

# ADHERENCE SUPPORT WORKER TRAINING FACILITATOR'S GUIDE

**ADHERENCE SUPPORT WORKER TRAINING**  
FACILITATOR'S GUIDE

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# ACKNOWLEDGMENTS

Family Health International (FHI) is proud to present *Adherence Support Worker Training: Facilitator's Guide*. This guide is one component of a training curriculum for ASWs that also includes a participant's guide and PowerPoint presentations.

We acknowledge the contributions of the following persons to the development of these training materials:

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## ACRONYMS/GLOSSARY

<b>AIDS</b>	Acquired Immune Deficiency Syndrome – the late stage of HIV disease. Persons are diagnosed with AIDS when they have fewer than 200 CD4 cells per ml <sup>3</sup> or they have experienced certain illnesses (called AIDS-defining illnesses).
<b>ART</b>	Antiretroviral therapy – a treatment for HIV using antiretroviral drugs (see ARV).
<b>ARV</b>	Drugs used to fight the HIV virus by making it difficult for them to multiply.
<b>ARV drug classes</b>	ART drugs are grouped into classes depending on how the drugs work to fight the virus. The classes include nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors and protease inhibitors.
<b>ASW</b>	Adherence support worker.
<b>CD4 cells</b>	A type of immune system cell that fights certain infections. These cells are the primary target of the HIV virus. The number of CD4 cells in the blood determines how well the immune system is functioning.
<b>CT</b>	Counseling and testing for HIV. Also called voluntary counseling and testing (VCT).
<b>First-line</b>	The combination of drugs that is usually used first with ART.
<b>FTC</b>	Emtricitabine.
<b>HIV</b>	Human Immunodeficiency Virus – the virus that causes AIDS.
<b>Immune system</b>	The systems in the body that work to fight off infection.
<b>Infection</b>	An infection is caused by a bacteria or virus entering the body. The body can naturally fight off some infections, while others cause illnesses.
<b>Opportunistic infection (OI)</b>	An infection that occurs in a person with a weak immune system.
<b>PLHA</b>	People living with HIV/AIDS.

<b>Resistance</b>	The ability of the HIV virus to change and resist the capacity of some drugs to work against it.
<b>Second-line</b>	The combination of drugs that is usually used to treat HIV once first-line drugs have failed.
<b>Side effects/toxicities</b>	Symptoms or problems caused by taking drugs; they can range from minor to major.
<b>TB</b>	Tuberculosis.
<b>TB/HIV co-infection</b>	Infection with both TB and HIV.
<b>Viral load</b>	A blood test that counts the amount of HIV virus in the blood. A higher viral load indicates that there is more virus in a person's blood and he or she may be sicker as a result.
<b>Viral replication</b>	A virus makes more copies of itself by viral replication.
<b>Window period</b>	The "window period" is the time between acquiring an infection, such as HIV, and obtaining evidence of that infection through a positive antibody test.

# JOB DESCRIPTION

## **ADHERENCE SUPPORT WORKER (ASW)**

Reports to an adherence counselor at the health center level.

### **BASIC FUNCTION**

Under the supervision of an adherence counselor, the ASW provides adherence counseling services to people living with HIV/AIDS (PLHA) both in the health facility and the community.

### **RESPONSIBILITIES**

- I. Provide adherence counseling to PLHA who are eligible to begin antiretroviral therapy (ART).
  - A. Assess each patient's knowledge of HIV/AIDS and ART and his or her beliefs.
  - B. Dispell myths regarding HIV/AIDS and ART.
  - C. Educate clients about HIV/AIDS and ART, including the benefits of ART.
  - D. Explain potential side effects and how they are managed.
  - E. Underscore the importance of 100 percent adherence.
  
- II. Provide follow-up adherence counseling to patients on ART.
  - A. Help a client adhere to the medication regimen.
  - B. Identify barriers to treatment.
  - C. Assist the client in solving problems that might compromise adherence.
  - D. Identify workable and realistic strategies to enhance adherence.
  - E. Provide continuing education to clients regarding HIV/AIDS and ART.
  - F. Provide HIV prevention strategies.

- III. Facilitate a patient's easy access to HIV-related services.
  - A. Work with the adherence counselor to refer patients (both on ART and not on ART) to other services in the referral network.
  - B. Actively follow up to determine if a patient has accessed services.
  - C. Document referrals (referral form, referral register).
- IV. Ensure documentation of patient encounters on the appropriate forms and report to the ART clinic according to the schedule provided by the ART adherence counselor.
- V. Where possible, participate in clinical meetings as a member of the ART clinic team.
- VI. Carry out any other duties assigned by the supervisor.

## INTRODUCTION

The Zambia HIV/AIDS Prevention, Care and Treatment (ZPCT) partnership, funded by the US President's Emergency Plan for AIDS Relief through USAID, works with the Ministry of Health/Central Board of Health, the provincial health offices and district health management teams to strengthen and expand HIV/AIDS related services in five provinces of Zambia and the rest of sub-Saharan Africa. The objectives of the program include

- Increasing access to and use of HIV counseling and testing services.
- Increasing access to and use of interventions for preventing mother-to-child transmission of HIV.
- Increasing access to and strengthening delivery of clinical care for HIV/AIDS, including diagnosis and prevention and management of opportunistic infections and other HIV-related conditions.
- Increasing access to and strengthening delivery of ART services at the provincial and district levels.

This training will teach community volunteers — called adherence support workers (ASWs) — to work alongside nurses and doctors as part of the clinical team at ART clinics. ASWs will work with patients both in the clinic and community to provide HIV education, treatment support, and ART adherence counseling. They will also improve patients' access to services by participating in the referral network and re-engaging treatment defaulters by tracking patients who miss clinic appointments. Each ASW will be assigned to work with patients in the clinic and, if the patients desire, in the home. The ASWs will be supervised by the ART adherence counselor and be expected to participate in consultations and meetings as part of the ART clinic team.

## **WHY USE ADHERENCE SUPPORT WORKERS?**

Community volunteers such as ASWs can improve patient adherence, knowledge and understanding. Additionally, they can provide education and counseling in the patient's own language. ASWs also play an important role in the clinic by freeing up time for nurses and doctors to focus on other clinical needs.

## **QUALIFICATIONS FOR ADHERENCE SUPPORT WORKERS**

It is expected that ASWs will have completed their basic education, have an interest in working with people living with HIV/AIDS (PLHA), and be committed to volunteering for 20 hours per week.

## **DETAILS OF THE TRAINING**

This training includes technical information as well as techniques for relationship building and counseling skills. The modules include didactic sessions as well as role plays and group exercises. Team-building exercises encourage cohesion and pride among ASWs; it is a good idea to start each day with a quick icebreaker or team-building exercise. Also, since this is a long training, the facilitator is encouraged to use creative techniques to create pairs or groups. Some ideas for icebreakers/team-building and forming groups are included in the training materials section of this manual. Since ASWs may not have a background in HIV/AIDS, it is important for the facilitator to be sensitive to participants' knowledge of and comfort with the content and plan on modifying content or speed of presentation as needed. The facilitator should have an open, relaxed attitude and make himself or herself available for questions between sessions. The sessions require a flipchart, markers, and a projection set-up for PowerPoint presentations. When other materials are required, they are listed. Note that PowerPoint presentations correspond to content and exercises. As some material requires multiple slides to cover, this is indicated in the facilitator's guide by (Slide 1), (Slide 2), etc.

## **TO SEND FEEDBACK**

We hope you find this material useful in your work and encourage you to provide us comments, corrections, and other feedback to help us improve future editions. Send comments to [aidspubs@fhi.org](mailto:aidspubs@fhi.org) with the words "ASW Training" in the subject line.



## UNIT A: INTRODUCTION AND ASSESSMENT



# UNIT A: INTRODUCTION AND ASSESSMENT

## COURSE INTRODUCTION AND ASSESSMENT OF PARTICIPANT KNOWLEDGE

### PURPOSE

- These first sessions will introduce participants to each other and the goals of the course. They will also lay the groundwork for the roles and responsibilities of the job and clarify any misconceptions.
- Participants will be asked to develop expectations and ground rules for the course.
- The facilitator will assess each participant's prior knowledge of course content. Also, many participants may not have had any formal education for some time; the introduction will enable the facilitator to get a better sense of each individual's abilities and background. Finally, these first sessions will introduce participants to the various forms of training (i.e., not just traditional teaching methods).

### OBJECTIVES

- Begin to get to know each other.
- Become familiar with the role of the ASW.
- Understand the overall goal and topics of the training.
- Define personal goals for the training.
- Create ground rules for the training.
- Participate in pre-training knowledge assessments.

### TIME

Total session time	3 hours
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### SESSION PLAN

- Present purpose and objectives of session.
- Present session and the following content and activities.

## ADDITIONAL PREPARATION/SUPPLIES NEEDED

- Copies of the course agenda for all participants (pages 181–183).
- Copies of the ASW job description for all participants (pages 3–4).
- Blank cards for the “What I know and don’t know about HIV” exercise.
- Copies of the pre-training knowledge assessment for all participants (pages 184–187).

## CONTENT

### Exercise: “In the Same Boat” or “In the River, on the Bank” (10 minutes)

- Ask all participants to stand in one line, facing the same direction.
- Explain that where you are standing is the bank of a river. When you, as the facilitator, say, “In the river” the participants should take one step forward. However, when you say, “On the river” no one should move. When you say, “On the bank,” participants should take one step backwards to the starting point (“On the bank”). If, however, you say, “In the bank” everyone should stand still. If anyone makes a mistake he or she should be eliminated.
- Start the game. Give commands quickly. If anyone makes a mistake, ask that person to leave the line. After a few minutes stop and debrief.
- Discussion points: Everyone probably laughed when the first person made a mistake. Ask the participants, “How did that make you feel?” Explain that the game illustrates that we are all “in the same boat” for many reasons: we all come wanting to work as ASWs, we all have some reason that makes us want to be here. Ask participants to name other reasons we are all in the same boat.

From *Understanding and Challenging HIV Stigma: Toolkit for Action*. CHANGE Project. Washington, D.C., 2003.

### Exercise: Two Items (20 minutes)

- Instruct participants to take two items out of their purses, pockets or wallets.
- Ask everyone to form a circle, facing each other.
- Ask the participants to go around the circle and introduce themselves by telling their names and what these two items tell about them.
- Start the game by introducing yourself with two items of your own.

### Why are we here?

- To train to become adherence support workers (ASWs). By learning technical knowledge and communication/counseling skills, we'll work effectively with patients to improve their adherence to ART.

### What does an ASW do?

- Works in the clinic and community.
- Conducts pre-treatment adherence counseling with patients ready to begin ART.
- Provides follow-up adherence counseling once patients begin ART.
- Educates patients on issues related to HIV, AIDS and ART.
- Monitors patients for adherence issues, including illness and side effects.
- Helps patients identify their problems with adherence and find solutions.
- Provides referrals for services as necessary.
- Participates as an active member of the healthcare team.

### Exercise: Review Agenda (20 minutes)

- List all the overall units of the course.
- Ask participants to take out their agendas and describe how all the units break down into modules.
- Answer any questions the participants have about content, schedules or logistics.

### Exercise: Why Are We Here? (30 minutes)

- Ask the participants to get into pairs and discuss the following:
  - Why are you here?
  - Why do you want to be an ASW?
  - What goals do you hope to accomplish by attending this training?
- Ask for volunteers to share with the group.
- Make note of their answers on a flip chart and post it in the room for the duration of the training.
- Remind the participants that this exercise allows them to get to know each other.

## Exercise: Setting Ground Rules (10 minutes)

- Ask participants to brainstorm some ground rules they think we should use throughout the training and write them on a flip chart.
- If they falter, give suggestions such as
  - Arrive on time each day.
  - Return promptly from breaks.
  - Maintain an environment where everyone feels comfortable to comment.
  - Participate in all activities.
  - Have sweets at each tea break.
- After all rules have been mentioned, ask the participants
  - Which rules are most important?
- Circle those rules on the paper, and post it in the room for the duration of the training.
- Tell them
  - These rules will be posted throughout the training.
  - These are YOUR rules and you may enforce them as you feel appropriate.

### Exercise: What I Know and Don't Know About HIV (45 minutes)

- Divide the group into pairs. Give each pair a stack of blank cards.
- Ask each pair to write on the cards at least one of the following:
  - “What I know about HIV/AIDS is \_\_\_\_\_” (something they already know about HIV/AIDS).
  - “What I know I don't know about HIV/AIDS is \_\_\_\_\_” (something they want to learn).
- Tell them they can complete as many cards as they like and should not include their names.
- Collect the cards. Review cards along with pre-course evaluations in the first evening to assess the general knowledge level and appropriateness of content.
- Make modifications as needed.
- Share the cards with participants as appropriate during the course.

### Pre-Course Evaluation (15 minutes)

- Pass out copies of the pre-training knowledge assessment to participants (pages 184–187).
- Ask them to complete the assessment to the best of their ability.
- Tell them that it is not a test and that it will help you, as the facilitator, adapt the course to their knowledge level. It will also be compared with the post-training knowledge assessment after the course.

## DISCUSSION OF HIV STIGMA AND DISCRIMINATION

### PURPOSE

- This session provides talking points and exercises on stigma and discrimination, introducing the topics and applying them to HIV/AIDS. Discussing stigma and discrimination will be a good way of understanding some of the values and beliefs about HIV that can then be “corrected” with basic technical information in the following modules.

### OBJECTIVES

- Define stigma and discrimination.
- Examine how stigma impacts PLHA.
- List ways ASWs can help reduce stigma and avoid discriminating against PLHA.

### TIME

Review objectives	5 minutes
Present content	15 minutes
Activities	1 hour 10 minutes
Total time	1 hour 30 minutes

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### ADDITIONAL PREPARATION/SUPPLIES NEEDED

- Prepared flip chart sheets with the headings listed in the “Things People Say” exercise
- Pictures for the “Naming Stigma through Pictures” exercise (see pages 197–202)

## CONTENT

### Exercise: How Stigmatized Is HIV? (10 minutes)

- As a group, brainstorm on why HIV/AIDS is treated differently than other illnesses.
- Write participant responses on a flip chart.
  - Discussion points: Make sure the following are included in the brainstorming: fear, sex, taboo, religion, contagion, judgment, immoral people, punishment, gossiping.

### What is stigma?

- Stigma
  - An attribute of a person that is considered unacceptable.
  - A mark of shame or discredit on a person or a group.

### Types of stigma

- Self-stigma: how people feel about themselves.
- Felt-stigma: perceptions or feelings toward other people, such as PLHA.
- Enacted stigma or discrimination: actions associated with those feelings.

### How does it affect us?

- People may avoid testing, treatment or prevention activities because they are scared of stigma.
- PLHA face more social isolation, distress and socioeconomic problems.
- People have views about PLHA and act according to those views, both consciously (for example, assuming someone is contagious) and unconsciously (for example, by avoiding someone).
- Healthcare providers may make assumptions, provide substandard care or may not maintain confidentiality.

### What is discrimination?

- Discrimination happens when a person is treated unfairly because of a particular attribute including
  - Race.
  - Religious affiliation.
  - Health status.
  - Economic status.
  - Others?
- Stigma and discrimination go hand in hand.

### Exercise: Things People Say (20 minutes)

- Prepare one sheet of flip chart paper with each of the following headings:
  - PLHA.
  - Sex workers.
  - Gay men.
  - Street kids.
  - Teenage girls.
  - Widows.
- Post the papers on the wall.
- Divide the class into six groups using the count-off method.
- Ask the groups to meet at their group number.
- Ask them to brainstorm all the things they have heard about that group and record it on the flip chart.
- After two minutes, rotate groups until all have had a turn at each paper.
- Discussion points: These groups are examples of “types” of people who face stigma. In looking at “what people say” about the groups, we can get a taste of the challenges they face.

### Exercise: Naming Stigma through Pictures (15 minutes)

- Divide the class into groups of two or three.
- Pass out pictures to each group (pages 197–202).
- Ask each group to examine their picture and discuss it together.
  - What do you see in the picture?
  - How does this picture show stigma?
- After the groups work through their pictures, ask them to share their thoughts with the class.

## Exercise: Our Own Experience as “Stigmatizer” and “Stigmatized” (25 minutes)

- Ask participants to work individually for this exercise.
- Tell them to think about either a time when they felt isolated or rejected for being different from others, or when they saw others treated this way.
- Ask them to consider
  - What happened?
  - How did it feel?
  - What impact did it have on you?
- Next, tell them to think about a time when they isolated or rejected other people because they were different.
- Ask them to consider
  - What happened?
  - How did you feel?
  - What was your attitude?
  - How did you behave?
- Ask the participants to get into pairs and share some thoughts about this experience. Then ask
  - How would you act now, knowing what you know?

### Who is affected?

- Certain groups may be affected by stigma about HIV:
  - Sex workers.
  - Injection drug users.
  - Men who have sex with men (MSM).
  - Migrant populations.

- Street kids.
- Widows.

#### Who is also affected by stigma/discrimination of PLHA?

- People who hold the perceptions.
- Families, including children.
- Communities.
- The world.

#### What can ASWs do?

- Be mindful of and correct their own stigmatizing and discriminatory beliefs.
- Address stigma when observing it in it in others.
- Treat patients and families with respect.
- Be proud of the work that they do.



UNIT B: TECHNICAL BACKGROUND FOR  
ADHERENCE SUPPORT WORKERS



# UNIT B: TECHNICAL BACKGROUND FOR ADHERENCE SUPPORT WORKERS

These technical background sessions will give ASWs the basic knowledge they will need in their work with patients. This technical information will be presented by the facilitator and applied in the exercises. It will continue to be applied in content and exercises throughout the rest of the training. The information should be presented in a manner and level appropriate to the trainer's assessment of the ASWs.

## MODULE 1: BASICS OF HIV AND HIV DISEASE PROGRESSION

### PURPOSE

This session outlines the basics of HIV and HIV disease progression. It includes definitions of HIV and AIDS, basics of transmission, HIV disease progression, HIV myths, HIV stages, and WHO staging and comprehensive care.

### OBJECTIVES

- Understand what HIV is.
- List the ways HIV is transmitted and not transmitted.
- Discuss the difference between HIV and AIDS.
- Understand the usual progression of HIV.
- Apply the topics in exercises and role plays.

### TIME

Review objectives	5 minutes
Present content	45 minutes
Activities	1 hour 40 minutes
Total time	2 hours 30 minutes

## SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

## ADDITIONAL PREPARATION/SUPPLIES NEEDED

- Review answers to the pre-test and “What I Know and Don’t Know about HIV” exercise.
- In preparation for the “Explaining HIV” exercise, make cards that have the following questions on one side. Prepare enough sets of cards so that if the class is divided into groups of four, each group will have a full set.
  - What is HIV?
  - How does HIV affect the body?
  - What is AIDS?

