere to ART, PMTCT and/or attending all health care appointments
 - \circ $\;$ The only way to know if your partner is HIV positive or negative is to get tested.
 - If the partner's test result is negative (discordance), the couple should use condoms to prevent the negative partner from getting infected.
 - If the result is positive (both positive), the couple should use condoms to prevent other STIs that can worsen their health.
 - Either way, it is important not to blame yourself if your partner is positive and to instead find productive ways to work with your partner as a team to address living positively with the virus and supporting one another in your joint care and treatment.
 - Talk with your partner about how you can manage the situation together without blame, self-stigma or judgement and work through the conflicting feelings that may come up.
 - Recommend people to join support groups for PLHIV and talk to others who are in similar situations and how they have dealt with it.

³ Adapted from *Positive Prevention*, 2013, Johns Hopkins Center for Communication Programs Mozambique PACTO programme

Activity 4: Close the Session

Duration: 10 minutes

Step 1: Session Evaluation

• Evaluate the session orally with participants, asking "What did we learn in today's session?"

Step 2: Summary of the Key Points

• Repeat the session's learning objectives and their relationship to the key points raised in the discussion, using the ideas brought by the participants to summarise the session's main topics.

Step 3: Preparation of Next Meeting

• Remind participants of the date and time of the next meeting.

Close the session by thanking everyone for their participation.

Session 3 – Feeling Good

Learning 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;
- recognise the importance of emotional well-being in order to lead long and productive lives;
- identify how we can help stay healthy emotionally; and
- identify ways that we can challenge stigma and cope with the effects of stigma.

Duration of session

• Two hours

Materials Needed

- Copies of case study
- Paper
- Crayons
- Markers

Topics Covered by the Session

- Keeping your status a secret
- Living positively with HIV
- How does it feel to be stigmatised
- How can you minimise self-stigma
- How can you support other PLHIV

Activities

- 1. The burden of secrecy
- 2. What makes you feel good?
- 3. Stigma and self-stigma
- 4. Close the session

Key Messages of the Session

- Keeping your HIV status a secret can be very stressful; disclosing to some people can help you to better accept your status and lead a healthier life.
- Looking after our emotional health is an important part of positive living. Sometimes stigma can really affect emotional health.
- Stigma by other people can lead PLHIV to self-stigmatise.

Activity 1: The Burden of Secrecy⁴

What We Want Participants to Achieve:

• Recognise the difficulties related to not disclosing their status

Duration: 40 minutes

Step 1: Case Study

- Give out copies of the case study. Ask one or two participants to read it aloud to the group.
- Tell the group you are all going to perform the case study as a drama. 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.

Step 2:

- 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.
- Ask volunteers to act out the scenes.

Step 3:

- After each scene, ask the volunteer playing Armando, "How are you feeling?"
- Write up key observations on a flipchart.

CASE STUDY

Armando is a 31-year-old, single man. He works at Mafambisse Sugar Refinery. He is on ARVs and takes them every evening at 7:00 pm when he returns home from work. His HIV status and the ARV treatment is a secret. He remembers his HIV counsellor telling him that everything is confidential.

One day, his older brother phones and says he will meet Armando after work so they can go to his uncle's place for funeral prayers. He quickly agrees, but after his brother has hung up he remembers that his 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 work the next day when he had requested it off to go for his six-month CD4 check. He tries to get out of working, but his boss insists.

When his brother arrives at 4:30pm, he goes with him. At his uncle's place everyone is talking about how the uncle died – people say he was "misbehaving" and that he had started "using those ARV drugs." Someone says, "Maybe the drugs killed him."

Armando reaches home at 10:00 pm, very hungry. He only had tea at the funeral. He does not have 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? What is he going to do about missing his appointment?