## CONTENT

### What is HIV?

- HIV is a virus that attacks the immune system (the immune system contains a body’s natural ability to fight infection).
- The virus attacks certain cells — called CD4 cells — in the immune system that help the body fight disease.
- The virus does not prefer certain types of people; anyone can get HIV if he or she is exposed to it.

### How does HIV affect the body?

- Since the HIV virus affects CD4 cells, the body is unable to fight off diseases as it normally would, and a person gets sick.
- HIV-positive people get infections that people with strong immune systems do not usually get.

- In some instances, HIV-positive people may get the same infections as those with healthy immune systems, but HIV-positive people will become sicker or become sick more often.
- There is no cure for HIV. Once a person has HIV he or she will always have it, despite treatment.

#### How do we measure sickness in someone with HIV?

- Counting CD4 cells is one way to measure how sick a person with HIV is. The fewer the number of CD4 cells, the sicker the person.
- A viral load test measures the amount of virus in a person's blood.
- We can also evaluate how many opportunistic infections the patient has.

#### Opportunistic infections

- Opportunistic infections (OIs) affect people with HIV depending on how well each of their immune systems is functioning.
- OIs do not usually affect people with strong immune systems.

#### What is AIDS?

- A person has AIDS when the HIV virus has severely damaged his or her immune system and the person can no longer fight infections.
- AIDS progresses from HIV. A person has AIDS when either
  - He or she displays certain illnesses (“AIDS-defining illnesses”).
  - His or her CD4 count is fewer than 200 cells per ml<sup>3</sup> of blood.

## Exercise: Explaining HIV (45 minutes)

- Divide the previously prepared question cards into piles according to the questions.
- Divide the class into groups of four.
- Pass out one card per group (all groups will work on the same question at the same time).
- Questions:
  - What is HIV?
  - How does HIV affect the body?
  - What is AIDS?
- Ask participants to take turns using simple terms to answer the question as briefly as possible according to the following plan:
  - Person #1: Answer the question as you would for a patient.
  - Group: Listen to and evaluate how well Person #1 presented the information.
  - Person #2: Answer the question using different words/phrases.
  - Group: Listen and evaluate how well Person #2 presented the information.
- Ask for a volunteer to offer his or her best answer to the question. Discuss both the wording and the thoroughness of the answers.
- Repeat the exercise with the next two questions.
- In the final discussion, remind the participants that:
  - It is not easy to explain these concepts to patients.
  - Many different words or phrases can be used and any of them are fine if they are simple and clear.
  - We will work on more communication exercises later in the training.

### How is HIV transmitted? (Slide 1)

- Sexual contact: semen and vaginal secretions.

- Male-to-female, female-to-male, male-to-male, and female-to-female
- Sexual intercourse, oral or anal sex
- Mother to child: blood and breast milk.
  - During pregnancy, during birth, and after birth through breastfeeding

#### How is HIV transmitted? (Slide 2)

- Exposure to blood and body fluids.
  - A blood transfusion contaminated by HIV, sharing of needles or sharp instruments, needle stick accidents, or splashes that enter open wounds or come in contact with mucous membranes (which are in the eyes and mouth).

#### How HIV is NOT transmitted

- HIV cannot be transmitted on surfaces or by insect bites, including mosquitoes.
- HIV cannot be transmitted by casual contact such as handshakes, hugging or touching an infected person, or sharing dishes or food.
- HIV cannot be transmitted by urine, saliva, or tears unless they contain visible blood.

## Exercise: HIV Transmission (20 minutes)

- Ask participants to get into pairs and discuss the following case study:
  - You are an ASW working with a 35-year-old man who has started ART treatment. He is living with his brother, his brother's wife, and their children. The patient tells you that his brother is worried that he will pass HIV to the children when he plays with them or shares meals with them. The patient asks you to discuss it with his brother when you are on a home visit.
- Ask the participants to discuss
  - What would you tell the patient about his brother's beliefs?
  - How would you discuss the spread of HIV with the brother?
  - What messages would you include?
- Ask one of the groups to share their answers.
- In the discussion at the end of the exercise
  - The ASW should stress that misconceptions about the spread of HIV are common.
  - The ASW should ask the family what they know about HIV transmission and discuss with them how HIV is spread.
  - The ASW should stress that HIV cannot be spread by casual contact and that patients can continue to act as they normally would in the home. He or she should give examples.

## HIV Myths and Realities

Myths	Realities
<b>Witchcraft causes HIV.</b>	HIV is a virus in the blood that is spread by sexual or body fluid contact.
<b>All people with TB have HIV.</b>	A person does not have to have HIV to get TB. Some, but not all, people with HIV do contract TB.
<b>Fat people cannot have HIV.</b>	A person cannot tell if someone else has HIV by the way he or she looks.
<b>Condoms do not protect you from HIV.</b>	When used correctly, latex condoms prevent the spread of HIV.
<b>Having sex with a very young virgin will cure you of HIV.</b>	There is no cure for HIV. Any unprotected sex with a person infected with HIV can spread HIV to others.
<b>Mosquitoes give you HIV.</b>	Insects cannot spread HIV.
<b>People with HIV are immoral and deserve it.</b>	No one does anything to “deserve HIV.”

From *Basic Counseling and Adherence Support Skills for Antiretroviral Therapy. Training and Counseling Resources Center*. Lusaka, Zambia, 2004.

## Exercise: HIV Myths and Realities (15 minutes)

- Lead a discussion with the group about the myths listed previously.
  - Do any of these myths exist in your community?
  - What other myths about HIV in your community have you heard?
  - How widespread are these myths?
  - Are they associated with specific groups? (For example, people in the country may believe a certain myth but people in the city may not.)
  - Why do you think people believe them?
  - After learning the truth about HIV and how it is spread, how would you dispel those myths?
- In the final discussion, remind participants that
  - Many myths about HIV exist.
  - People want to believe them because they provide answers.
  - It is important to try to learn about the myths that exist in the community in which you work; this way, if patients talk about them, you will be better prepared for a discussion.

## Progression of HIV/AIDS (Slide 1)

- HIV usually follows a predictable course of phases, from initial infection to AIDS.
- How quickly HIV progresses varies from person to person and depends on many factors including
  - Regular healthcare.
  - Other infections.
  - Nutrition.
  - Alcohol/drug use.

- Stress.
- Depression.

### Progression of HIV/AIDS (Slide 2)

- As a person becomes sicker
  - His or her immune system becomes more damaged (CD4 cell count drops).
  - The amount of virus in his or her blood increases (viral load rises).

### Phases and ASWs

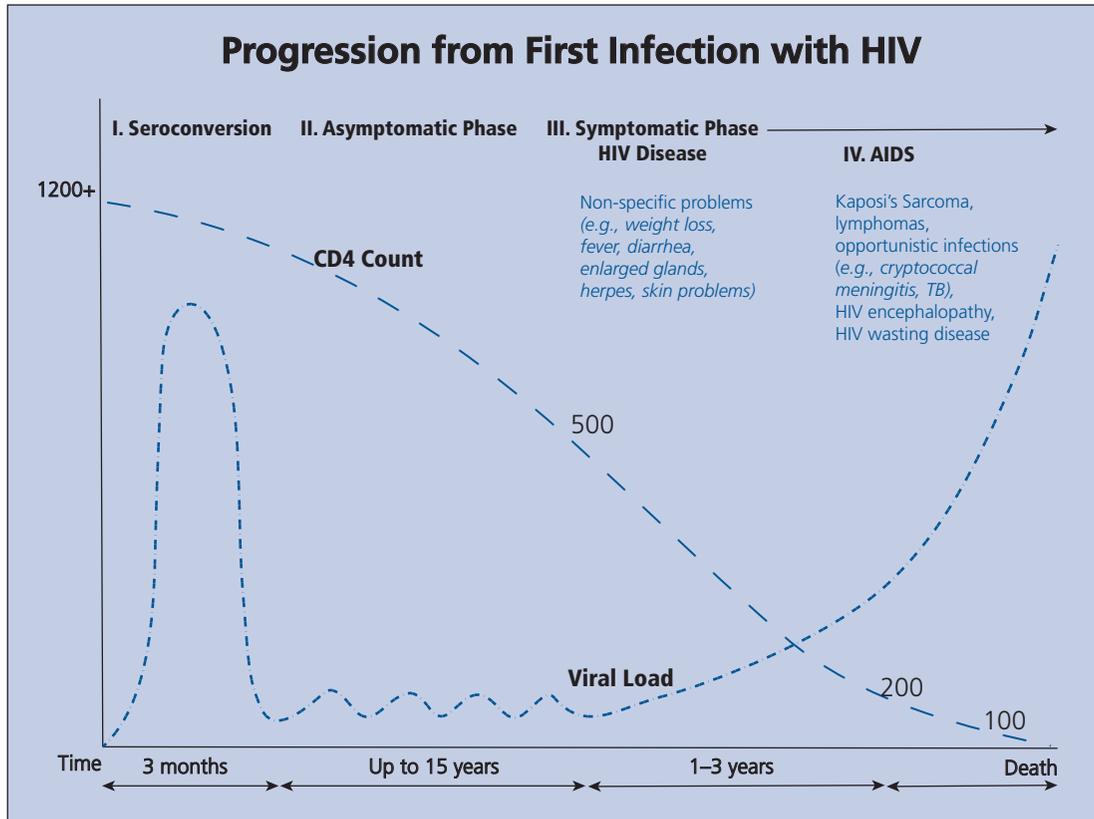
- As an ASW, you will be working with patients and their families.
  - There is no need to memorize these phases, just become familiar with how HIV progresses.
- Take-home messages:
  - HIV progresses from initial infection to AIDS in a predictable fashion.
  - The length of time for this progression varies from one person to another.
  - There are times when a person with HIV may not have symptoms or even test positive for the virus.
  - ART is not appropriate for all people with HIV (this will be discussed in the next session).

### Phases of HIV (Slide 1)

The phases of HIV include:

- Infection/seroconversion phase (going from negative to positive).
- Asymptomatic phase.
- Symptomatic phase.
- AIDS phase.

## Phases of HIV (Slide 2)



### Infection/Seroconversion phase (Slide 1)

- At this stage
  - Some people have flu-like symptoms such as fever, muscle and joint pains, or swollen lymph nodes for one to two weeks.
  - Some people do not have any symptoms at all.
  - People can have HIV, but still test negative.

### Infection/Seroconversion phase (Slide 2)

- The window period

- This is the time after HIV infection when a person has the virus but will test HIV-negative.
- A person in the window period can still spread the virus to others, even if he or she tests negative.
- The window period lasts several weeks to three months.
- To verify an HIV-negative status, an HIV test should be repeated after three months. The test could be performed three months after the last time a person was potentially exposed to HIV.
- A person in this phase is not ready to start taking HIV drugs (ARVs).

### Asymptomatic phase

- During this stage
  - The infected person has no symptoms.
  - The immune system (determined by CD4 cell count) manages to control the virus (though cannot get rid of it).
  - A person may stay symptom-free for up to 10 years.
  - A person in this phase is not ready to begin taking ARVs.

### Symptomatic phase

- During this stage
  - The immune system (CD4 cell count) falls to very low levels.
  - The viral load rises.
  - The infected person begins to have symptoms such as weight loss and difficulty swallowing.
  - A person may be in this phase for one to three years.
  - Taking HIV drugs (ARVs) at this phase may slow the progression of disease.

## AIDS phase

- During this stage
  - The immune system (CD4 cell count) has been severely weakened.
  - The viral load is high.
  - The infected person develops OIs and other HIV-related illnesses.
  - Taking ARVs at this phase may slow progression of HIV and improve quality of life.

### Exercise: HIV Phases (20 minutes)

- Ask participants to get into pairs and discuss the following case study:

A friend tells you she tested positive for HIV. She knows very little about HIV. She says she does not believe she has HIV because she does not feel sick.

  - How would you respond to your friend?
  - How would you describe HIV to her?
  - What would you tell her about
    - › How HIV is spread?
    - › How HIV affects the body?
    - › How HIV progresses?
  - How would you describe the difference between HIV and AIDS?
- Ask for one group to volunteer to share their answers.
- As a group, discuss the answers.
- During the discussion, help participants understand and explain the following concepts in simple terms:
  - It is difficult for people to understand and accept that they have HIV (or any other illness) if they do not feel ill.
  - Understanding how the virus enters the body, progresses, and affects the body can help people understand what is happening to them.

## MODULE 2: HIV AND TB

### PURPOSE

This session will introduce tuberculosis (TB), the basics of the interaction between HIV and TB, and how ART treatment is affected when a patient has TB.

### OBJECTIVES

- Understand what TB is and how it is spread.
- Understand the difference between active and latent TB.
- Discuss important aspects of the TB/HIV relationship.
- Understand how treatment of TB and treatment of HIV affect each other.

### TIME

Review objectives	5 minutes
Present content	15 minutes
Activities	10 minutes
Total time	30 minutes

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### CONTENT

#### What is TB? (Slide 1)

- TB (tuberculosis) is an illness caused by a bacteria that usually infects the lungs, but can also infect other parts of the body.
- TB usually spreads from person to person when a person with TB coughs and another person breathes in the bacteria.
- TB can cause a person to become sick and eventually die.
- TB can be treated and cured.

### What is TB? (Slide 2)

- TB can be “latent” or “active.”
  - Latent TB occurs when bacteria are in the body but the immune system can control it; in this case, it does not cause illness.
  - A person with latent TB cannot spread it to others.
  - Latent TB can be diagnosed by a skin test. A healthcare worker injects a small amount of liquid under the skin and monitors the area for a reaction.

### Active TB (Slide 1)

- Active TB occurs when bacteria are in the body and the person is ill.
- If a person with latent TB contracts HIV he or she is more likely to progress to active TB because the immune system cannot control the latent TB.
- Symptoms of active TB include
  - Cough.
  - Chest pain.
  - Breathlessness.
  - Fatigue.
  - Weight loss.
  - Night sweats.

### Active TB (Slide 2)

- If a person has symptoms of active TB, a test can determine whether TB is in the lungs.
- The person coughs up sputum (phlegm).
- A healthcare worker examines the sputum under a microscope to see if it contains the TB bacteria.

### Link between HIV and TB (Slide 1)

- HIV and TB are closely linked.
  - People with HIV are more likely to contract TB.
  - TB progresses more rapidly in those with HIV.
  - People with HIV are more likely to die of TB than those without HIV.
  - HIV-positive people can progress more rapidly to AIDS if they have TB.

### Link between HIV and TB (Slide 2)

- In some countries, especially many in sub-Saharan Africa, more than half of persons with TB are also HIV-positive.
- However, one cannot assume that a person with TB has HIV. Not everyone with HIV gets TB, and not everyone with TB has HIV.

### Treating HIV and TB

- In people with both TB and HIV, a doctor must make a decision about whether to treat the TB first (before starting ART) or to treat both the TB and the HIV at the same time.
- Adherence to TB drugs is very important for treatment to be effective. TB drugs are taken for a specific period of time determined by the doctor—usually less than a year.

### HIV and TB drugs affect each other

- Some HIV drugs cannot be used at the same time as some TB drugs. (This is especially true of rifampicin). Therefore, the doctor will prescribe the special first-line ART drug combination for patients with TB.

### Monitoring for side effects

- Patients taking both ART and TB drugs should be monitored for side effects, including
  - Abdominal pain.

- Jaundice (yellowing of the skin).
- Numbness, tingling, or pain in the hands and feet.

### Exercise: TB and HIV (10 minutes)

- Lead the group in a discussion on the following:
  - What special information should an ASW discuss with a patient who is taking both TB drugs and ART?
- Be sure all the following messages are discussed:
  - Having HIV may cause a patient to become sicker with TB because HIV has already weakened his or her immune system.
  - One person's ART drug combination may be different from that of another person taking ART (who does not have TB).
  - Patients should report any of the side effects listed.
  - Patients should take all doses of their TB and HIV drugs on time.

## MODULE 3: BASICS OF COUNSELING AND TESTING (CT)

### PURPOSE

This session will familiarize participants with the basics of CT, including the definition of CT, the benefits of knowing one's status, what a positive result means, how to discuss CT with families, and how to access CT.

### OBJECTIVES

- Become familiar with the practice and basic principles of CT.
- Feel confident describing, recommending, and referring people to CT services.

### TIME

Review objectives	5 minutes
Present content	55 minutes
Activities	30 minutes
Total time	1 hour 30 minutes

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### CONTENT

#### What is CT?

- CT is the process by which a person finds out whether he or she is infected with HIV (the virus that causes AIDS).
- CT services are always voluntary and strictly confidential. Dignity for the client is carefully maintained.
- CT includes HIV and AIDS information and specialized counseling including
  - Pre-test or test-decision counseling
  - Post-test counseling

- Plans for reducing risk behaviors
- CT services are increasingly providing same-day results.

CT is at the center of HIV prevention. It can provide an entry point for care and behavior change.



### Why is CT important?

- Many infected people are still healthy and don't realize they need to protect their partners.
- Knowing your HIV status helps reduce risky behavior.
- CT helps clients plan for the future.
- CT services include early referral for appropriate health services.

### CT is voluntary

- Informed consent ensures that all persons being tested have voluntarily and freely consented to being tested.
- Clients receive complete information about HIV and AIDS.
- Counselors make sure that the client requests the service without any coercion.

### How can CT prevent HIV?

- CT helps reduce risky behavior.
- Testing negative creates a powerful motivation to reduce risk behaviors and remain uninfected.
- Testing positive and receiving counseling can help clients and patients avoid passing the virus to anyone else, including loved ones and children.

### What is professional counseling?

- Professional counseling is a confidential dialogue between a client and a care provider aimed at enabling the client to cope with stress and make personal decisions related to HIV and AIDS.
- Counseling helps clients decide if they are ready to take the test and receive results; it also helps them understand the results.
- Counseling helps clients develop a plan to reduce future risk of infection.

### CT includes HIV testing

- Rapid tests are increasingly used in CT services.

- Results can be ready within a short time (usually the same day).
- All positive results are confirmed with a second test.
- Test results are very accurate.

#### HIV testing (Slide 1)

- Most HIV tests look for antibodies to HIV (antibodies are produced by the body in reaction to the presence of a foreign invader, such as a virus like HIV).
- HIV antibody tests can be machine-read or rapid.
- Tests that directly look for the virus are expensive and not readily available.

#### HIV testing (Slide 2)

- Many CT sites perform two different rapid tests for every positive client. This means that both positive results are confirmed again. If the results are different, a third test is done to determine the true result.
- Rarely, the results are “indeterminate,” meaning that the person needs to be tested again in three months.

#### HIV testing (Slide 3)

- They are extremely accurate. HIV tests are probably more accurate and reliable than any other medical tests available today.
- Rapid tests do not require special equipment, electricity, or refrigeration and are as accurate as machine-read HIV tests.
- Most rapid tests use whole blood from a finger-prick sample.
- Results are usually available in 10–20 minutes.
- Clients can see their own test results if they choose.

#### Who can perform tests at CT sites?

- Laboratory technicians.
- Counselors who are trained in testing procedures.

- All persons conducting tests should be supervised and adhere to standard infection prevention and safety procedures.

### Different types of HIV testing and terms one might encounter

- Currently five terms are used to describe HIV testing:
  - VCT: Voluntary counseling and testing (the subject of this module).
  - DCT: Diagnostic counseling and testing (when a counselor refers a client with a condition that might be HIV-related).
  - RCT: Routine counseling and testing (testing for all people with certain conditions, such as STIs, TB, and pregnancy).
  - MCT: Mandatory counseling and testing (testing required for blood donors or during medical exams for employment, insurance, or international travel).
  - Surveillance testing: Scientists test blood samples previously drawn for other purposes to determine how many people in a community might be infected. This method is completely anonymous.

### What are possible test results?

- HIV-negative means that antibodies to HIV were not detected. In almost all cases this means the person is not infected; however, it's necessary to ensure that the person is not in the window period (see below).
- HIV-positive means that antibodies to HIV were detected. Testing positive means that the person is infected with the virus, although there are exceptions in the case of infants.

### What is the window period?

- Antibodies against HIV take from one to three months to develop after the initial infection.
- The period between infection and testing positive is called the window period.
- People in the window period can transmit the virus easily.

- People who have had recent risky behavior, but test negative, may be in the window period and need to be tested again in three months.

### Exercise: Counseling and Testing (30 minutes)

- Ask participants to get into pairs.
- Ask the pairs to take turns with the following exercises:
  - Describe in two short sentences the definition of window period.
  - Describe the main benefits of CT.
  - List the sites near you where CT services are located.
- Ask for volunteers to share their answers and then discuss the answers. Ask participants
  - Was it difficult to describe the window period so briefly?
  - How many people could list all the available CT sites?

## MODULE 4A: POSITIVE LIVING

### PURPOSE

This session introduces the concept of positive living, including a definition of positive living (be informed, take medications as prescribed, work as your energy allows, avoid stress, maintain good nutrition, prevent infections, get regular exercise, prevent the spread of HIV, seek regular medical care) and how ASWs can counsel PLHA on positive living.

### OBJECTIVES

- Define positive living.
- Understand the importance of positive living, including medications, nutrition, preventing infections, and regular medical care.

### TIME

Review objectives	5 minutes
Present content	55 minutes
Activities	30 minutes
Total time	1 hour 30 minutes

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### CONTENT

#### What is positive living?

- Positive living is a lifestyle adopted by a person with HIV in order to live life as fully as possible while slowing progression of the disease. It includes
  - Making positive choices to care for one's mental and physical health.
  - Having a positive outlook on life.
  - Avoiding risky behaviors.

### Positive living and ASWs

- As an ASW, it is important to become familiar with aspects of positive living, as patients may ask you about them.
- Positive living includes many topics that can help a person with HIV/AIDS live a healthier life.
- ASWs may provide referrals, if necessary, to guide patients to services that will help them live positively.

### Tips for positive living

- Be informed.
- Take medications as prescribed.
- Work as your energy allows.
- Avoid stress.
- Maintain good nutrition.
- Prevent infections.
- Get regular exercise.
- Prevent the spread of HIV.
- Seek regular medical care.

### Be informed

- Encourage patients to learn what they can about HIV infection.
  - Understanding more about HIV may lessen a patient's fear of HIV and help him or her learn ways to stay healthy.
- Knowing more about HIV may help patients remember to take their medications.
  - When working with patients, ask if they have any questions. Encourage them to ask questions when they are with other members of the clinical team as well.

### Take medications as prescribed (Slide 1)

- HIV has no cure, but medications can help a patient live healthier and longer.
  - OI prevention medications (such as cotrimoxazole)
  - OI treatment medications (such as antibiotics)
  - ARVs
- Some medications must be taken even if the patient feels well (OI prevention, ARVs).
- Medications may be available to help manage some side effects (such as pain, vomiting, and diarrhea).
- All medications should be taken in the proper doses and on time.

### Take medications as prescribed (Slide 2)

- Many herbal/traditional medications can interact with ARVs. Patients should not take them without first consulting their doctors.
- Patients should avoid alcohol, cigarettes, and illicit drugs.

### Work as your energy allows

- Encourage patients to continue working as long as they are well and to return to work after illness.
- Work provides income, stability, routine, friendships, and fulfillment to many people and may promote their health.

### Avoid stress

- Avoiding stress and dealing with worries is important to maintaining health.
- PLHA need to find positive ways to deal with stress (such as talking with friends or family) and avoid negative ways of dealing with stress (such as abusing alcohol or drugs).

### Maintain good nutrition (Slide 1)

- HIV affects proper nutrition and can cause poor nutrition and weight loss.

- Nutrients are not absorbed correctly (resulting in diarrhea and vomiting).
- Less food is eaten (appetite can be affected by nausea, pain, and poverty).
- Because of HIV, the body has a higher need for nutrients.
- Many HIV-related illnesses lessen a person’s appetite or result in difficulty eating.
- Side effects of ART can include nausea or vomiting.
- When people have poor nutrition, their immune systems do not function well and they get more infections as a result.
- Many people do not have the resources to buy enough food.

### Maintain good nutrition (Slide 2)

- People with HIV/AIDS should
  - Eat a well-balanced diet with regular meals, even if they’re not hungry.
    - › Meals should include protein, fat, carbohydrates, and vitamins; suggest the patient discuss nutritious foods with the clinic health team.
  - Wash vegetables and fruits with clean water.
  - Drink plenty of clean water (up to two liters per day).
  - A patient should follow these steps if feeling nauseated or without appetite:
    - › Eat small frequent meals.
    - › Eat bland foods (rice, porridge, or toast).
    - › Don’t eat greasy or spicy foods.
    - › Take ART drugs with food.
    - › Ask someone else to cook for you.
- ASWs should refer patients to food support if necessary.

### Prevent infections

- Since HIV affects the immune system, a person with HIV is more susceptible to infections.

- People with HIV/AIDS should take steps to prevent infection, including
  - Drink clean water (boil water vigorously for a few seconds, then let it cool).
  - Wash vegetables and fruit with clean water.
  - Eat well-cooked food (meat is brown, soups are boiled).
  - Wash hands with soap frequently, including after using the restroom.
  - Avoid sexually transmitted infections (STIs) and HIV reinfection by abstaining from sex or using condoms.
  - Take steps to avoid malaria (such as using bed nets).
  - Avoid contact with others who are sick.
  - Clean and cover wounds.

#### Get regular exercise and rest

- Benefits of regular exercise include
  - Increased energy levels.
  - Increased appetite.
  - Decreased nausea.
  - Maintenance of muscle tone.
- Exercise can range from moderate (being more active around the house) to active (team sports or jogging).
- Sufficient rest and sleep help restore energy.

#### Prevent the spread of HIV

- HIV can still be spread to others, even if the patient is on ART.
- People with HIV/AIDS should take measures to prevent themselves from spreading HIV to others, including
  - Remaining faithful in current relationships.
  - Using condoms.
  - Abstaining from sex.

### Seek regular medical care (Slide 1)

- A clinic schedule will be assigned to all patients on ART.
  - This schedule will include regular follow-ups and medication refills, even if the patient is feeling well.
  - Patients should be encouraged to keep all appointments.
- ASWs can help by reminding patients when their next appointments are scheduled and encouraging them to keep all appointments.

### Seek regular medical care (Slide 2)

- Patients should go to the clinic promptly when they feel ill.
  - Early treatment of infection can prevent further illness.
  - ASWs can help by asking patients about new symptoms at each visit and encouraging them to get treatment for any problems that cannot be managed at home.

### Exercise: Positive Living (30 minutes)

- Ask participants to get into pairs and discuss how an ASW can assist a patient with positive living in the following scenarios:
  - When the patient visits the clinic, he or she reports not understanding what the virus is.
  - At a home visit you notice that the patient is taking a traditional remedy for headaches.
  - During a clinic visit, a patient tells you that he or she has been nauseated and asks you for advice.
  - When you go to a home visit of a patient who has missed an appointment, the patient asks you, “Why do I need to come to the clinic if I don’t feel sick?”
- Ask for volunteers to share their answers to each scenario.

## MODULE 4B: SAFER SEX

### PURPOSE

This session will discuss safer sex, inviting participants to reflect on their feelings about sexuality. The session will also review sexual transmission of HIV, introduce the concept of safer sex, and list traditional safer sex practices. In addition, this session offers participants the opportunity for self-awareness in how they communicate about sensitive subjects, ones that may challenge their comfort levels and/or involve cultural barriers.

### OBJECTIVES

- Understand difficulties in discussing sexual issues and develop skills in discussing them with others.
- Explore feelings about sex and sexuality.
- Understand the sexual transmission of HIV.
- Be familiar with safer sex practices.

### TIME

Review objectives	5 minutes
Present content	45 minutes
Activities	40 minutes
Total time	1 hour 30 minutes

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### ADDITIONAL PREPARATION/SUPPLIES NEEDED

- Blank cards for “How to Start Talking about Sex” exercise.
- Condoms and supplies for the condom demonstration exercise.

## CONTENT

### Exercise: How to Start Talking about Sex (15 minutes)

- Tape a card with the word “sex” to the middle of the wall.
- Pass out one blank card to each participant.
- Ask participants to write down the first thing they think of when they hear the word “sex.”
- Ask participants to bring their cards up and tape them to the wall around the “sex” card.
- During the discussion, explore all the words on the cards. Ask participants what this tells us about how people think about sex.

From *Understanding and Challenging HIV Stigma: Toolkit for Action*. CHANGE Project. Washington, D.C., 2003.

### Exercise: Exploring Our Feelings about Sexuality (15 minutes)

- Ask participants to get into pairs and discuss the following topics:
  - What has influenced your attitudes and feelings toward your sexuality?
  - Whom can you talk to about intimate feelings? Is it easy?
  - Why did you choose that person?
  - Whom would you find it difficult to talk to?
- Ask for volunteers to discuss the answers to their questions.
- During the discussion, remind participants that there are many beliefs and people who influence what we think about sexuality. Issues around sexuality are sometimes difficult to discuss, especially with strangers. Patients feel the same way. Think about how you can make them feel more at ease.

### Discussing sexual issues

- ASWs may encounter people from different communities and regions, and of different races and ages.
- As an ASW, it is important for you to
  - Know your own feelings about sex and sexuality.
  - Know when you do not feel comfortable and know how to seek help and support from other clinical team members.
  - Know and be able to discuss sexual transmission of HIV and safer sexual practices with patients.
  - Maintain a nonjudgmental and open attitude with patients, even if their feelings and beliefs are different from yours.

### Review of sexual transmission of HIV (Slide 1)

- HIV is transmitted in blood or sexual fluids (from a man's penis or woman's vagina) and transmitted when infected fluid gets into someone's body (usually through the vagina, mouth, or anus).
  - Sexual intercourse.
  - Anal sex.
  - Oral sex.

### Review of sexual transmission of HIV (Slide 2)

- People on ART can still transmit HIV to others.
- People who have HIV but test negative for HIV (those in the window period) can still transmit HIV to others.
- People with HIV can get reinfected with another type of HIV or can get a sexually transmitted infection.

### Goal of safer sex

- The goal of safer sex is to reduce the possibility of transmitting HIV (and other STIs) by reducing the possibility of exchange of blood or sexual fluids.
- The only way to be absolutely safe from HIV transmission is through total sexual abstinence.

### Safer sexual practices

- Abstinence.
- Faithfulness to one's partner(s).
- Non-penetrative sexual activities.
- Use of condoms.

### Abstinence

- If someone with HIV does not have sex, there is no chance of sexually transmitting the virus.
- Abstinence is not for everyone.
- Some myths about abstinence include
  - Abstaining will make me weak.
  - Abstaining will make me sick.
  - I need to practice.

### Faithfulness

- Having multiple partners increases a person's chances of contracting or spreading HIV (the more partners the worse the chances).
- Being faithful to one partner (or multiple partners in a polygamous marriage) decreases those chances.

### Non-penetrative practices

- Alternatives to sexual intercourse include hugging, kissing, rubbing, and masturbation; these are all considered low risk for transmitting HIV.

### Condoms

- Only latex condoms should be used.
- A new condom should be used for each sex act.
- A damaged condom can allow HIV to be transmitted.
- Many condoms have expiration dates — always check them.
- Oil-based lubricants such as Vaseline or creams can cause condoms to break and should not be used.
- Water-based lubricants can be used.
- ASWs should know how to use condoms in case patients ask about them.

#### Exercise: Condom Use (15 minutes)

- Ask for two volunteers.
- Ask the first volunteer to read the instructions out loud and for the second volunteer to follow the instructions to put a condom on a cucumber.
- Lead a discussion on the following:
  - Were the directions clear enough?
  - Are these the words you would use if a patient asked you how to use a condom?
  - How would you change the directions to put them in your own words?

### Condom use instructions

- To teach patients how to use a condom, provide the following instructions:
  - Check the expiration date.

- Open the package carefully. Take care not to tear the condom or damage it with your fingernails.
- Pinch the end of the condom and place it on the erect penis.
- Still pinching the end, unroll the condom right to the base of the penis.
- If you want to use a lubricant, choose one that is water based. Oil-based lubricants cause condoms to tear.
- After ejaculation, hold the condom and withdraw the penis before it becomes soft. Never reuse a condom.
- Wrap and dispose of a condom in the trash bin, not in a toilet.



UNIT C: BUILDING HELPFUL RELATIONSHIPS  
FOR ADHERENCE SUPPORT WORKERS



# UNIT C: BUILDING HELPFUL RELATIONSHIPS FOR ADHERENCE SUPPORT WORKERS

These sessions focus on building skills that help ASWs make and nurture relationships with patients, including values and beliefs, problem-solving, and communication. Exercises in these sessions will ask participants to use these skills to apply technical knowledge from previous sessions.

## MODULE 5A: BUILDING HELPFUL RELATIONSHIPS

### STEP 1—EXAMINING OUR OWN VALUES AND BELIEFS

#### PURPOSE

This session encourages participants to examine their own values and beliefs. It will pick up on themes from the earlier technical session in activities and explore how awareness of our values is important in dealing with people.

#### OBJECTIVES

- Participants should think about their own values and beliefs and how these might help or hinder their helping relationships.
- They should think about ways that they might put those values aside in their professional work and be less judgmental and, therefore, more helpful.

#### TIME

Review objectives	5 minutes
Present content	15 minutes
Activities	1 hour 10 minutes
Total time	1 hour 30 minutes

#### SESSION PLAN

- Present purpose and objectives of session.

- Present the following content and activities.

## CONTENT

### Why do we need to think about our own values? (Slide 1)

- It is important to understand oneself when trying to help others.
- It is important to know one's values and attitudes and how they affect relationships with others.
- Understanding how you feel can improve your relationships with others.

### Why do we need to think about our own values? (Slide 2)

- ASWs may work with people who have different values and beliefs than they do.
- ASWs need to be able to “stick to the facts” and put aside their own beliefs in order to help patients.

### Exercise: Personal Strengths and Weaknesses (20 minutes)

- Ask participants to take out a blank sheet of paper and list five of their strengths and five of their weaknesses.
  - Ask them to consider how they think these strengths or weaknesses will influence their ability to perform as an ASW.
  - Ask them to describe what they can do to improve strengths and overcome weaknesses.
- Share with the class some of your own strengths and weaknesses and how they influence your ability to be a good facilitator.
- Ask for volunteers to share some of their strengths and weaknesses.
- Ask the class to comment on how these can influence a person's performance as an ASW.
- During discussion, remind participants that awareness of our own attributes and feelings can help us perform better as ASWs.

## Exercise: Values Awareness (20 minutes)

- Ask participants to take out another blank sheet of paper and briefly answer the following questions:
  - How would you describe yourself to others?
  - List five values that are important to you (for example, fidelity in a marriage or telling the truth).
  - Why do you think those values are important to you (for example, my parents or the church)?
  - How would you react to a patient who does not share those values?
  - After they finish, ask the participants to get into pairs and discuss their answers to the questions (those they feel comfortable sharing).
  - Ask for volunteers to share their answers.

## Exercise: Values and Patient Interaction (10 minutes)

- Ask participants to get into pairs and read the following scenarios. Then ask them to discuss these questions with their partners:
  - A married woman patient tells the ASW that she contracted HIV through an affair. The ASW replies, “You got HIV because you were a loose woman. It is your fault.”
  - A patient asks an ASW about how to prevent the spread of the HIV virus when he has sex with different women he meets. The ASW replies, “You don’t need to be having sex.”
  - A patient tells his ASW that he does not know which ART medications he is taking and does not care to learn. The ASW asks, “Why don’t you know more about your medications? If I were you, I would learn as much as I could.”
  - An ASW exclaims, “What is wrong with you? This is the only way to save your life!” when a patient tells her that she missed two doses of her ART drugs last month.
- By reading the statements, what values do you think are important to the ASW?
- How could each of the ASW statements be changed so they are fact driven and not value loaded?
- Ask for volunteers to share what they discussed.
- During discussion, remind participants that it is important to know how to work with patients who may not share their own values. It is best to find a way to give them the factual information they need and while putting one’s own values aside. It may also be of interest to discuss with them the consequences to the ASW of putting their own values aside.

### Values and beliefs take-home messages

- ASWs are not immune to the emotions that all people deal with when facing HIV/AIDS.
- ASWs are entitled to personal beliefs, but they must not impose them on others.
- ASWs can help others better if they are aware of their own strengths, weaknesses, and values and beliefs.
- ASWs should try to avoid expressing their own values when working with patients, using their technical knowledge to guide their interactions with patients.

## MODULE 5B: BUILDING HELPFUL RELATIONSHIPS

### STEP 2—GOOD COMMUNICATION SKILLS

#### PURPOSE

This session will familiarize participants with the basics of communication and the communication skills that are necessary to effectively work with patients. It will also cover barriers that may impede good communication and suggest ways to interact with people more effectively.

#### OBJECTIVES

- Understand how communication between two people works.
- List specific communication skills.
- List specific barriers to communication.
- Demonstrate the barriers and use of communication skills in activities with other participants.