- Scene 1: Brother phoning him to go to the prayers/boss asking him to work on his day off
- 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

⁴ Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action,* 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Step 4: Follow-up Discussion

- Ask participants:
 - How does the secrecy impact Armando's life and ARV treatment?
 - Will the treatment taken without food bother him? Does it matter that he took it three hours late?
 - Why is it important to break the secrecy and tell someone?
 - Who should he tell to lighten his burden of secrecy?
 - What could help him to manage his treatment more effectively in different places (home, extended family, workplace, etc.)?

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

Activity 2: What Makes You Feel Good about Life?⁵

What We Want Participants to Achieve:

• Reflect on the positive things in their life

Duration: 30 minutes

Step 1:

- Ask participants to think about what makes them feel good they should draw a picture, write a song or poem or come up with some other creative way to illustrate this.
- After about five minutes, ask them to pair up and share what they have come up with.

Step 2:

- In the same pairs, have participants discuss:
 - What do you, as a man living with HIV, need to feel good about yourself?
 - Why is "feeling good" (i.e., emotional well-being) important for living a long, healthy life?
 - What might prevent you from feeling good?

What do PLHIV need to feel good about themselves?

- To be loved and cared for
- To be listened to
- Given information about HIV
- Good food and nutrition
- Being involved in family decision-making
- Access to proper medical services
- Considered to be productive, contributing to the family like others
- Legal protection to stop them from being fired from jobs
- Prayer and encouragement from spiritual leaders.

Why is "feeling good" important for PLHIV living a long life?

- If our mind feels good, so does our body
- Less likely to fall sick
- More likely to share problems

What prevents PLHIV from feeling good?

- Stigma lack of attention, isolation and lack of care and support
- Self-stigma feeling guilty
- Loss of friends
- Stigma by neighbours

⁵ Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action,* 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Activity 3: Stigma, Self-Stigma and Self-Esteem⁶

What We Want Participants to Achieve:

- Understand and recognise stigma in their lives
- Come up with tips and strategies for mitigating stigma

Duration: 40 minutes

Step 1:

 Ask participants to volunteer for a role play (at least four people, five to six is best) and give them the scenario below to act out for the group.

At the market, a man living with HIV is refused service and shunned by the traders, who gossip about him being "promiscuous." He returns home, where he pours out his heart to his brother, talking about his frustration and feeling of rejection. He blames himself, saying he was "reckless" and therefore deserves to be treated like this.

Step 2:

- Ask participants to get into pairs and discuss the following questions
 - What happened? Who is stigmatising the man? Why?
 - How does the way he has been treated affect his emotional health?
 - What are the indicators of self-stigma?

Step 3:

- Bring the group back together to continue the dicussion, making sure the following points are raised:
 - What happened?
 - The traders were stigmatising the man by shunning him, refusing him service and gossiping about him.
 - What are some emotional health effects that might arise for men living with HIVs?
 - Feelings of rejection, hopelessness, self-blame, loss of face in the community, loss of self-esteem and loss of confidence
 - o Indicators of self-stigma
 - Feels guilty blames himself for his situation
 - Regret "I shouldn't have"
 - Acceptance he "deserves to be treated like this"
 - Self-isolation

Step 4:

- Ask the group "How can we support each other and everyone living with HIV to cope with stigma?" Examples include:
 - Talk openly with friends and family about our feelings and our situation, and be listened to with empathy.
 - Get supportive counselling from family, friends or health professionals.
 - \circ $\;$ Join a support group. Share feelings and experiences with other PLHIV.
 - o Continue being productive. Do things which build confidence and self-esteem.
 - Focus on the positives "I want to stay alive for my children."
 - Talk with other PLHIV about feelings of anger.
 - Use positive anger to fight back join campaigns and/or lobby for human rights.

⁶ Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action,* 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Activity 4: Close the Session

Duration: 10 minutes

Step 1: Session Evaluation

• Evaluate the session orally with participants, asking "What did we learn in today's session?"

Step 2: Summary of the Key Points

 Repeat the session's learning objectives and their relationship to the key points raised in the discussion, using the ideas brought by the participants to summarise the session's main topics.

Step 3: Preparation of Next Meeting

Remind participants of the date and time of the next meeting.

Close the session by thanking everyone for their participation.

Session 4 – Antiretroviral Treatment

Learning Objectives

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

- recognise that many opportunistic infections are curable and can be prevented;
- identify how to prevent and minimise opportunistic infections;
- explain some of the basic facts about ARVs/ART;
- understand the importance of adherence to ART, follow-up visits and viral suppression;
- be able to say what the essential information is to be promoted to encourage adherence;

Duration of the Session

• Two hours

Preparatory Activities

• Familiarise yourself with the concepts that you will present.

Materials

- Copies of fact sheets
- Index cards
- Tape
- Flip Chart
- Markers

Topics Covered by the Session

- ARV Treatment
- Medication Adherence
- How to stay adherent

Activities

- 1. ARV treatment
- 2. Adherence
- 3. Treatment problems
- 4. Close the session

Key Messages of the Session

- ARVs can help a person with HIV lead a long life.
- Taking your pills every day around the same time of day is important for adherence, even if you are feeling good.
- By taking ARVs, you will lower the amount of virus in your body (your viral load), making it more difficult for you to transmit HIV to others.
- Not having enough information about treatment can often lead to stigmatising beliefs, such as "HIV means you just get sick and die."
- ARVs are free, widely available and provide hope for a healthy future.
- It is helpful if families know about treatment and ways they can support someone on ARVs.
- In order to stay healthy, a person has to take ART for life.

Activity 1: ARV Treatment⁷

What We Want Participants to Achieve:

- Have a thorough understanding of ARV treatment/ART
- Recognise the importance of ART

Duration: 40 minutes

Step 1:

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

Step 2:

- Cluster common points, then review each point by asking:
 - \circ $\;$ Do you agree with this point?
 - $\circ \quad \text{Any corrections or additions?}$

Step 3:

- Go through the ARV fact sheet (found at the end of this session) with the group, making sure the following issues are covered:
 - Combination therapy
 - o When to start treatment
 - CD4 and viral load tests
 - Adherence (right time of day, every day)
 - $\circ \quad \text{Adverse side effects} \\$
 - Toxicity
 - Where to get the pills
 - What do the pills cost?
 - Drug resistance use common knowledge of resistance in other situations to explain ARV resistance (e.g. chloroquine or pesticides that insects get used to)
 - Length of treatment

⁷ Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action,* 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Activity 2: Adherence⁸

What We Want Participants to Achieve:

- Understand the importance of adherence
- Explore barriers to adherence and how to overcome them
- Learn about a healthy diet and how it can help with adherence

Duration: 40 minutes

Step 1:

- Ask participants: "What does ART adherence mean to you"? Clarify, if necessary:
 - It is taking medication according to the recommendations of the health providers at the same time, every day, even if the person is feeling good.
 - Adherence mainly refers to ARV treatment, but also applies to other prescription drugs from the health facility.

Step 2:

- Divide the participants into four groups. Ask each group to do a simulation on the following topics (allow 30 minutes for the task):
 - a. Group 1: Existing barriers to ART adherence
 - **b.** Group 2: Factors encouraging adherence
 - c. Group 3: Encouraging messages for PLHIV to adhere to ART
 - **d.** Group 4: What to say to the families of PLHIV on how to support them to adhere to ART
- Carefully observe the presentations, ensuring the groups mention or allude to the concepts below. If they did not, call attention to these at the end of the presentations.

Group 1 should mention or allude to:

- fear that people may discover their HIV status;
- not disclosing their HIV status to others;
- long distances between home and the health facility where they receive medicines;
- no money for transportation or food;
- lack of medicine in the health facility;
- sharing medications with family members;
- feeling healthy;
- fear of the side effects;
- actual side effects;
- alcohol consumption; and
- forgetfulness.

Group 2 should mention or allude to:

- social support partner, family or someone who supports the taking of medication;
- having disclosed being HIV positive;
- trust that the medication works feel that health status improved;
- trust in health care providers;
- finding out through personal experience that interruption of treatment is not good;
- ability to take the medication routinely; and
- valuing life.