#### TIME

Review objectives	5 minutes
Present content	30 minutes
Activities	45 minutes
Total time	1 hour 30 minutes

#### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

#### ADDITIONAL PREPARATION/SUPPLIES NEEDED

- Cards for body language activity (see page 203)

## CONTENT

Communication is the sharing of

- Information.
- Ideas.
- Beliefs and opinions.
- Feelings and emotions.

### Channels of communication

- Messages are sent by verbal and nonverbal communication.
- The majority of information is conveyed nonverbally, through body language.
- When you work with patients, it is important that you notice their body language and remain aware of your own body language.

### Body language

- Body language consists of
  - Eye movements.
  - Facial expressions.
  - Nods of the head.
  - Posture.
  - Gestures.
  - Arm and leg positioning.
  - Physical distance between people.
  - Touch.

## Exercise: Body Language (15 minutes)

- Ask participants to get into pairs.
- Each pair should take a card from the facilitator.
- One participant will read the message silently and then communicate the situation using only body language.
- Then, the other participant will react to the message sent by the first participant.
- Ask both participants how they felt during the interaction.
- Lead a discussion on the messages the participants sent through their nonverbal behavior. How did their body language support or conflict with their verbal messages?
- During discussion, remind participants that nonverbal behavior can indicate messages even more strongly than verbal communication. Take care that both nonverbal communication and verbal communication are the same. Observe the nonverbal communication of patients and be aware when it says something different from their words.

### Good communication skills

- Attend and listen to patients.
- Use appropriate language levels and practice speaking.
- Be aware of body language.
- Use impersonal statements.
- Ask open-ended questions.
- Use a nondirective approach.
- Repeat information.

### Attend and listen (Slide 1)

- Give the patients your full attention.

- Your feelings on certain subjects or lifestyles may differ from theirs. Don't judge, just listen (as discussed in Module 5A).
- Listen with a purpose. You are there for a reason: to help the patient succeed in his or her ART treatment.

#### Attend and listen (Slide 2)

- Actively listen. For example, in addition to his or her words, pay attention to
  - The patient's experience.
  - The patient's behavior.
  - The patient's feelings.
  - The patient's problems and worries.
  - The patient's perceptions.
- Pay attention to your own body language. Let the patient know you are listening by nodding or saying something brief and encouraging (like "tell me more").

#### Use appropriate language

- Communicate in the patient's native language, if possible.
- Avoid using medical or technical terms.
- Ask the patient if he or she understands what you are saying.
- Evaluate the patient's understanding by asking him or her to repeat your message in his or her own words.
- Practice the words you use with patients.

#### Body language (Slide 1)

- Tips for ASWs:
  - Face the person with your whole body.
  - Make eye contact, but don't stare.
  - Lean slightly forward toward the speaker to show interest.

- Try to be relaxed but alert.

### Body language (Slide 2)

- Indications that the patient is uninterested or annoyed:
  - Crossing his or her arms or legs.
  - Turning his or her body away from the speaker.
  - Looking down and avoiding eye contact.
  - Moving slowly when assigned a task or activity.

### Use impersonal statements

- When discussing a difficult topic, using impersonal statements can decrease the chance of the patient feeling accused or defensive.
- Some examples:
  - “Sometimes patients have difficulty taking their medications at the prescribed time. Do you find yourself having this problem?”
  - “Often people think that once they take ART drugs they are not able to infect others with the virus. Do you think this is true?”

### Ask open-ended questions (Slide 1)

- Asking questions that require more than a simple “yes” or “no” will give more information and encourage the person to talk; in addition, this can help build rapport.
- Some examples:
  - “How do you think your family can help you take your medications on schedule?”
  - “What do you think you can do to keep from spreading the virus to others?”

### Ask open-ended questions (Slide 2)

- Examples continued:

- “Who is the one person who will be most helpful to you in taking your medications?”
- Asking why can quickly make the patient feel defensive. Avoid using “why” unless it is in a positive way. For example, “You report that you took all your medications on schedule this month. That is great. Why do you think it went so well this month?”
- “Tell me more about your relationship with your husband.”

### Exercise: Open or Closed (10 minutes)

- Sometimes we need very specific information and open-ended questions are not appropriate.
- Present the following situations and ask participants if the ASW should use open-ended or closed questions when asking about them:
  - Reasons for missing pills.
  - Number of pills missed.
  - Times a person has vomited.
  - Traditional remedies taken in addition to ART drugs.
  - Problems the patient has outside of medical issues.
- Discuss how the questions can be formulated and what information they will yield.

### Use a nondirective approach

- Remember, you are in a partnership with the patient and are not telling him or her what to do.
- Avoid statements such as, “You must...”
- Give the patient various options, along with the meanings of each.

- For example: “It is important to take all your medications on schedule. Some people use a diary; others link medication taking to mealtime or daily activities such as prayer. We can work together to determine some ways that will work for you.”

#### Repeat information (Slide 1)

- HIV issues are complicated and come with misinformation, emotion, and stress.
- Patients may need to hear information multiple times before they understand it.
- The clinical protocol allows for multiple visits and opportunities to educate and discuss patient adherence issues.

#### Repeat information (Slide 2)

- A good tool for repeating information is to rephrase the patient’s statements. For example,
  - A patient states, “I cannot talk to the doctor about how many pills I missed!”
  - The ASW says, “So you find it difficult to talk to the doctor about your adherence?”
- Repeating information that the patient has told you is also a good way to be sure you have understood the patient.

#### Barriers to communication

- Premature evaluation.
- Language.
- Status.
- Information overload.
- Worry.
- Physical environment.

### Barrier: Premature evaluation

- Premature evaluation means listening to only part of a message, or answering before the patient finishes speaking.
- Always let the patient finish speaking before you respond.
  - It is important to truly hear the patient and not decide that you know what he or she is going to say.
  - It is also important not to miss valuable information that he or she may fear telling you.

### Barrier: Language

- Communication in a second language or using technical terms is difficult and may create misunderstandings.
  - Communicate in the patient's native language when possible.
  - Avoid technical or medical terms; also, use an appropriate level of language (one that is not too difficult).
  - Encourage the patient to ask questions if he or she does not understand.

### Barrier: Status

- The status or power held by ASWs (age, gender, race, economic status) may influence how you communicate with patients or how patients communicate with you.
- Patients may consider ASWs to hold high-status positions.
- Always be respectful toward patients. Try to recognize when they may feel intimidated and take steps to make them comfortable. Do not abuse your privileged access.

### Barrier: Information overload

- Giving the patient too much information at once may make him or her confused and uncomfortable.

- You are in a unique position to help patients understand information they may not have understood from the doctor or nurse.
- Be clear. Ask patients how well they understand before giving more information.

#### Barrier: Worry

- An individual who focuses on his or her internal thoughts or feelings during a conversation may not communicate clearly or understand what is being said.
- Try to recognize when you or your patients are worried or overwhelmed. Explore what they think and feel; they may be worried about specific issues.

#### Barrier: Physical environment (Slide 1)

- Physical environment (lack of privacy, noise, or weather) can affect how well we communicate.
- Try to make the place in which you are working appropriate for communicating with patients.

#### Barrier: Physical environment (Slide 2)

- Privacy guidelines:
  - When in the clinic, talk to patients about their needs in a private area.
  - When on a home visit, ask, “Is this a good place to talk?” Try to go to a quiet area that has some privacy.

## Exercise: Communication Skills Activity #1 (15 minutes)

- Ask participants to work in pairs and evaluate the following statements made by an ASW to a patient:
  - You are taking both NNRTIs and NRTIs; some people take PIs. (This overloads patients with information they probably won't understand).
  - Why in the world don't you take your ART drugs on time? (While open-ended, the question is too personal.)
  - I don't understand why someone like you doesn't use condoms. (This implies status and value judgments.)
- Lead a discussion on what is inappropriate about the statements (see above).
- Ask participants to change the statements to make them more appropriate.

## MODULE 5C: BUILDING HELPFUL RELATIONSHIPS

### STEP 3—DEVELOPING A GOOD RELATIONSHIP

#### PURPOSE

The purpose of this session is to present the basics of developing a good working relationship, including identifying the qualities of a good helper.

#### OBJECTIVES

- Understand how to develop good working relationships with people.
- Understand the feelings and needs of the people being helped.
- List and demonstrate the qualities of a good helper.
- Describe how an ASW can use counseling skills in carrying out his or her roles and responsibilities.

#### TIME

Review objectives	5 minutes
Present content	45 minutes
Activities	1 hour 10 minutes
Total time	3 hours

#### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

#### CONTENT

What is a good working relationship?

- ASWs should offer time, attention, and respect.
- Remember: ASWs are not there to be friends, but to help patients solve their problems.

### Supporting a patient

- ASWs should help the patient
  - Effectively cope with concerns, issues, and problems.
  - Develop skills and potential.
  - Make informed choices and implement those choices.
  - Understand his or her needs and feelings.

### Inappropriate ASWs behaviors. (Slide 1)

- Engaging in casual conversation (this work is not simply about people exchanging information and opinions).
- Disagreeing or debating with patients.
- Interrogating patients.
- Emphasizing personal viewpoints.
- Passing moral judgment or encouraging patients to make confessions.

### Inappropriate ASWs behaviors. (Slide 2)

- Giving diagnoses. ASWs should simply give information.
- Ordering the patient to do something. ASWs can make suggestions, however.
- Working independently. ASWs should work together with patients.

## Exercise: Being a Good Helper (20 minutes)

- Ask the class, “Who helped you in a difficult time?”
  - What were the qualities and characteristics of that person? Was he or she wise? A gossip? Did he or she do all the talking? Did the person allow you to talk?
- List all the qualities participants mention on a flip chart.
- Ask the group, “Which of these characteristics do you think are important for ASWs?”

### Qualities of a good helper (Slide 1)

- A good helper should be
  - Thoughtful and quiet.
  - Empathetic, and able to “put himself in another’s shoes.”
  - Unbiased and nonjudgmental.
  - Able to guide patients, not just direct them.

### Qualities of a good helper (Slide 2)

- A good helper should also be
  - Objective (not emotionally involved or seeing things only from a personal viewpoint).
  - Realistic (not expecting the impossible or perfection).
  - Authentic or genuine (making sure that what he or she says corresponds with what he or she does).
  - Open minded (not defensive).
  - Warm and friendly.
  - Patient.
  - Self-controlled and professional.

### Forming a good relationship

- Demonstrate your own interest in and respect for patients' issues and concerns.
  - Show respect and do not judge patients.
  - Present common goals (for example, the patient feeling better).
  - Use good verbal and nonverbal communication skills.
  - Establish mutual trust.

### Ensure privacy and confidentiality

- Giving the patient privacy and ensuring confidentiality is very important in the relationship.
- A patient cannot feel safe or comfortable without privacy.
- Privacy and confidentiality are also ethical issues.

### Show respect

- All health-related behaviors are uniquely personal, especially those related to HIV care and treatment.
- Respect each patient's experiences and choices without regard for gender, race, ethnicity, religion, sexual orientation, disability, or socioeconomic status.
- Be nonjudgmental.

### Guidelines for showing respect

- Help patients make informed decisions without telling them what to do.
- Keep appointments and apologize if you are late or have kept the patient waiting.
- Be a guide, not a preacher.
- Show concern for the patient's welfare.
- See each patient as unique.
- Help patients identify and cultivate their own resources.
- Provide encouragement and support.

## Exercise: Showing Respect for Others (20 minutes)

- Lead the group in a discussion on respect. Ask the following questions:
  - How do people show respect for you?
  - What are some ways you show someone respect?
  - What are some ways you show people you do not respect them?
  - How do you feel when you think someone is not treating you with respect?

### Guidelines for being genuine with patients

- Do not overemphasize your role.
- Remain open and nondefensive, even when feeling threatened.
- Be consistent.
- Be willing to share your experiences with patients when it is appropriate and you feel comfortable.

### Show empathy

- Empathy is the ability to imagine how the other person feels, even if the person's situation is different from your own.
- Try to imagine how you would feel if you had to deal with the patient's realities.
- Ask yourself: What is the patient expressing to me? What experiences underlie these feelings? What is most important in what the patient is saying to me?

### Empathy is not sympathy

- Sympathy is feeling pity or sorrow for another person.
- Expressing sympathy means you feel sorry for the patient.
- Expressing empathy means you try to understand the person's situation from his or her point of view.

## Exercise: Showing Empathy for Others (20 minutes)

- Explain to the class that one way to practice empathy is by using the formula, “You feel \_\_\_\_\_ because \_\_\_\_\_ .”
- Lead the group in an exercise using the formula.
- Demonstrate use of the formula in the first situation, then ask for volunteers to respond to the other situations:
  - A 25-year-old woman states, “I cannot tell my mother about my HIV status because she will think I am a bad person.”
  - A 30-year-old woman says, “There are so many things to handle right now: work, children, husband, family, money. I don’t know if I can do it all.”
  - A 40-year-old man states, “I don’t think I can get tested for HIV. What kind of life would I have if I were positive?”
  - Ask the other participants to comment on their answers.
  - Remind the participants during discussion that practicing empathy is about trying to understand how the other person feels. It is more about a style of relating to others than a set of words. However, practicing with the “you feel” exercise can illustrate how it is sometimes difficult to verbalize an understanding of how others feel.

### Acknowledge difficult feelings

- Often patients express complicated feelings or describe difficult situations.
- It is natural to want to try to fix the feelings or resolve the problems.
- It is better to acknowledge such feelings with statements such as, “That must have been difficult for you,” or “That sounds difficult.”

### Offer acceptance

- For a patient to be open and honest, the patient must feel accepted.

- Do not react to hostility or anger that seems directed at you.
- Recognize the patient’s feelings in a direct, nonemotional way such as, “You seem to be feeling angry about what just happened.”

### Exercise: Relationship Skills (20 minutes)

- Lead the group in a discussion about how an ASW can best use previous relationship skills to respond to the statements below.
- Also, ask for volunteers to discuss how they would respond and which counseling skills they are using.
- Ask for multiple volunteers per statement to demonstrate how different the responses can be.
  - “It really makes me mad when my family talks about me as if I were not here.”
  - “My husband died last year from AIDS and now I have it.”
  - “All you health workers care about is whether I take my drugs or not.”
- During discussion, remind participants that an ASW may respond in many different ways. There is no perfect message. The most important thing is to use good relationship skills.

## MODULE 6: BASICS OF ANTIRETROVIRAL THERAPY (ART)

### PURPOSE

The purpose of this session is to introduce the basics of ART, including how ART works, who should take ART, why a combination of drugs is taken, benefits and challenges of ART, goals of therapy, ART drugs, the importance of adherence, side effects and their management, and symptoms for referral to a physician. A strong understanding of these topics will lay the foundation for later modules.

### OBJECTIVES

- Understand how antiretrovirals (ARVs) work.
- List the goals of ART therapy.
- Discuss the general benefits and challenges in the use of ARVs.
- Be familiar with the schedule and side effects associated with first-line ART drugs.
- Understand how ASWs can discuss side effects and management of them with patients.
- List symptoms that should be referred to the physician.
- Apply the topics in case studies.

### TIME

Review objectives	5 minutes
Present content	1 hour 25 minutes
Activities	1 hour 30 minutes
Total time	3 hours

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

## CONTENT

### What is ART (antiretroviral therapy)? (Slide 1)

- ART is a combination of drugs used to treat patients with HIV.
- ART does not completely destroy the virus or cure the disease.
- ART reduces the amount of virus in the body (also called viral load) by stopping it from multiplying.

### What is ART? (Slide 2)

- With less virus in the body, the immune system can become stronger and resist infections better. Thus, the patient gets sick less often.
- Patients taking ART must continue taking it for the rest of their lives.
- ART drugs must never be shared with others.

### How does ART work?

- The drugs work by making it difficult for the virus to multiply.
- Different types (classes) of ART drugs work in different ways.
- A combination of several classes of ART drugs should be used to reduce the level of virus in the blood and prevent development of resistance to the medications.
- Standard combinations (first-line/second-line) of drugs are used.

### CD4 cells, HIV, and ART

- When on ART
  - The number of CD4 cells increases.
  - The amount of virus in the blood decreases.

### Who needs to take ART?

- Not all people with HIV need to take ART.
- ART treatment should start when the virus has damaged the immune system to a certain level.

- This damage is determined by finding out whether the patient has developed specific infections and by measuring the level of CD4 cells.
- The doctor will also do blood tests to check for anemia or liver disease.
- The doctor will decide if the patient would benefit from ART treatment (but the doctor and patient decide together if the patient is ready to start).

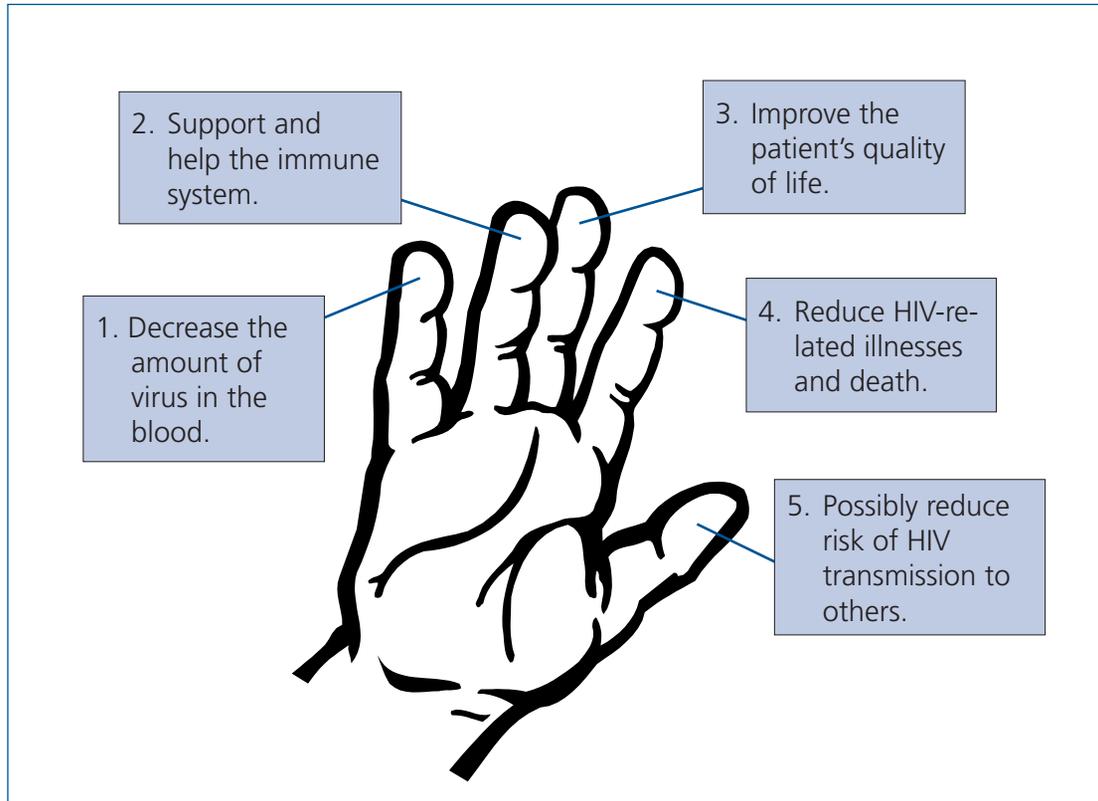
## ART

- The drugs have side effects and can cause short- and long-term physical problems.
- Patients must take 100 percent of scheduled doses for the drugs to work effectively.
- If ART is not taken properly, the virus may become resistant to the drugs and they will not work (more on drug resistance later).

### Exercise: Readiness to Start ART (15 minutes)

- Ask participants to get into pairs and discuss the following case study:
  - You are an ASW working with a patient who is taking ART. The patient's sister tells you that she just tested positive. She says she's heard of ART and thinks she should also start taking it.
  - Using the relationships skills you developed in Unit C, how would you explain ART to her?
  - How would you describe how ART works?
  - What would you tell her regarding when the body is ready for ART treatment?
  - What would you suggest she do?
- Ask one of the pairs to share their answers.
- During discussion, remind participants that important points include the following:
  - ART is made up of drugs that stop the HIV virus from growing in the body.
  - The doctor will help you decide if you are ready for ART by examining you, then discussing illnesses you have had and what is happening in your life.
  - ASWs must be able to use appropriate relationship skills when discussing this with the patient.

## Five Goals of ART



### Goals of therapy (Slide 1)

- Goal #1: Decrease the amount of virus in the blood.
  - The goal is to reduce the amount of virus so it cannot be found in the blood (remember, it's still there, we just cannot measure it).
  - Doctors will perform periodic tests to measure the amount of virus in the blood of ART patients (called viral load tests).

### Goals of therapy (Slide 2)

- Goal #2: Support and help the immune system.

- When a patient is on ART, the immune system should get stronger and the CD4 cell count should rise.
- The immune system can then fight infections better.
- A patient should get sick less frequently and his or her sicknesses should be less severe with ART.
- If the patient is already sick with OIs, the infection may be made less severe with ART.

#### Goals of therapy (Slide 3)

- Goal #3: Improve the patient's quality of life.
  - Patients often gain weight, are less fatigued, and generally feel better when taking ART.
  - Often, they can return to work and to their other usual activities; hope is restored.

#### Goals of therapy (Slide 4)

- Goal #4: Reduce HIV-related illness and death.
  - Taking ART usually slows or stops the progression of HIV.
  - Development of new OIs is unlikely; also, patients are less likely to require hospitalization or to die from AIDS.
  - ART has been shown to benefit both adults and children.

#### Goals of therapy (Slide 5)

- Goal #5: Possibly reduce transmission of HIV to others.
  - People on ART can still transmit the virus to others. However, ART decreases the amount of virus in the blood. A person is less likely to transmit HIV to others if he or she has a lower level of virus in the blood.
  - ART has been shown to decrease the risk of mother-to-child transmission of HIV.
  - Patients must still prevent possible transmission, however (for example, by using latex condoms).

## Exercise: Goals of ART (20 minutes)

- Lead the group in a discussion on the following:
  - With the five goals of ART already presented, how would you tell a patient what he or she might hope to achieve by taking ART?
- During the discussion, ensure that all five goals are covered and that participants are able to translate the goals into language specific to an individual patient.

### Antiretroviral treatment

Advantages	Inconveniences/Challenges
It works!	High level of adherence required Needs to be taken for a lifetime Side effects/toxicities Drug interactions Costs

#### Advantages of ART (Slide 1)

- If taken correctly
  - ART increases the number CD4 cells.
  - ART allows the body to better fight infections by restoring immunity.
  - ART can reduce the number of hospitalizations.

#### Advantages of ART (Slide 2)

- If taken correctly, ART can also
  - Allow people to live longer and care for children and family.
  - Help people gain weight and feel more energetic.
  - Decrease the risk of (but not prevent) transmission of HIV.
  - Improve quality of life.

## Challenges of ART

- Adherence: Drugs must be taken correctly (take all of the pills on time for a lifetime).
- Side effects/toxicities: Drugs have side effects that range from minor (nausea) to major (liver damage).
  - Side effects vary. Some can be managed at home and some require medical attention.
  - Some occur after the drugs have been started and some after taking the drugs for months or years.
- Adherence and side effects will be explored further in later modules.

### Exercise: Advantages/Challenges of ART (15 minutes)

- Ask the class to get into pairs and discuss the following case study:
  - A friend who has HIV tells you she has just heard about a “wonder drug” called ART that cures HIV.
  - What would you tell her about the benefits and challenges of ART?
- Ask one of the groups to share their answers.
- During the discussion, remind the group that in addition to all the benefits, it is important that the participants know how to explain that ART is not a wonder drug. It comes with side effects and restrictions. They should be able to correct the patient in a respectful way using appropriate language and without overwhelming the patient.

## Classes of ART drugs (Slide 1)

- There are three types (classes) of ART drugs:
  - Nucleoside reverse transcriptase inhibitors (NRTIs).
  - Non-nucleoside reverse transcriptase inhibitors (NNRTIs).
  - Protease inhibitors (PIs).
- A patient needs to take several of these drugs in combination.
- Patients may take several different pills or one pill containing several drugs.

## Classes of ART drugs (Slide 2)

- Standard combinations exist (called first-line and second-line).
- Patients are initially prescribed a three-drug combination as a first-line therapy.
- The doctor will decide which combination of drugs will be best for the patient depending on certain issues (including pregnancy and TB).
- If first-line drugs do not work, or if the patient experiences side effects, the doctor can change one drug in the combination or select second-line therapy.

### ARV drugs

NRTIs	NNRTIs	PIs
Zidovudine (AZT) Lamivudine (3TC) Stavudine (d4T) Didanosine (ddI) Abacavir (ABC) Tenofovir (TDF) Emtricitabine/Truvada (FTC)	Nevirapine (NVP) Efavirenz (EFV)	Nelfinavir (NFV) Lopinavir/Ritonavir (LPV/r)-also known as Kaletra/Aluvia

### First-line regimens

- One NNRTI and two NRTIs

### Second-line regimens

- One PI and two NRTIs

### Fixed-drug combinations

- One pill contains multiple drugs:
  - ZDV/3TC (Combivir).
  - d4T/3TC (Lamivir-s).
  - ZDV/3TC/NVP (Duovir-n).
  - d4T/3TC/NVP (Triomune 30 or 40).
  - Lopinavir/Ritonavir (LPV/r) = Kaletra/Aluvia.
  - TDF/FTC (Truvada).
  - TDF/FTC/EFV (Atripla).

### For patients with both HIV and TB

- Because patients with TB have special concerns (such as drug interactions), there is a preferred/recommended ART regimen for patients who have both HIV and TB:
  - Stavudine (D4T) (NRTI) + Lamivudine (3TC) (NRTI) + Efavirenz (EFV) (NNRTI).
- **OR**
  - Zidovudine (ZDV) (NRTI) + Lamivudine (3TC) (NRTI) + Efavirenz (EFV) (NNRTI).
- **OR**
  - Tenofovir (TDF) (NRTI) + Lamivudine (3TC) (NRTI).
- **OR**
  - Emtricitabine (FTC) (NRTI) + Efavirenz (EFV) (NNRTI).

### ASW take-home messages for ART drug classes and lines

- Triomune (Stavudine, Lamivudine and Nevirapine) is one of the most commonly used combinations. Patients take one tablet, twice daily.
- Stavudine
  - Stavudine (D4T, Zerit).
  - Nucleoside reverse transcriptase inhibitor (NRTI).
  - Dosing:
    - › ADULT: More than 60 kg – 40 mg every 12 hours; less than 60 kg – 30 mg every 12 hours.
    - › PEDIATRIC: 1 mg/kg every 12 hours.
  - Take with or without food.
  - Primary side effects include
    - › Abdominal pain, nausea, vomiting, diarrhea, abdominal distension, muscle pain, difficulty breathing, rapid weight loss.
    - › Numbness or tingling in hands and feet.
    - › Loss of fat in face, arms, or legs.

- Lamivudine
  - Lamivudine (3TC, Epivir).
  - Nucleoside reverse transcriptase inhibitor (NRTI).
  - Dosing:
    - › ADULT: 150 mg every 12 hours
    - › PEDIATRIC: Child: 4 mg/kg every 12 hours; neonatal: 2 mg/kg every 12 hours.
  - Take with or without food.
  - Primary side effects:
    - › Generally well tolerated with minimal side effects.
- Zidovudine
  - Zidovudine (AZT, Retrovir).
  - Nucleoside reverse transcriptase inhibitor (NRTI).
  - Dosing:
    - › ADULT: 300 mg every 12 hours.
    - › PEDIATRIC: Child: 180 mg/m<sup>3</sup> every 12 hours OR 90-180 mg/m<sup>3</sup> every 8 hours ; neonatal: 2 mg/m<sup>3</sup> every 6 hours.
  - Take with or without food (decreased gastrointestinal side effects if taken with food).
  - Primary side effects:
    - › Gastrointestinal intolerance (nausea, vomiting, or abdominal discomfort).
    - › Muscle pain.
    - › Fatigue.
    - › Lightheadedness.
    - › Headache.

- › Anemia.
  - › Insomnia.
- Nevirapine
  - Nevirapine (NVP).
  - Non-nucleoside reverse transcriptase inhibitor (NNRTI).
  - Dosing:
    - › ADULT: First 14 days: 200 mg once daily. If no major side effects, then 200 mg every 12 hours.
    - › PEDIATRIC: First 14 days: 120 mg/m<sup>3</sup> once daily. If no major side effects, then 120-200 mg/m<sup>3</sup> every 12 hours.
  - Take with or without food.
  - Primary side effects:
    - › Rash (the rash can progress into a serious hypersensitivity reaction, usually during first eight weeks of treatment).
    - › Liver damage (jaundice/abdominal pain).
- Tenofovir (TDF)
  - Non-nucleotide reverse transcriptase inhibitor (NtRTI)
  - Dosage:
    - › ADULT: 300mg once daily (usually in combination with Emtricitabine [Emtriva] 200mg once per day, as Truvada)
    - › PEDIATRIC: Not recommended for children < 18 years
  - Take with or without food
  - Primary side effects:
    - › Feeling weak or tired
    - › Trouble breathing
    - › Stomach pain, nausea, vomiting

- › Feeling cold especially in arms and legs
  - › Feeling dizzy or lightheaded
  - › Kidney function problems
  - › Muscle pain
  - › Liver problems
  - › Fast or irregular heartbeat
- Emtricitabine or Emtriva (FTC)
  - Non-nucleoside reverse transcriptase inhibitor (NRTI)
  - Dosage:
    - › ADULTS: 200mg once daily (usually in combination with Tenofovir [TDF 300mg once daily] as Truvada)
    - › PEDIATRIC: not approved for infants < 3 months; 3 months–17 years: weight > 33kg, dose as in adults; lower weights, give 6mg/kg oral solution once per day
  - Primary side effects:
    - › Generally well tolerated) but can cause
    - › Headache
    - › Insomnia
    - › Nausea
    - › Diarrhea
    - › Rash
    - › Hyperpigmentation of palms and sores (especially in blacks)
- Efavirenz (Slide 1)
  - Efavirenz (EFV).
  - Non-nucleoside reverse transcriptase inhibitor (NNRTI).

- Dosing:
  - › ADULT: 600 mg at bedtime
  - › PEDIATRIC:

<b>Weight</b>	<b>Dose</b>	<b>Frequency</b>
10–15 kg	200 mg	Once daily at night or bedtime
15–20 kg	250 mg	Once daily at night or bedtime
20–25 kg	300 mg	Once daily at night or bedtime
25–32.5 kg	350 mg	Once daily at night or bedtime
32.5–40 kg	400 mg	Once daily at night or bedtime
> 40 kg	600 mg	Once daily at night or bedtime

- Efavirenz (Slide 2)
  - Take with or without food, but eat a low-fat meal if taken with food.
  - Primary side effects:
    - › Dizziness, mild disorientation (during first two to three weeks).
    - › Abnormal dreams (during first two to three weeks).
    - › Rash.
    - › Avoid pregnancy.
- Side effects (Slide 1)
  - All medicines can cause side effects.
  - These unwanted effects of medicines can vary from minor (such as nausea) to major (such as liver damage) and be temporary or last a long time.
  - Most patients do not experience all side effects.
  - Side effects are a concern because
    - › They can interfere with drug adherence.
    - › They can lessen quality of life.
    - › They can cause long-term health conditions.

- › They can be life threatening (in rare cases).
- Side effects (Slide 2)
  - If a patient experiences side effects, he or she may not be taking ART drugs appropriately.
  - Part of an ASW’s responsibilities include
    - › Monitoring patients for side effects.
    - › Educating patients about side effects.
- Monitoring patients for side effects
  - At all patient visits, ask about side effects.
  - Ask the patient if side effects are new or established.
  - For minor side effects, ask how the patient currently deals with them and suggest ways to manage them.
  - Report serious side effects to the doctor or help the patient to get immediate medical attention, if needed.
- Teaching patients about side effects
  - Remember: adherence increases when the patient knows what to expect and how to manage any side effects.
  - Teach the patient about potential side effects before he or she starts ART.
  - Continue to teach about side effects after the patient starts ART.
  - Instruct the patient and family how to manage minor side effects and how to recognize when they need to seek medical attention.
- Messages for patients
  - Side effects are symptoms that can occur once patients start ART.
  - They usually become less intense or go away as the body gets used to ART; it may take up to six weeks, but it could take longer.

- There are ways to manage side effects at home, but some should be reported to the clinic.
- Patients should report any new side effects at each clinic visit and each meeting with their ASWs.
- Patients should not stop taking ART, even if they experience side effects.

### Exercise: Quiz on Helping Relationships and Patient Messages on ART (5 minutes)

- Use the following quick quiz to remind participants how to best monitor patients for side effects. Read the question aloud and ask for a volunteer to answer it and explain why he or she chose that answer.
- When communicating with a patient who is on ART about side effects, it is best to (choose one):
  - Ask the person directly at each visit if he or she has any new symptoms.
  - Use examples of other people’s experiences as a way to introduce your questions, such as, “Some people get nausea. Do you find yourself nauseated?”
  - Repeat the list of symptoms, causes, and ways to manage them, and ask if the patient has experienced any of them.
- Symptoms for referral to the physician
  - Difficulty breathing
  - Abdominal pain.
  - Red rash that is intensifying and that may occur with fever, blistering, and mucous membrane involvement (eyes, mouth).
  - Persistent vomiting (lasting two to three days).
  - Persistent diarrhea (lasting two to three days).
  - Moderate to severe numbness/tingling/burning in hands and feet.
  - Severe headache with neck stiffness.

- Thoughts of suicide or increasing depression.
- Seizure.

**Patient education on mild to moderate side effects (Slide 1)**

Side effect	What a patient can do	When a patient should seek help/go to the clinic
Fatigue	Get up and go to bed at the same time each day. Exercise. Keep easy-to-prepare foods in house.	The patient is too tired to eat or move. The patient cannot swallow or eat enough to feel strong.
Headache	Rest in a quiet, dark place. Place cold cloths on your eyes. Rub the base of your head and your temples with your thumbs. Take a warm bath. Avoid coffee, tea, soft drinks, and foods with caffeine. Take Paracetamol.	The patient's vision becomes blurry or unfocused. Paracetamol does not relieve the pain. Headaches are frequent or very painful. The patient's neck is stiff.

**Patient education on mild to moderate side effects (Slide 2)**

Side effect	What a patient can do	When a patient should seek help/go to the clinic
Tingling or pain in feet and hands	Wear loose-fitting shoes and socks. Keep feet uncovered in bed. Walk a little, but not too much. Soak feet in cold water. Rub feet and hands.	The tingling does not go away or gets worse. The pain is so intense the patient cannot walk.
Dry mouth	Rinse mouth with clean water and salt. Suck on crushed ice or sip clean water. Avoid sweets, soft drinks, and coffee.	The patient also has white or red spots on the tongue or in the mouth.

### Patient education on mild to moderate side effects (Slide 3)

Side effect	What a patient can do	When a patient should seek help/go to the clinic
Diarrhea	<p>Eat frequent, small meals.</p> <p>Eat easy foods: bananas, rice, and toast.</p> <p>Avoid milk.</p> <p>Don't eat spicy or greasy foods.</p> <p>Peel fruits and vegetables before eating.</p> <p>Drink lots of clean water and tea.</p> <p>Take oral rehydration salts (ORS).</p>	<p>There is blood in the stool.</p> <p>The patient has a fever.</p> <p>The patient has more than four watery or soft bowel movements per day.</p> <p>The patient is thirsty, but cannot eat or drink properly.</p>
Nausea, vomiting, and low appetite	<p>Take ART drugs with food.</p> <p>Eat frequent, small meals.</p> <p>Eat bland foods (rice, porridge).</p> <p>Take sips of tea or ORS until vomiting stops.</p> <p>Don't eat greasy or spicy foods.</p>	<p>The patient has sharp stomach pains.</p> <p>The patient also has a fever.</p> <p>The patient is vomiting blood.</p> <p>Vomiting lasts more than one day.</p> <p>The patient is thirsty, but cannot drink or eat.</p>

### Patient education on mild to moderate side effects (Slide 4)

Side effect	What a patient can do	When a patient should seek help/go to the clinic
Hair loss	<p>Protect hair from damage. Don't dye, straighten, or plait.</p> <p>Don't buy products that promise to grow hair back.</p>	
Anemia	<p>Increase foods such as fish, meat, chicken, spinach, asparagus, dark leafy greens, and lima beans.</p>	<p>The patient has been feeling tired for three to four weeks and it is worsening.</p> <p>Both of the patient's feet are swelling.</p>

**Patient education on mild to moderate side effects (Slide 5)**

Side effect	What a patient can do	When a patient should seek help/go to the clinic
Dizziness	Sit down until it goes away. Avoid lifting anything heavy or moving quickly. Take Efavirenz right before going to sleep. Avoid driving a car, motorcycle, or bicycle when dizzy.	The dizziness lasts more than two weeks.
Unusual or bad dreams	Try to do something that makes you happy and calm right before going to sleep. Avoid alcohol and street drugs. Avoid food with a lot of fat.	If patient cannot sleep for three or more nights.