⁸ Adapted from *Positive Prevention*, 2013, Johns Hopkins Center for Communication Programs Mozambique PACTO programme

Group 3 should mention or allude that:

- Anti-retroviral dugs are important to prevent the advancement of HIV, protecting the person from more serious health problems.
- It is important to never to fail to take your medication in order to stay healthy, to have energy to work and live normally.
- It is important to continue taking the medication even if you already feel good. This prevents a person from becoming ill and helps maintain a low viral load.
- For women, it is important to do pre-natal care from the start of the pregnancy and to continue taking ART even after birth.
- Taking ARV drugs does not prevent an infected person from transmitting HIV through sexual intercourse, but it can reduce the chances.
- You must use a condom even if you are taking ARV drugs to prevent HIV from passing to the other person.

Group 4 should mention or allude to:

- encouraging them and reminding them to take their pills;
- going with them to follow-up visits;
- helping the person in their daily tasks when they are not feeling well or when they have to go to a health facility appointment.

Step 3:

Considering that food shortages are one of the barriers most frequently cited in relation to ART adherence, provide some information about nutrition using the information below.

Food	Groups	Description
		Make Use of the Food Available in Your Area:
		 A. The ones that give strength: sweet potato, potato, rice, millet, maize, cassava and sorghum. B. The ones that give a lot of strength: groundnut, cashew nut and coconut milk.
		 C. The builders: fish, eggs, beans, chicken, beef, pork and goat meat. D. The ones that protect against disease: banana, mango, pineapple, papaya, orange, avocado, pear, lettuce and other dark green leaves.

Step 4:

Ask participants to discuss why they think ART adherence is so important and what are some ways they can support each other to ensure adherence.

Make sure the points below are brought up:

- If ARV treatment is not followed properly, you can get sick instead of better because:
 - $\circ \quad$ the drugs will not have the desired effect; and
 - the virus can become resistant to the drugs.
- If a person on ART stops taking their pills, or does not take them as directed, their viral load will increase. When a person's viral load is high, it increases the chances that they will get another infection as well as making it easier for them to pass HIV on to another person.

- By taking ART, two main functions can be monitored through testing at health facilities: (1) **increasing** a person's CD4 count, the cell's in the body that fight illness and (2) **lowering** a person's viral load, which is the amount of virus that is in the body. The viral load test is very important as it tells you if your treatment is working. If the viral load is not decreasing while you are on ART, it means that you may need a different type of medication to fight the HIV.
- Encourage people to talk with their providers about viral load testing, if it is available and when they should have their viral load monitored.

Activity 3: Treatment Problems – Critical Incidents⁹

What We Want Participants to Achieve:

Brainstorm ways they can handle situations that may lead to non-adherence

Duration: 30 minutes

Step 1:

- Divide participants 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 man says to his nephew, "I am really sorry. We no longer have money to travel to the health facility for your check-up and to pick up your medicine." Privately he tells his brother, "Why should we waste money on him? He is only going to die! And besides, he brought these problems on himself."
- b. A family goes into debt trying to find a cure for their father living with HIV, moving back and forth between private doctors and traditional healers.
- c. A family member on ARVs approaches you and says, "You are already well, why are you taking medication? Stop this remedy. It can kill you."
- 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.

Step 2:

- Have each group present their role play and address the following questions for each one:
 - What happened in the role plays?
 - \circ $\;$ What did we learn?
 - How can we overcome some of the obstacles we might face on our treatment journey?

⁹ Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action,* 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Activity 4: Close the Session

Duration: 10 minutes

Step 1: Session Evaluation

• Evaluate the session orally with participants, asking "What did we learn in today's session?"

Step 2: Summary of the Key Points

• Repeat the session's learning objectives and their relationship to the key points raised in the discussion, using the ideas brought by the participants to summarise the session's main topics.

Step 3: Preparation of Next Meeting

• Remind participants of the date and time of the next meeting.

Close the session by thanking everyone for their participation.