**Patient education on mild to moderate side effects (Slide 6)**

Side effect	What a patient can do	When a patient should seek help/go to the clinic
Feelings of sadness or worry	Talk about feelings with others (family, friends or other PLHA).	The patient experiences intense sadness or very worrying thoughts. The patient is thinking of harming himself. The patient feels very aggressive or very scared.
Difficulty concentrating	Use reminders (notes to self or help from family members) for important tasks. Allow extra time for activities.	

**Patient education on mild to moderate side effects (Slide 7)**

Side effect	What a patient can do	When a patient should seek help/go to the clinic
Skin rash	Keep the skin clean and dry. Wash with unscented soap and water. Use calamine lotion for itching. Avoid hot baths or showers. Avoid the sun.	Rash is accompanied by a general ill feeling, fever, muscle or joint aches, blisters or mouth sores, inflammation of the inside of the eyelids, swelling of the face, or tiredness.

## Exercise: Side Effects (40 minutes)

- Divide the class into groups of four and ask them to discuss the following regimen: stavudine + lamivudine + nevirapine.
- Using the information presented in the module,
  - Identify the common side effects and food restrictions of each drug.
  - Identify which side effects require immediate referral to a physician.
- Lead a discussion on the answers above. Be sure all side effects, including those that require immediate referral, are covered.
- Ask the groups to split up into pairs; discuss the drugs' side effects in a role play with an ASW and patient (one person is the patient and one person is the ASW).
  - ASW: Discuss the side effects with the patient before he or she starts taking the drugs. Monitor and educate the person about side effects after he or she begins taking the drugs.
  - Patient: Participate in the discussion and ask questions as appropriate.
- Lead the group in a discussion on the following:
  - How did the ASWs feel about discussing side effects with the patient?
  - Was there anything that was difficult to discuss or explain?
  - What communication skills did the patient use?
  - How did the patients feel when they learned about the side effects?
  - Did the patients feel they understood everything they were told?

## MODULE 7A: ADHERENCE

### PURPOSE

The purpose of this session is to present the key concepts of adherence. It includes why adherence to ART is important, what influences adherence, factors that influence adherence from the patient and facility perspective, and how ASWs can work with patients to achieve optimal adherence.

### OBJECTIVES

- Describe the importance of optimal adherence and the consequences when adherence is poor.
- Discuss factors affecting adherence in terms of patients and healthcare providers.
- Describe some adherence intervention strategies for patients before and after starting ART.

### TIME

Review objectives	5 minutes
Present content	1 hour 40 minutes
Activities	1 hour 15 minutes
Total time	3 hours

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### CONTENT

What is adherence? (Slide 1)

- Adherence means that a patient is taking drugs correctly. It involves taking
  - The right drug.
  - In the right dose.

- With the right frequency (number of times per day).
- At the right time.
- Adherence also means patient attending all scheduled clinical visits/procedures, including
  - Clinic appointments.
  - Lab tests.
  - Prescription refills.

#### What is adherence? (Slide 2)

- Adherence involves a partnership between the patient and the healthcare team.
- A critical aspect of adherence is the patient's involvement in deciding whether to take the drugs. It is a decision patients make for their own health.
- ART has to be taken for life; adherence is essential.

#### What is nonadherence?

- Nonadherence is the patient's inability to take his or her drugs or attend scheduled clinical visits in the prescribed manner.

#### What is special about ART and adherence?

- Patients need to achieve 100 percent adherence to ART to keep the correct amount of drugs in their bodies to fight the virus.
- Poor adherence leads to drug resistance, increased viral load, increased sickness, and increased possibility of death.

#### Adherence: General comments (Slide 1)

- Adherence is one of the key determinants of ART treatment success.
- Adherence may vary with life situations. Some patients may do well, but then have problems adhering to ART. Adherence support and monitoring are important throughout the patient's life.

- Patients need to be supported, not blamed, punished, or made to feel guilty.

#### Adherence: General comments (Slide 2)

- Working as a team is important; all of these persons need to be involved: nurses, doctors, adherence counselors, pharmacists, pharmaceutical technicians, and ASWs.
- It is important to involve a treatment supporter — a friend or family member chosen by the patient to help him or her remember to take the drugs and keep clinic appointments.
- A PLHA support group or PLHA treatment supporters can encourage adherence.

#### What is resistance?

- If ART drugs are not taken correctly, the virus can change so that it resists the action of the drugs (the drugs do not stop it from reproducing itself).
  - The patient then becomes sicker.
  - The resistant virus can be spread to others and drugs will not work on them either.
- Malaria offers an example of drug resistance. Doctors treated malaria with Chloroquine for years. Now the parasite that causes malaria is not killed by Chloroquine and other drugs must be taken.

#### Why don't people take their drugs correctly?

- Many factors positively and negatively influence adherence. They are
  - Related to the patient.
  - Related to the healthcare provider (ASWs included).

#### Factors affecting adherence (Slide 1)

- What patient factors negatively influence adherence? Barriers to adherence include
  - Forgetfulness.

- Travel away from home.
- Lifestyle.
- Depression or other mental illness.
- Cultural beliefs.
- Socioeconomic.
- Food availability.
- Competing priorities (caring for children or work).
- Alcohol or drug abuse.
- Tired of taking drugs.
- Stigma.
- Unstable housing.
- Low understanding of HIV or AIDS.
- Low literacy.
- Special developmental issues (for example, pediatrics).
- Lack of transportation.

#### Factors affecting adherence (Slide 2)

- What patient factors positively influence adherence?
  - Ability to make taking pills part of routine.
  - Effective use of reminders.
  - Belief that ART drugs work.
  - Self-confidence.
  - Belief in treatment adherence.
  - Patient readiness and commitment.
  - Social support.

- Having a treatment supporter.
- A patient feeling needed by his or her family or community.

#### Factors affecting adherence (Slide 3)

- What healthcare provider factors positively affect patient adherence?
  - Provider knowledge and skills about ART.
  - Good skills in patient education and counseling.
  - Providing medication alerts, charts, diaries, and other reminders and tracking mechanisms.
  - Provider support for patient.
  - Client comfort with and trust in clinic healthcare staff.
  - Consistent drug supply.

#### Factors affecting adherence (Slide 4)

- What healthcare provider factors negatively affect patient adherence?
  - Negative attitudes toward patient ability to adhere (not believing they can do it).
  - Neglecting to discuss and measure adherence.

#### Factors affecting adherence (Slide 5)

- What other factors negatively affect adherence?
  - Large number of pills has to be taken.
  - Frequency of doses (two versus three times per day dosing).
  - Side effects (especially nausea and vomiting).
  - Food restrictions.
  - Drug interactions.
  - Storage.
  - Cost of drugs.

### Exercise: Factors Affecting Adherence (#1) (15 minutes)

- Tape two pieces of flip chart paper to the wall labeled “positive” and “negative.”
- With the group, create a list of how the ASW role can positively or negatively affect patient adherence. Note patient responses.
- After the list is created, ask
  - What do you think are most important on this list?
- During the discussion, remind participants there are many factors that influence adherence. Factors related to healthcare providers (and ASWs) are very important. It is important to discuss how the good relationship and communication skills (Module 5) can influence a patient’s adherence or reporting of adherence. For example, if patients feel the ASW is not listening, they may be less than truthful about their reporting adherence. If patients feel the ASW is judgmental, they may not report risky behaviors.

### Exercise: Factors Affecting Adherence (#2) (15 minutes)

- Ask the class to get into pairs.
- Ask participants to discuss the experiences related to adherence of a person that know who has taken ART. Ask them not to use names.
  - Were they able to adhere to treatment 100 percent of the time?
  - What positive or negative factors influenced them?
- Ask several of the pairs to share what they discussed.
- During the discussion, remind participants that this is an opportunity to make the theoretical discussion more real. After the pairs share their stories, identify the positive or negative factors.

### Adherence goals

- The goal is 100 percent adherence.
- Adherence is a learned skill.
- Patients need to be able to
  - Understand the regimen.
  - Believe they can adhere.
  - Remember to take medicines at the right time.
  - Integrate the prescribed regimen into their lifestyles.
  - Problem-solve changes in schedule or routine.

### Before starting ART

- Define ART.
- Teach the goals of therapy.
- Define adherence.
- Discuss reasons why adherence is important.
- Help patients learn what to expect from treatment.
- Tell them what to do if they miss a dose.
- Help them identify potential barriers and create plans for success.

### After starting ART (Slide 1)

- Discuss adherence at each visit.
- Ask specifically about new symptoms or a change in health status.
- Reinforce education on HIV and ART.
- Assess adherence.
- If a patient misses doses
  - Get specific information about missed doses.

- Work with patients to determine why they encountered problems and which specific strategies might enable them to achieve 100 percent adherence.

#### After starting ART (Slide 2)

- Recognize and acknowledge the difficulty of adherence.
- Provide support and encouragement.
- Notify a medical officer if there are adherence difficulties and discuss it with the care team.
- Follow up with the patient. Work with the patient to identify strategies for improving adherence (such as using a treatment supporter, more home visits by the ASW, or a referral to home-based care [HBC]).

#### Strategies for helping patients with adherence (Slide 1)

- Create a comfortable atmosphere where patients can ask questions.
- Use simple terms and visual aids, if available.
- Provide a nonjudgmental, trusting environment. Ask questions and listen to answers.
- Make no assumptions. Ask all patients about adherence in the same way. For example, “Sometimes it is difficult to take medications on time. Have you missed any pills since your last appointment?” or “Why do you think you were unable to take your pills on time?”

#### Strategies for helping patients with adherence (Slide 2)

- Ask open-ended questions.
- Assess a patient’s readiness to start ART, including assessment of the patient’s support system, prior to dispensing drugs.
- Enhance self-confidence of the patient.
- Help the patient identify reminders and strategies (daily activity link, pill box, blister pack, diary, calendar, telephone reminder, or directly observed treatment [DOT]).

### Strategies for helping patients with adherence (Slide 3)

- Educate the patient on the following: basic drug information, reason for treatment, importance of adherence, consequences of nonadherence, timing of medications, drug interactions, and side effects.
- Identify potential barriers to adherence and support systems.
- Refer the patient to services to help address barriers (financial, transportation, housing, and food support).
- Discuss delaying the initiation of ART until significant barriers are addressed.

### Strategies for helping patients with adherence (Slide 4)

- Tailor treatment to the patient's lifestyle and routine. For example, cue ART dosing to regular daily events such as meals or prayer, or designate specific places and times for taking medications.
- Plan ahead for changes in routine, such as travel.
- Prepare the patient for possible side effects; instruct the patient on how to manage them.
- Tell the patient what to do if he or she misses a dose.

### Strategies for helping patients with adherence (Slide 5)

- Discuss the role of social support, including
  - Participation in a PLHA support group.
  - Involvement of a treatment supporter.
  - Home visits by the ASW.
  - Referral to HBC.

### Strategies for helping patients with adherence (Slide 6)

- Include the following topics in discussions with the patient and the treatment supporter (if involved):
  - Goals of treatment.
  - Disclosure issues: Who will the patient disclose to and how will he or she do it?

- Education on HIV transmission and prevention.
- Education on drugs and disease process.
- Ways the treatment supporter can help the patient.

#### Rule for missing doses

- Teach the patient what to do if he or she has missed a dose of the drugs.
  - “If you do miss a dose, take the dose as soon as you remember, but not if it is almost time for your next regular dose. Never take a double dose.”
  - If the drug is taken twice a day the missed dose can be taken up to six hours late, but no later than that. For example, if the normal dose is taken at 7 AM, the missed dose can be taken up to 1 PM.

#### Topics to include in discussions with the patient and treatment supporter (if involved)

- Goals of treatment.
- Disclosure issues: Who will the patient disclose to and how will he or she do it?
- Education on HIV transmission and prevention.
- Education on drugs and disease process.
- Ways the treatment supporter can help the patient.

#### After starting ART

- Discuss adherence at every visit.
- Ask specifically about new symptoms or a change in health status.
- Reinforce education on HIV and ART.
- Assess adherence.
- If patients miss doses
  - Get specific information about missed doses.
  - Work with patients to determine why they encountered problems and which specific strategies could work for their lifestyles.

- Recognize and acknowledge the difficulty of adherence.
- Provide support and encouragement.
- Notify a medical officer if there are adherence difficulties and discuss with the care team.
- Work with the patient to identify strategies for improving adherence (such as a treatment supporter if the patient doesn't have one, more home visits by the ASW, or a referral to HBC).

### Exercise: Adherence (45 minutes)

- Ask participants to get into pairs and discuss the following case study:

Maurice is a 35-year-old unmarried man with HIV. He drives trucks and is frequently away from home for at least three days at a time in different cities. He shares the route with another driver, his cousin, who takes turns driving with him. While on the road, he occasionally has sex. When he is in his hometown, he stays with his sister. When he is on the road, he sleeps in the truck. He believes that taking ART will help him feel better, but is not sure he will be able to remember to take the medications on time.

- List some of the challenges that Maurice may face in achieving 100 percent adherence.
- What are some ways he can overcome these challenges?
- What are some of the positive factors at work for him?
- Can you identify any potential barriers to communication?
- What are some potential issues that the ASW should be mindful of when building a relationship with Maurice?

Ask one of the pairs to share what they discussed. Discuss the potential barriers to communication such as Maurice's language level. Also discuss any potential relationship issues. For example, if the ASW believes in abstinence until marriage, how would the ASW put his or her feelings aside when talking with Maurice?

- Continuing in the same pairs, ask the participants to practice a role play with Maurice and an ASW assigned to him.
  - ASW: How would you discuss adherence with Maurice before he starts ART? Educate him on ART and adherence. Assist him in identifying possible barriers and solutions.
  - Maurice: Answer questions and participate in the discussion as appropriate.
- Ask one of the pairs to volunteer to act out their role play for the group.
- During discussion, ask the ASWs if they feel they presented all the information necessary to prepare Maurice to start ART. What other information could be added? Were the solutions appropriate for Maurice’s situation?

Consider this second scenario as a group:

- Maurice now has been taking ART for two months. In the last month, he missed two doses of his ART medications because he left his drugs at home when he went on the road. Now, an ASW visits him at home.
- Break into pairs. In each pair, practice a role play with Maurice and the ASW assigned to him.
  - ASW: How would you discuss adherence with Maurice now that he has started taking ART? Ask him about new symptoms and evaluate if he needs medical attention. Discuss his adherence with him and help him create a plan for adherence.
  - Maurice: Answer questions and participate in the discussion as appropriate.
- Ask one of the pairs to volunteer to act out their role play for the group.
- During discussion, ask the participants if the ASW helped Maurice determine a way to overcome his challenge to adherence. If he reported any new symptoms, ask whether the ASW evaluated them and educated Maurice appropriately.

## Exercise: Communication Skills Activity #2 (15 minutes)

- Ask for volunteers to form pairs and role play the following scenarios in front of the group.
- Scenario 1
  - Patient: Everyone wants me to take my medications at an exact time, but I don't understand why.
  - ASW: Evaluate what the patient knows about adherence to ART and how well he or she is adhering using a nondirective approach. Explain why adherence is important using language appropriate for the patient's level of understanding.
- Lead the group in a discussion regarding the communication style used.
  - Why would the ASW use a nondirective approach when asking the patient about adherence?
  - How well did the approach work?
  - What other ways can this approach be used to assess adherence?
  - Did the ASW present the information at the level the patient could understand?
  - Are there other words and phrases that could be used?
  - What barriers to communication were there?
  - In assessing adherence, there is the risk that the patient could elevate the status of the ASW to the point that he or she does not feel comfortable confiding in the ASW. How can an ASW work with the patient to overcome this?

## MODULE 7B: PEDIATRIC ADHERENCE

### PURPOSE

This session will introduce the special issues involved in pediatric patients' adherence. These include challenges in ART administration for pediatrics, such as disclosure, rules for pediatric adherence, strategies for medication administration with children, and tools for helping adolescents with adherence.

### OBJECTIVES

- Discuss the special adherence challenges for children.
- Discuss the pros and cons of disclosure of HIV status.
- Describe some strategies to teach parents in giving medications to babies, toddlers, and older children.
- Describe some special adherence barriers for adolescents and strategies to deal with them.

### TIME

Review objectives	5 minutes
Present content	1 hour 25 minutes
Activities	1 hour 30 minutes
Total time	3 hours

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### CONTENT

#### Challenges in ART adherence for pediatrics

- Liquid formulations.
- Weight-based dosing (as the child's weight increases, doses must change).

- Cost (they are often more expensive).
- Bad taste of liquid drugs.
- Frequency of doses.
- Food restrictions.
- Dependence on caregivers.
- Difficulty in taking pills for children (learning to swallow pills).
- Fear of disclosure (to child and others).

### What is disclosure?

- Definitions of “disclosure”
  - To reveal
  - To expose
  - To make known
  - To make public
  - To share

### Disclosure issues (Slide 1)

- Disclosure to the child may start as early as 5 to 7 years of age, but it must be done gradually in a culturally sensitive manner, and with the consent and participation of the parent or caregiver (ANECCA, 2004).
- Basic considerations when working with families with HIV-infected children on disclosure issues include the needs, feelings, and beliefs of the family and child.

### Disclosure issues (Slide 2)

- Benefits of disclosure:
  - It can help patients and families adopt a positive living attitude.
  - A child may cope as well as an adult if told at a young age.

- If the community is supportive, disclosing to the community can help a parent or caregiver obtain support.
- A child may suspect his or her status already.
- Older children and adolescents can more fully participate in their care if they understand it better.
- Adolescents may need prevention counseling (how to avoid spreading HIV to others).

#### Disclosure issues (Slide 3)

- Risks of disclosure:
  - If transmission was from mother to child, when disclosing, parents need to face their own positive status and transmission to the child.
  - Stigma may be present in the community.
  - Disclosure needs to be gradual, and at the child's level of understanding.

#### Disclosure issues (Slide 4)

- Confidentiality and trust must always be maintained.
- ASWs may help parents or caregivers with disclosure by listening to their concerns, helping them reason through disclosure, or by participating in disclosure if the parent or caregiver desires.

## Exercise: Disclosure (45 minutes)

- Discuss as a group:
  - Why would a family choose not to disclose an 8-year-old child's HIV status to the child? The child's school? The community as a whole?
  - What are the challenges the child may face?
  - Are there any benefits to disclosing to the above groups?
- Ask for volunteers to share an experience in which they had to explain something difficult to a child and how they changed the message so that the child could understand.
  - What did they learn from the experience that can be applied to disclosure of HIV to a child?
  - If there are no volunteers, create a scenario of your own for discussion.
- Ask for volunteers to share an experience in their own family or community related to disclosure to a child. Remind them that they should not use names and can change the story to protect confidentiality.
  - Was a healthcare worker involved with the family? If yes, how? If not, how could a healthcare worker have helped the family?
  - If there are no volunteers, create a scenario of your own for discussion.
- During discussion, remind participants that it is important to understand that there are benefits and risks of disclosure. ASWs can assist patients by listening to them, helping them think about options, and being a part of the disclosure process if the family desires.