What Is ARV Treatment?

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 will not fall sick as often and will feel better. ARVs are usually a combination of medicines. This combination is often referred to as ART or antiretroviral therapy.

People who start taking ARVs have already tested positive for HIV and, in most cases, are given a CD4 test. You should be sure to talk to your health care provider about the best time for you to start treatment. They may have you start taking medication even though you still feel healthy. It is important to take the pills every day once you start taking them, even if you do not feel sick. ARVs are helping to prevent the HIV from spreading in your body so that you stay that way.

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. When your CD4 test shows a low number of CD4 cells (your CD4 count), it means there is a large amount of the HIV virus in your body and it is killing many of your CD4 cells. A normal CD4 count is between 500 and 1500. If your CD4 count drops below 250, it means that your immune system is very weak and you are more likely to catch opportunistic infections.

Viral Load Test

A viral load test measures the amount of HIV in the blood. This test is important because it lets you know if treatment is working or if you are developing resistance to one of the drugs. The higher your viral load is, the more HIV is in your body. If your treatment is working, your viral load will begin to go down, and the lower your viral load is, the healthier you will be. Differences between viral load and CD4 can be confusing, look at the tables below to help remember.



HIV is taking over, may feel weak or sick, hard to maintain normal lifestyle

Body is strong and healthy, able to maintain normal lifestyle



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 cell phone. Others take their drugs at the same time as doing something else that they always do – brushing their teeth or drinking tea. You can also keep a diary where you mark every time you take your dose if that helps.

Stopping and restarting, or missing tablets, stops the ARVs from working well and you can develop drug resistance. Once you begin treatment, you will be taking it for life. There is no cure for HIV, and if you stop taking your treatment, HIV can take over your immune system again and make you very sick.

Drug Resistance

Drug resistance means that the drugs you were taking do not work anymore 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, which may be difficult and expensive. The best way to find out if you have developed resistance is to have your viral load tested. If you have been taking ART for a month or more, and your viral load has not decreased, there is a good chance that you are resistant to one of the ARVs in your treatment. Be sure to talk with your healthcare provider to find out the best option for you.

Side Effects

Some of the ARVs you will take may give you side effects such as nausea, headaches or make you feel tired. Often, these side effects will go away after a few weeks. It is important to keep taking your pills, even if they make you feel sick at first. If you are still feeling side effects after one month,

you should talk to your health care provider and let them know. They will be able to help you manage these side effects so that you can continue taking your medication.

Session 5 – Living Positively

Learning Objectives

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

- identify ways to live positively and support others living with HIV to live positively;
- understand how positive living can help us to combat stigma;
- identify some of the main features of positive living in order to support us;
- begin to understand how HIV stigma can affect access and adherence to ARV treatment;
- share ideas and experiences of stigma related to living with HIV;
- analyse how stigma in the family affects treatment; and
- explore strategies that can help a family support someone on treatment.

Duration of the Session

• Two hours

Preparatory Activities:

• Review the material in the session

Materials

- Two role play scenarios written on cards
- Index cards
- Markers

Topics Covered by the Session

- Ways to live positively
- How stigma can affect access and adherence
- How to support people living positively

Activities

- 1. Living positively
- 2. Treatment and stigma problem analysis
- 3. Treatment in the family
- 4. Close the session

Key messages of the session

- ART is for life; once you start ART, be sure to continue in order to stay healthy and keep the virus suppressed.
- Stigma can have an impact on access to and adherence to ART.
- There are many ways to live positively, including attending all health facility visits, prevent other STIs, keep active, eat healthy and adhere to treatment.
- Stigma can from friends, family, your church or community.

Activity 1: Living Positively¹⁰

What We Want Participants to Achieve:

- Understand what it means to live positively
- Recognise steps they can take to improve their life

Duration: 20 minutes

Step 1:

- Divide participants in two groups. Ask them to discuss the following question and present it through a drawing:
 - \circ $\$ "What are the attitudes and behaviours of people who live more positively with HIV?"
- Allow 15 minutes for the task and five minutes for each presentation.
- Encourage discussion after the presentations have finished and for participants to build off of the groups' drawings.
- Be sure to mention the following points about living positively if they are not raised in discussion:
 - Accept your HIV status.
 - Disclose your status to those you are closest to.
 - \circ $\;$ Keep your body active by walking or working, as you always did.
 - Eat better, taking advantage of nutritious food that is locally available.
 - Sleep and rest well.
 - o Avoid excessive consumption of alcohol and other drugs.
 - Spend time with friends chat and share your feelings.
 - Look for emotional support when you feel physically weak or sad.
 - Prevent malaria and tuberculosis (TB).
 - Treat opportunistic infections if they arise.
 - Attend all scheduled appointments at the health facility.
 - Prevent other STIs.
 - Take steps to prevent transmitting HIV to others.
 - Remember that other people depend on you and love you.
 - Be adherent to ART (for those who have already started).
 - Remember, after starting ART, it is for life.

Step 2:

- After the presentations, ask:
 - "How can these attitudes and behaviours be reinforced in the community and among yourselves?"

¹⁰ Adapted from *Positive Prevention*, 2013, Johns Hopkins Center for Communication Programs Mozambique PACTO programme

Activity 2: Treatment and Stigma Problem Analysis¹¹

What We Want Participants to Achieve:

- Recognise how stigma may impact their treatment adherence
- Brainstorm ideas on how they can begin to change stigma

Duration: 45 minutes

Step 1:

- Ask participants to get into pairs. Give each pair cards and markers.
- Ask them to discuss with their partner some of the ways in which stigma affects living positively and effective ARV treatment.
- They should write one point per card.

Step 2:

- Stick the cards up on the wall and ask some participants to help group similar points.
- Make sure everyone agrees with how the points are grouped.
- Label each of the groups.

Step 3:

- Divide the participants into small groups. Give each group one of the groups of cards to analyse further.
- Ask them to share stories and experiences to try to understand the problems more.

Step 4:

- Each group should present a summary of their discussions in any way they choose, such as a flipchart, story or role play.
- Ask participants:
 - What do we learn from this?
 - What are some initial ideas about how we could change things in our community?

FACILITATOR'S NOTE

Examples of treatment and stigma:

- Disclosure you do not tell your family and keep your ARVs hidden.
- Secrecy your colleagues do not know you are taking ARVs.
- The church teaches that you need to pray instead of taking medicine.
- Health workers do not take time to tell you about adherence, especially if you look dirty or poor.
- Myths and rumours about ART side effects persist.
- The family does not want to spend money to support your treatment.

¹¹ Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action,* 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Activity 3: Treatment in the Family¹²

What We Want Participants to Achieve:

• Recognise the important role family plays in treatment success

Duration: 45 minutes

Step 1:

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

Family A: Daniel is a 27-year-old who works at the Dondo Community Radio. His father is a teacher and his family is well respected in the community. Daniel is HIV positive. He has not disclosed his status to his family. He is taking ARVs secretly and hides them in his bedroom. His 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: Antonio is 28 years old and works as a seller of mobile credits. He stays with his aunt, uncle and cousins. Antonio is HIV positive. He has disclosed his status to family members. He is taking ARVs. Antonio's family gives him lots of support around taking his treatment.

Step 2:

- Divide into small groups and ask each group to select one of the examples.
- Ask each group to devise a new role play based on the following question:
 - What could happen to change the attitudes of Daniel's family members to make them more accepting/supportive?

Step 3: Have each group perform their role play and use stop-start drama to explore it further.

Step 4:

- Lead a discussion with the groups and reflect on the following questions:
 - What do they feel worked in the role plays? How could they be improved?
 - What are some ways they may help to communicate with their family about these strategies?
 - Have their families been supportive of them?
 - If not, what are some strategies they feel they may be able to use?
 - What other support can you get in family/community/faith group? How can you do it?