## Rules for pediatric adherence

- Children need to maintain the same adherence levels (100 percent) as adults.

- Use the same adherence strategies and steps as adults with age-appropriate modifications.
- Educate the caregiver on how to give medications to a child.
- Involve and educate both caregivers and children at the child's level of understanding.
- Provide the family with support for other needs (such as food, housing, or spiritual support) to strengthen the household and optimize adherence success.
- Peer education or involvement in PLHA family groups may be helpful.

#### Caregiver education (Slide 1)

- How to give medicines to babies and toddlers (ages birth through 2 years).
  - Use a syringe or soft plastic dropper, or a spoon for medicine mixed with food. Carefully label dose on syringe.
  - With the baby on your lap, brace the baby's head close to your body so the head stays still. Tilt the head back a little.
  - Put the medicine in the corner of the baby's mouth toward the back, along the side of the tongue. This makes it more difficult for the baby to spit it out. Give the baby a little at a time to prevent choking and spitting.
  - Gently keep the baby's mouth closed until he or she swallows.
  - Never yell or show anger. Speak softly and say kind things.
  - When all the medicine is finished, keep the baby sitting upright for a few minutes and cuddle or comfort him or her. Offer water or juice only after the procedure is finished.

#### Caregiver education (Slide 2)

- Tips for giving medicines to children over age 2 years.
  - Keep trying different foods to cover the taste (such as juices, sweets, or porridge).

- Offer your child choices (such as types of food, spoon, or drink).
- Never ask children if they want to take the medicine.
- Some children do best when encouraged to take a deep breath and drink fast. Others take medicine one step at a time with a drink in between. Sometimes it helps to count for your child while he or she takes it.
- Offer praise afterward.
- Connect the medicine to the children’s feeling better, their bodies working better, or another desired activity or outcome.
- Involve children in their medication administration as appropriate for their levels of understanding.

#### Caregiver education (Slide 3)

- Troubleshooting for parents or caregivers.
  - Vomiting the medicine: Repeat the dose if the child vomits within two hours of taking the medicine.
  - Missing a dose: If the child misses a dose, give it as soon as he or she remembers (up to six hours after the missed dose time for a twice per day medicine) and continue on the regular schedule. Do not give two doses at the same time.
  - Refusing the medicine: Let the child know that you understand that taking medicine is not fun. Do not threaten, punish, or scold the child. This will only make the situation worse and could make the child feel bad.

#### Caregiver education (Slide 4)

- Troubleshooting for parents or caregivers.
  - Mixing medicines with food or drinks:
    - › Mix medicine with a small amount of food or liquid (such as porridge, clean water, or juice).

- › Do not mix medicine with food that is essential to the child’s diet (like milk). The child may associate the bad taste with milk and stop taking it even if it does not contain medicine.
- › Keep trying new methods and don’t give up.

#### Adolescent adherence (Slide 1)

- Barriers to adolescent adherence include
  - Disclosure issues.
  - Sexual development.
  - Depression.
  - Active alcohol/substance abuse.
  - Peer pressure.

#### Adolescent adherence (Slide 2)

- Barriers to adolescent adherence also include
  - Fear.
  - Low self-esteem.
  - Misinformation.
  - Concrete thought processes (thinking in terms of “black and white”).
  - Sense of invincibility (feeling that they can do anything and never be harmed).

#### Adolescent adherence (Slide 3)

- Strategies to help adolescents with adherence to ART include
  - Help them achieve self-confidence and maintain positive attitudes toward ART.
  - Help them practice with other drugs (such as vitamins) before starting ART.
  - Remind them to take drugs even if they are feeling well.
  - Develop a good, open relationship with them to encourage trust.

- Be aware of issues of alcohol or substance abuse or depression.
- Connect them with an age-appropriate PLHA group or other adolescents facing similar issues.

### Exercise: Barriers to Pediatric Adherence (45 minutes)

- Divide the class into groups of three. Ask them to discuss strategies for caregivers/patients when they report the following barriers to pediatric adherence.
- Remind the participants that creative strategies are important.
- For each scenario, the first person should read the barrier and offer a strategy. The second person will offer another strategy and the third person another strategy.
- Barriers:
  - An infant who spits out the medicine.
  - A caregiver who does not understand how much liquid medication to give to the infant.
  - A 5-year-old who refuses to take medication.
  - A 7-year-old who asks the caregiver why other children don't take medicines.
  - A teenager who says, "These medications don't do anything anyway."
- For each barrier, discuss in your groups which strategy seemed to be the most useful.
- Lead a discussion with the large group commenting on
  - What were the most useful strategies for each barrier? Why did your small group think it was the best?
  - What were some of the most creative strategies from the group?





## UNIT D: ROLES AND RESPONSIBILITIES OF ADHERENCE SUPPORT WORKERS



# UNIT D: ROLES AND RESPONSIBILITIES OF ADHERENCE SUPPORT WORKERS

The modules in this unit will outline the roles and responsibilities of the ASW in both the facility and community settings. These modules will teach participants exactly what they will be expected to do in their roles as ASWs and prepare them for the practicum. Substantial role plays and other exercises will allow participants to learn to implement the skills and knowledge they have obtained in previous sessions in their roles as ASWs.

## MODULE 8: ROLES AND RESPONSIBILITIES OF ASWS IN HEALTH FACILITIES

### PURPOSE

The purpose of this session is to outline the roles and responsibilities of ASWs in health facilities, including the ASW as a part of the clinic team, the education and support of the patient, common adherence difficulties and solutions, referrals, and home visits.

### OBJECTIVES

- Define the role of the ASW within the health facility.
- Define the responsibilities of the ASW in providing adherence support to patients on ART within the health facility.
- Describe the information on ART adherence that the ASW will discuss with patients.
- Discuss the psychosocial support the ASW will provide to patients that will contribute to their adherence to ART.
- Demonstrate the ART adherence support provided by the ASW through role plays and case studies.

### TIME

HIV/AIDS	1 hour 30 minutes
Pre-ART adherence and follow-up ART adherence	1 hour 30 minutes
Determining adherence and support	1 hour 30 minutes
Referrals and home visits	1 hour 30 minutes
Total time	6 hours

## SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

## CONTENT

### Why are ASWs important?

- The number of people being treated with ART has increased quickly and will keep increasing.
- Adherence is crucial for ART success.
- Current staff cannot meet all of the patients' needs, including adherence education and support; ASWs help fill this need.

### Role of the ASW

- ASWs educate and provide psychosocial support to patients starting or continuing on ART to help them:
  - Adhere to drugs.
  - Adhere to clinical monitoring protocol.
- ASWs support patients (both on ART and not on ART) by providing referrals according to their needs.
- ASWs participate as members of the ART clinic team.

### Responsibilities of the ASW (Slide 1)

- Report to the ART clinic according to the schedule provided by the ART adherence counselor.
  - Each ASW will be expected to work 20 hours per week.
- Provide information to patients and dispel myths on topics such as
  - Adherence.
  - ART.
  - Clinical monitoring protocol.

- HIV.
- Positive living.

### Responsibilities of the ASW (Slide 2)

- Offer psychosocial support to patients on ART and encourage them to adhere to ART and the clinical monitoring protocol.
- Help patients identify barriers to adherence and define realistic solutions to overcome barriers.
- ASWs participate as members of the ART clinical team and communicate about patient issues as appropriate.

### Responsibilities of the ASW (Slide 3)

- Document patient encounters on the appropriate forms.
- Facilitate a patient's access to HIV-related services by referring patients (both on ART and not on ART) through the referral network, actively following up to determine if patients accessed services, and documenting referrals (referral form, referral register).

### Educating the patient about ART

- Essential information includes
  - What does the patient know about HIV/AIDS?
  - What is ART?
  - What does adherence to ART mean?
  - Why is adherence to ART important?
  - What should the patient do if he or she forgets a dose?
  - How can the ASW determine if the patient is adhering to treatment?

### What does the patient know about HIV/AIDS?

- Ask the patient to describe HIV and AIDS in his or her own words.

- Determine if the patient’s descriptions are accurate.
- Reinforce accurate statements.
- Correct inaccurate statements.
- All patients should know
  - How HIV is and is not transmitted
  - How a person can find out if he or she has HIV
  - The difference between HIV and AIDS
- It is important that all patients have accurate information about HIV/AIDS and to understand treatment information.

### Exercise: HIV/AIDS Role Play (45 minutes)

- Ask for two volunteers to play the roles of the ASW and a patient who is starting treatment. The rest of the group will observe the session and comment.
- ASW: Discuss the following topics with the patient:
  - What are HIV and AIDS?
  - How HIV is transmitted?
  - How is HIV not transmitted?
  - How can someone get tested?
- Patient: Participate in the discussion and ask questions as needed.
- After the role play, lead the group in a discussion about the following:
  - How accurate was the information provided?
  - Are there any inaccuracies to correct?
  - Do you think that the ASW presented the information clearly to the patient?
  - What was the patient’s reaction to the information?

### What is ART?

- ART is a combination of drugs that controls HIV's ability to multiply.
  - The drugs do not completely eliminate the virus from the body.
  - The drugs must be taken for the patient's entire life.
- With less virus in the body, the immune system can recover and become stronger.
  - The person gets fewer infections and illnesses.
- ART drugs are prescribed for this patient only.
  - They can be dangerous if shared with others.

### What does adherence to ART mean?

- Taking the drugs as prescribed means
  - Taking all doses.
  - Taking medications at the right time.
  - Observing food restrictions.
- It is important for the patient to keep all visits to the ART clinic according to the schedule provided, and not to miss any appointments.
- The patient should remember to refill medications at the pharmacy on time.

### What should the patient do if he or she misses a dose?

- Tell the patient: "If you miss a dose, take the next dose as soon as you remember, but not if it is almost time for your regular dose."
- Never take a double dose.
- If drugs are taken twice per day, the missed dose can be taken up to six hours late, but not more than six hours late. For example, if the regular dose is to be taken at 7 AM, the missed dose can be taken up to 1 PM.

## Exercise: Pre-ART Adherence Role Play (20 minutes)

- Ask for two volunteers to play the roles of the ASW and the patient who is starting treatment. The rest of the group will observe the session and comment.
- ASW: Discuss the following topics:
  - What is ART?
  - What is adherence and why is it important?
- Patient: Participate in the discussion and ask questions as needed.
- After the role play, lead the group in a discussion about the following:
  - How accurate was the information provided?
  - Are there any inaccuracies to correct?
  - Do you think that the ASW presented the information in a way that a typical patient would understand?
  - What relationship or communication skills did the ASW use? Were they appropriate?
  - What was the patient's reaction to the information?

## Exercise: Follow-Up Adherence Role Play (20 minutes)

- Ask for two volunteers to play the roles of the ASW and the patient who has been on ART for nine months.
  - ASW: Discuss adherence with the patient focusing on any issues that may occur for patients who have been receiving treatment for several months.
  - Patient: Participate in the discussion and ask questions as needed.
- After the role play, lead the group in a discussion about the following:
  - How accurate was the information provided?
  - Are there any inaccuracies to correct?
  - Do you think that the ASW presented the information in a way that a typical patient would understand?
  - What relationship or communication skills did the ASW use? Were they appropriate?
  - What was the patient's reaction to the information?

## How can the ASW determine if a patient is adhering to treatment?

- There is no best way.
- Ask the patient and trust what he or she tells you.
- Ask the patient about adherence at each visit in a sensitive, nonjudgmental manner.
  - “It is not easy to remember to take your medications every day. Have you forgotten any doses since your last visit?”
  - “How many doses did you miss yesterday?”
  - “How many doses did you miss in the last three days?”

## Exercise: Determining Adherence Role Play (20 minutes)

- Ask for two volunteers to play the roles of the ASW and the patient who has been on ART for six months. This patient has had many problems with her adherence in the past.
  - ASW: Ask the patient about her adherence to ART since your last visit.
  - Patient: Participate in the discussion and ask questions as needed.
- After the role play, lead the group in a discussion about the following:
  - Do you agree with the way the ASW asked the patient about adherence?
  - What are different words, nonverbal communication, or relationship skills that could be used?
  - How would you feel if you were the patient?

## Supporting the patient (Slide 1)

- Taking multiple medications every day for the rest of one's life is difficult.
- ASWs support patients when they
  - Encourage them.
  - Affirm their ability to succeed.
  - Remind them that the clinic team is there to help them.
  - Help them identify barriers to adherence.
  - Ask them to report any difficulties.
  - Let them know that help is available for them (such as a treatment supporter). Encourage them to identify someone to be a treatment supporter.
  - Remind them of practical ways to link taking medication with everyday activities (for example, when getting up in the morning and going to bed at night, and at prayer times in the morning and evening).

### Supporting the patient (Slide 2)

- ASWs support patients continuing on treatment when they
  - Praise them for taking drugs day after day.
  - Acknowledge that it is difficult to take drugs when they feel well.
  - Encourage them to persevere.
  - Remind them of the long-term benefits of ART.
  - Encourage them to discuss difficulties so you can find solutions together.

### Steps to take when a patient reports missing doses (Slide 1)

- Remember to ask why the patient missed taking the medication.
  - There are many reasons why a patient does not take medication, including
    - › Forgetfulness.
    - › Experiencing or fearing side effects.
    - › Feeling reluctant to take drugs in front of the family.
    - › Traveling away from home and being on a different schedule.
    - › Feeling well and not wanting to take drugs every day.
  - It is important to help patients identify their reasons for missing medication so you can figure out how to address their specific challenges.

### Steps to take when a patient reports missing doses (Slide 2)

- Always discuss a possible solution for the reason given.
  - Be practical.
  - Offer realistic ideas based on the patient's unique situation.
  - Follow up if necessary (for example, if the patient requests a treatment supporter, help the patient identify someone or make a referral to a PLHA support group or HBC services).
- Emphasize the importance of adherence.
- Support patients, don't blame them.

## Exercise: Support Role Plays (45 minutes)

- Ask for two volunteers to play the roles of the ASW and a patient who is just about to start ART.
  - ASW: Demonstrate how to support the patient's treatment adherence.
  - Patient: Participate in the discussion and ask questions as needed.
- Ask for two volunteers to play the roles of the ASW and a patient who has been on ART for nine months.
  - ASW: Demonstrate how to support the patient's adherence.
  - Patient: Participate in the discussion and ask questions as needed.
- Ask for two volunteers to play the roles of the ASW and a patient who reported missing doses since the last clinic visit.
  - ASW: Demonstrate how to support a patient who has not taken all prescribed doses.
  - Patient: Participate in the discussion and ask questions as needed.
- After each role play, lead the group in a discussion.
  - Discuss how practical the ASWs advice and solutions were. Was the ASW sensitive to the patient's needs and feelings?
    - › Could alternative approaches have been used?
    - › How accurate was the information?
    - › Are there any inaccuracies to correct?
  - What was the patient's reaction to the ASW's support? Was it beneficial?

### Difficulty: Forgetfulness (Slide 1)

- A patient has difficulty remembering when to take medications.
  - What are some possible solutions?

- What resources do they require?

#### Difficulty: Forgetfulness (Slide 2)

- Possible solution: A treatment supporter visits and observes the patient taking his or her drugs every day.
- Required resource: A referral to a PLHA support group that has members who function as treatment supporters.

#### Difficulty: Lack of transportation (Slide 1)

- A patient has no means to get to the clinic, which is 15 km from home
  - What are some possible solutions?
  - What resources do they require?

#### Difficulty: Lack of transportation (Slide 2)

- Possible solution: Church members in the patient's community transport neighbors to the health facility when needed (one has a car, two have motorbikes).
- Required resource: A referral to the church to request transport for the patient on scheduled clinic visit days.

#### Difficulty: Nondisclosure (Slide 1)

- A patient is fearful of her family's reaction and has not disclosed her HIV-positive status or mentioned that he or she is on ART therapy.
  - What are some possible solutions?
  - What resources do they require?

#### Difficulty: Nondisclosure (Slide 2)

- Possible solution: Counseling can help the patient decide whether or not to disclose, and a mediator can accompany the patient if and when the patient chooses to disclose.
- Required resource: A referral for psychological counseling.

### Exercise: Disclosure Discussion (15 minutes)

- Lead a discussion about how to work with patients who have not disclosed their status to a sexual partner.
- Ask participants to volunteer what they would say to patients who tell them they have not disclosed their status to their sexual partner.
- Remind them that it is important to use a nonjudgmental, non-value-driven approach. They should also avoid telling the patients what to do, yet work with them in their decisions. Use the third person to introduce the subject by saying, “Sometimes people do not disclose their status and risk infecting their partner. Have you disclosed to your partner?”

### Referring the patient on ART to HIV-related services

- To achieve excellent treatment adherence, patients may need additional help to overcome difficulties in taking drugs and attending clinic visits.
- The nature of the assistance depends on their particular challenges and situations.
- Patients may need access to other types of assistance (such as psychosocial, spiritual, or economic) via a referral network.

### Referrals

- ASWs and patients should identify difficulties affecting treatment adherence and other parts of life and discuss possible solutions.
- ASWs should draw upon resources in the community and make referrals on the patient's behalf.
- ASWs should give the patient a referral form with the name, location, and contact person for the needed services.
- ASWs should document the referral in the health facility's referral register.

- ASWs should follow up with the patient to determine if the patient accessed services and if needs were met.

### Referring the patient not on ART to HIV-related services

- Patients not on ART and their families may also have nonmedical needs and difficulties.
- Access to services to meet those needs via a referral network may help improve their quality of life.

### Exercise: Referrals Role Play (30 minutes)

- Ask for two volunteers to play the roles of the ASW and a patient who is just about to start ART.
  - ASW: Discuss the patient's current situation and referral needs.
  - Patient: Participate in the discussion and ask questions as needed.
- Ask for two volunteers to play the roles of the ASW and a patient who is not on ART and has no plans to start anytime soon.
  - ASW: Discuss the patient's current situation and referral needs.
  - Patient: Participate in the discussion and ask questions as needed.
- After each role play, lead the group in a discussion.
  - Determine the level of practicality and sensitivity demonstrated by the ASW.
    - › Did the ASW show that he or she is knowledgeable about community resources?
    - › Do you agree with the referral for services provided by the ASW?
    - › Was the referral useful?
    - › Was the ASW sensitive to the patient's feelings?
  - Review the interaction between the ASW and the patient.
  - What was the patient's reaction to the ASW's referral?