Step 5:

• **Practice Activity for Reflection:** Think about anything that you need to change to live better with your conditions (status). Try to do that in your house, with your family or community.

¹² Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action,* 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Activity 4: Close the Session

Duration: 10 minutes

Step 1: Session Evaluation

• Evaluate the session orally with participants, asking "What did we learn in today's session?"

Step 2: Summary of the Key Points

• Repeat the session's learning objectives and their relationship to the key points raised in the discussion, using the ideas brought by the participants to summarise the session's main topics.

Step 3: Preparation of Next Meeting

• Remind participants of the date and time of the next meeting;

Close the session by thanking everyone for their participation.

Session 6 – Dealing with Stigma

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

Duration of the Session

• Two hours

Preparatory activities

• Familiarise yourself with the concepts that you will present.

Materials

- Flip Chart
- Markers
- Index Cards

Topics covered by the session

- Self-stigma
- How to deal with stigma

Activities:

- 1. Self-stigma
- 2. Strategies for coping with stigma
- 3. Close the session

Key Messages of the Session

- Self-stigma happens because of the climate of stigma. It is a reaction to, or fear of, being stigmatised.
- Encourage friends and family to be supportive and not to treat you any differently.
- There are many possible strategies for dealing with stigma: ignoring stigmatisers, taking ARVs so you look and feel health, being in a support group or disclosing your status, to name a few.

Activity 1: Self-Stigma¹³

What We Want Participants to Achieve:

Reflect on the role of self-stigma

Duration: 45 minutes

FACILITATOR'S NOTE

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

Step 1: Paranoia – Story Role Play

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

Three weeks ago, Joaquim 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 chapa 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 treatment. Joaquim 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 beginning next week, and although this is an opportunity he has looked forward to, now he thinks she is trying to move him out of her department because of his status.

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.

Step 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?

¹³ Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action,* 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Step 3: Summarise the Story

- Make sure all participants understand the following points and are able to reflect on and discuss them.
 - Learn to recognise that we will face stigma in society and it can be very difficult to handle. Being able to walk away, and having people who support you, can help you to overcome it.
 - \circ $\;$ Do not 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 be supportive, but also treat you the same way that they treat everyone else. You are no different and do not want to be treated differently, even if they mean the best by it.
 - Gain control over your feelings and emotions.
 - If you like, you can use humour as a way to cope with stigma, especially among others in the same situation. Making people laugh can sometimes ease the tension of a situation.

Activity 2: Strategies for Coping with Stigma¹⁴

What We Want Participants to Achieve:

• Develop skills to deal with stigma

Duration: 45 minutes

Step 1: Stigma Stories – Individual Reflection and Group Work

- 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.
- Have the larger group break off into pairs and share their experiences.

Step 2:

- In the large group, ask if anyone wants to share their story.
- Ask the group to choose one of the stories and role play it.
- After the role play, discuss:
 - What happened? How did the person feel? How did he react?
 - Describe the power relationship between stigmatiser and stigmatised.
 - What are the root causes of this stigma or discrimination?

Step 3: Card Storm in Pairs

- 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.

Step 4:

- Ask participants to form small groups. Pick the three strategies that they think work the best and explain the reasons why.
- Ask the participants to think about a time they were in a difficult situation and what they did to overcome it. Who helped them? What allowed them to move past the situation? Have them share their experience with their group.
- Next, 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? What advice would you give others who may be going through a hard time?" 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
- To be part of an Action Group of GAAC

¹⁴ Adapted from *Understanding and Challenging HIV Stigma Toolkit for Action,* 2007, Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance

Activity 3: Close the Session

Duration: 10 minutes

Step 1: Session Evaluation

• Evaluate the session orally with participants, asking "What did we learn in today's session?"

Step 2: Summary of the Key Points

• Repeat the session's learning objectives and their relationship to the key points raised in the discussion, using the ideas brought by the participants to summarise the session's main topics.

Step 3: Preparation of Next Meeting

• Remind participants of the date and time of the next meeting.

Close the session by thanking everyone for their participation.