### Discussing home visits (Slide 1)

- Through home visits, ASWs provide continuity of care.
- Before making home visits, ASWs must discuss the purpose of the visit and obtain written consent.
- Home visits
  - Are important in supporting adherence.
  - Can help identify side effects in patients just starting ART.
  - Can help patients with emergency needs.
  - Are offered to all patients.
  - Are voluntary (patients have the right to refuse).
  - Are different from HBC.

### Discussing home visits (Slide 2)

- Ask if the patient has specific concerns about home visits.
- Discuss concerns and attempt to solve issues if possible.
- When a patient agrees to home visits
  - Ask what day of the week and time is best.
  - Schedule the first home visit.
  - Confirm the patient's home address and get directions.

### Exercise: Home Visit Role Play (20 minutes)

- Ask for two volunteers to play the roles of the ASW and a patient who is starting ART.
  - ASW: Discuss visits to the patient’s home by an ASW.
  - Patient: Participate in the discussion, ask questions as needed, and raise any concerns you have as a patient receiving home visits.
- After each role play, lead the group in a discussion.
  - Discuss the manner in which the ASW raised the possibility of home visits.
  - Did the ASW effectively address any concerns raised by the patient?
  - Did the patient have a choice and freely agree to home visits?

### ASWs as part of the clinic team (Slide 1)

- ASWs are an important part of the team.
- ASWs contribute to the clinic’s ability to meet patients’ needs.
- ASWs will work with other team members to help patients achieve 100 percent ART adherence and clinical visits.

### ASWs as part of the clinic team (Slide 2)

- When should an ASW report a patient’s adherence to the ART adherence counselor?
  - At the time of the clinic visit
    - › Serious difficulties in taking ART (more than three doses missed since last visit).
    - › If there is a new symptom or change in health status since the last visit.
  - On the same day of a clinic or home visit or missed appointment.
    - › One or two missed doses since the last visit.
    - › A missed clinic visit.

### ASW as part of the clinic team (Slide 3)

- ASWs should promptly offer to help complete required documentation, including
  - Pretreatment adherence form.
  - Follow-up adherence form.
  - ASW register.
  - Referral form.
  - Referral register.

## MODULE 9: NEEDS OF PEOPLE LIVING WITH HIV/AIDS (PLHA)

### PURPOSE

The purpose of this session is to introduce the broad spectrum of needs of PLHA and how ASWs can help them access services to meet those needs.

### OBJECTIVES

- List the different areas that should be addressed in comprehensive HIV care.
- Discuss the spectrum of needs of PLHA.
- Explain how these needs can be met with a referral network.
- Identify the referral needs of a client in a case study.
- Define the referral activities the ASW will perform for patients.

### TIME

Review objectives	5 minutes
Present content	40 minutes
Activities	45 minutes
Total time	1 hour 30 minutes

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### CONTENT

#### Comprehensive care of HIV (Slide 1)

- People with HIV and their families have many needs. As members of the clinical team, ASWs should be aware that these needs include
  - Adherence counseling and ongoing support.
  - Economic support.
  - HIV testing and counseling.

- Nutrition support, including food resources.
- Ongoing prevention support.
- Psychosocial support.
- Regular medical care, including OI treatment, OI prophylaxis, palliative care, and ART either in the clinic or at home.
- Social work.
- Spiritual support.

#### Comprehensive care of HIV (Slide 2)

- You may need to provide patients and their families with referrals for appropriate services to help meet their needs.
- A system for referrals exists and is included in this training.

#### Broad spectrum of needs

- HIV is a chronic disease (one that lasts a lifetime). It affects the whole family and is often associated with stigma.
- PLHA have many needs beyond just medical care. These needs vary with the individual patient and his or her family and their circumstances.

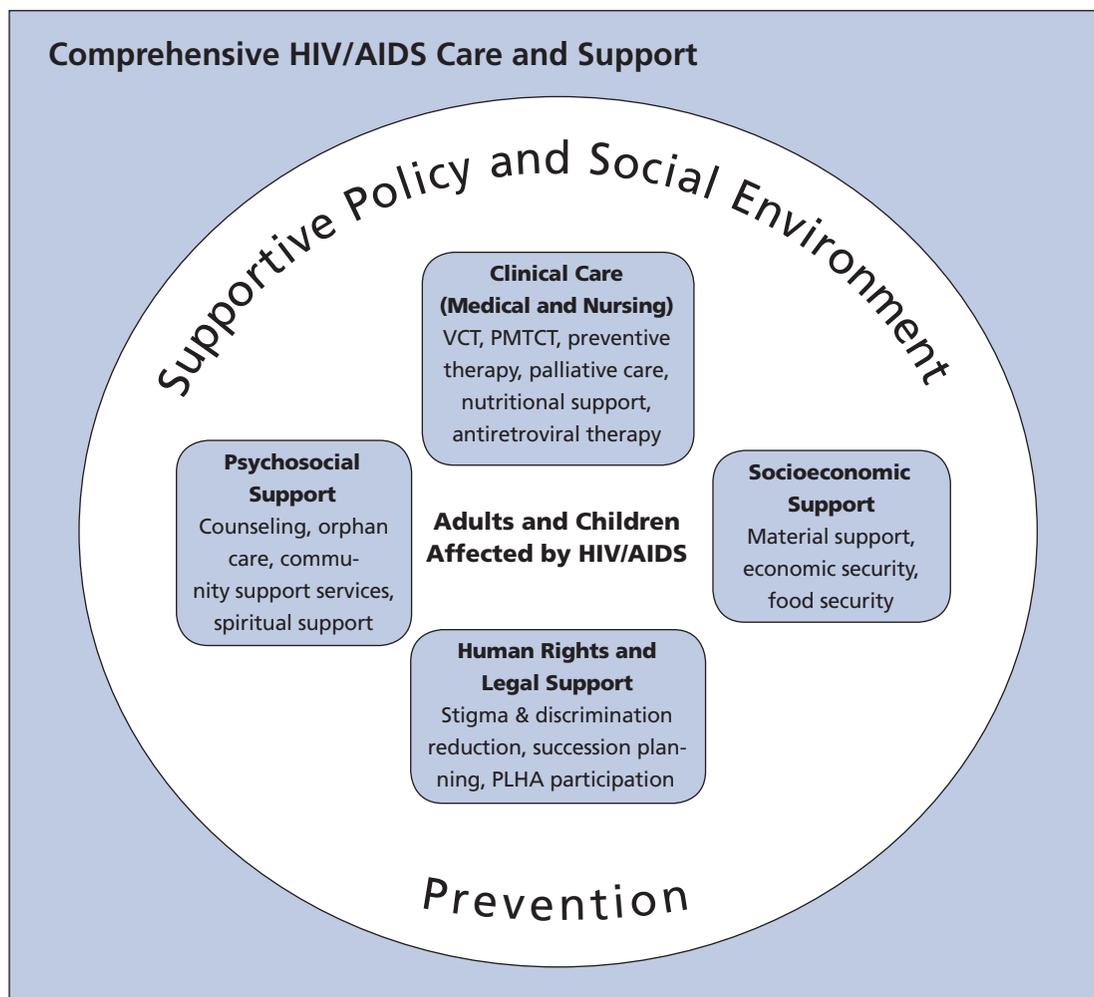
#### Needs may change

- The needs of each patient and his or her family will change over time as circumstances, including disease status, change.
  - For example, when first starting ART, a patient may need support from a PLHA group to help him or her adhere to treatment.
  - After a patient's health improves with treatment, he or she may have job training needs.
  - Later, the patient may request spiritual support if feeling lonely.

### Comprehensive care and support (Slide 1)

- Communities may have different resources.
- To provide comprehensive care and support to PLHA, caregivers, and families, services should include
  - Economic.
  - Legal.
  - Medical/nursing.
  - Psychosocial.
  - Spiritual.

## Comprehensive care and support (Slide 2)



### What is a referral network?

- A group of health facilities and community services within a geographic area that communicate regularly and work together to provide a broad range of services for HIV-infected persons and their families.

- The network has a directory of services, a referral form, and a register to document referrals for each facility's or community service's use. These items increase access to needed services for patients.

### Services included in the referral network

- Adherence counseling
- ART
- Child care
- Clinical care
- Education/schooling
- Family planning
- HIV counseling and testing
- Home-based care
- Hospice
- Legal support
- Material support
- Mental health services
- Microfinance
- Nutrition counseling
- OB/GYN services
- Peer counseling
- Post-exposure prophylaxis
- Pharmacy
- PLHA support
- PMTCT services
- Post-test clubs
- Prevention services
- Psychosocial services
- Social services
- Spiritual support
- STI services
- Substance abuse management
- Support for domestic violence victims
- Treatment support
- TB services
- Voluntary counseling and testing
- Youth support groups

### ASW role

- Help each patient and family identify needs.
- Refer the patient to appropriate resources.
- Document referral.

- Follow up with patient and family to determine if needs were met.
- Refer patients to other resources if necessary. (Referrals will be covered in detail later in the training.)

### Exercise: Identifying the Needs of PLHA (45 minutes)

- Ask participants to form pairs and discuss the following case study.
- Cassandra is a married 25-year-old mother of two children ages 2 and 4; she lives with her husband and children. She also cares for her two nephews who lost their parents to HIV. She recently started ART treatment at the clinic. She is unaware of the HIV status of her husband or children. She is thin and says she has been ill with diarrhea and respiratory problems for the last six months, leaving her unable to work.
  - What needs, aside from medical care, does Cassandra have?
  - What referrals will Cassandra need?
  - If she lived in your community, what resources exist that could help her?
- Ask groups to share their answers to the above questions.
  - Make a list of needs on the left side of a flip chart.
  - List the resources on the right side and connect them to the needs with arrows.
  - List the names of the specific resources that exist in the community above the arrows. For example, use an arrow to connect the need “more food” and the resource “food support” and write “East Community Church Food Bag Program” above the arrow.
- During the discussion, remind the participants that one PLHA can have many needs. While ASWs cannot provide services to fulfill all needs, they can help patients access the services they need through referrals (this will be covered later in the training).

## MODULE 10: ROLES AND RESPONSIBILITIES OF ASWS IN THE COMMUNITY

### PURPOSE

This session will introduce the roles and responsibilities of ASWs in the community, including when home visits should be made for patients on ART and not on ART, reporting to the clinic, and logistics.

### OBJECTIVES

- Define the role of the ASW within the community.
- Discuss the circumstances that determine when a home visit with a patient on ART is appropriate.
- Discuss the support that the ASW will provide during the home visit.

### TIME

Review objectives	5 minutes
Present content	40 minutes
Activities	1 hour 15 minutes
Total time	2 hours

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### CONTENT

#### Community role of the ASW

- Home visits
  - For those on ART
    - › Provide additional support for nonadherent patients on ART.
    - › Follow up with patients who have side effects to monitor their health status and any effects on adherence.

- For those who default
  - › Contact any patient who has missed a scheduled clinic visit.
  - › Allow the ASW to better understand the patient’s home situation and family needs.
- For those not on ART
  - › Maintain ongoing contact with patients not on ART to monitor health status and facilitate care and treatment when needed.

#### When should those on ART receive home visits?

- Following patient requests
  - A patient requests additional adherence support and wants a home visit by an ASW.
  - A patient identifies specific barriers to adherence and thinks a home visit may help.
- Healthcare worker
  - An ASW knows the patient and feels a home visit is necessary.
  - The patient has missed a scheduled appointment or drug refill.
  - The ART adherence counselor has specific reason.

#### When should a home visit be made to those not on ART?

- A patient’s last clinic visit was three months ago and there has not been any contact with the patient since then.
- A patient had a scheduled clinic visit and has not kept the appointment.

#### Responsibilities during a home visit for a patient on ART (Slide 1)

- Determine if the patient has an emergency need and help with transport if necessary.
- Ask the patient about any changes in his or her health status (such as new symptoms).

- Ask the patient about taking ARVs.
  - What is the patient’s usual schedule (such as with meals)?
- Assess the patient’s adherence.
  - If there are adherence problems, identify barriers and suggest solutions.

#### Responsibilities during a home visit for a patient on ART (Slide 2)

- If the patient has stopped taking ART (defaulted), ask him or her about the challenges that make it difficult to adhere. Work to identify ways you can help the patient return to treatment. Some examples include
  - The ASW can educate the patient and family on ART.
  - The ASW can provide referrals to meet the patient’s needs, such as housing and transportation.
  - The ASW can act as the treatment supporter.

#### Responsibilities during a home visit for a patient on ART (Slide 3)

- Explain again why adherence is important.
- Determine if the ARVs are being stored safely, and help the patient improve storage, if needed.
- Review the day and time of the patient’s next appointment.
- Quickly assess the patient’s home situation.
- Provide other assistance if needed (such as referrals to meet basic needs).

## Exercise: ASWs in a Community Group (45 minutes)

- Lead the group in a discussion on the following scenarios and how the ASW could help the patient in each:
  - The patient has missed one or more doses of ARVs.
  - The patient reports that his or her ARVs have been lost.
  - The patient reports new symptoms since the last clinic visit (such as nausea, headache, diarrhea, or bad dreams).
  - The patient is very sad and seems depressed.
  - The patient does not want to take drugs anymore.
  - The patient does not like going to the health facility.
  - The ASW notices there is no food in the house.
  - A neighbor tells the patient that ARVs are poison.

### Home visit for a patient not on ART (Slide 1)

- Some patients with HIV are not yet ready to begin ART, but go to the clinic for routine checkups.
- The ASW will make home visits if patients have missed a scheduled visit or have not been seen in the clinic for three months.

### Home visit for a patient not on ART (Slide 2)

- Determine if the patient has an emergency need and help with transport if necessary.
- Ask the patient about any changes in health status (such as new symptoms).
- Determine the reason the patient has not been to the clinic (such as no transport) and address barriers.
- Discuss the importance of regular contact with the clinic.

- Quickly assess the home situation.
- Provide other assistance if needed (such as referrals to meet basic needs).

### Exercise: ASWs in a Community Role Play (30 minutes)

- Ask for two volunteers to participate in the following role play. One will play the role of the patient, and one will play the role of the ASW.
  - Sam, a 35-year-old man who is not on ART and has not been to the clinic in four months.
  - An ASW who visits Sam's home.
- After the role play, lead a discussion asking the participants
  - How did the ASW support Sam?
  - What was Sam's reaction to the ASW?

### Reporting to the ART clinic: documentation

- After each home visit the ASW will complete
  - A pre-treatment form **or** treatment adherence form.
  - An ASW register.
- If a referral was given, the ASW will complete
  - A referral form and give it to the patient.
  - A referral register.
- Instructions on how to complete these forms will follow.

### Reporting to the ART clinic: problems to report immediately (Slide 1)

- Certain problems experienced by the patient should be reported immediately (the same day) to the ART adherence counselor, detailing any action taken by the ASW. These problems include

- Difficulty breathing or shortness of breath.
- Nausea with low food/water intake for two days.
- Vomiting with low food/water intake for 24 hours.
- Diarrhea more than three times per day for two days, or if associated with fever or dehydration.
- Persistent headache that does not get better with Paracetamol, or if the headache is associated with a stiff neck.

#### Reporting to the ART clinic: problems to report immediately (Slide 2)

- Problems to report immediately also include
  - Rash (any new rash should be reported).
  - Itching or swelling anywhere on the body.
  - Abdominal pain.
  - Fever lasting more than 24 hours.
  - Numbness, tingling, or pain in the foot, leg, or hand (if it is new or has worsened since the last visit).
  - Dizziness or lightheadedness (experienced when standing from a seated position or lying down).
  - Difficulty urinating.

#### Logistics for home visits

- At the end of each clinic day, the ART adherence counselor will meet with the ASWs to make a list of patients who require home visits.
- The ART adherence counselor will ensure that transport is available to all ASWs for home visits.
- The ASW will carry out the home visits within two to three days.
- ASWs will be rotated between the clinic and home visits depending on need, according to the schedule prepared by the ART adherence counselor.



UNIT E: QUALITIES OF A GOOD ADHERENCE  
SUPPORT WORKER



# UNIT E: QUALITIES OF A GOOD ADHERENCE SUPPORT WORKER

Modules in this unit are designed to continue building skills that help the ASW develop and nurture relationships with patients.

## MODULE 11: ETHICS AND PROFESSIONAL BEHAVIOR

### PURPOSE

This session will outline ethical guidelines for working with patients, including the Zambia Counseling Center (ZCC) code, respect and confidentiality, and identifying ethical conflicts in case studies. The concepts of professional behavior will also be addressed.

### OBJECTIVES

- Identify ethical responsibilities of ASWs.
- Discuss how to maintain patient confidentiality.
- Understand how to show and support professional behavior.

### TIME

Review objectives	5 minutes
Present content	25 minutes
Activities	60 minutes
Total time	1 hour 30 minutes

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### ADDITIONAL PREPARATION/SUPPLIES NEEDED

- Handout for ethics and professional behavior exercise (page 204)

## CONTENT

### Why ethics?

- ASWs should have knowledge of the values (or ethics) of proper helping relationships so they can maintain professional relationships with all patients.

### Ethical guidelines

- Ethical guidelines protect patients and guide ASWs to make appropriate choices in their work with patients.
- Making the ethical choice is not always clear.
- These guidelines relate to both present and past patients.
- If you, as an ASW, have any questions about your work with a patient, discuss them with your supervisor.

### Principles

- Do no harm.
- Autonomy.
- Equality.
- Confidentiality.
- Consent.

### Do no harm

- ASWs are responsible for their patients and should ensure that their patients suffer no physical or psychological harm from their relationship.
- The ASW should help the patient and his or her family achieve and maintain adherence to ART.
- Engaging in a sexual relationship or activity with a patient is unethical.

### Autonomy

- Autonomy is the patient's right to make his or her own decisions.

- The ASW must respect the patient’s and the family’s autonomy.
- The ASW should work with patients to achieve their goals.
- The ASW should not tell patients what to do or make decisions for them.

### Equality

- All patients should be treated equally despite age, gender, sexual orientation, or social status.
  - ASWs must not accept gifts or favors from patients for their services.
  - ASWs must treat all patients the same, despite any previous relationships (for example, familial or tribal).

### Confidentiality (Slide 1)

- The ASW must treat all information or material heard, obtained, or provided as confidential.
- The ASW must not disclose any information about the patient to anyone (except clinic staff) without first seeking the patient’s consent.
  - If you are asked to reveal information about a patient, it is appropriate to say, “I cannot talk about that.”
  - Do not talk about your patients with friends, family, or neighbors.
  - Do not discuss patients with colleagues in public areas of the clinic or outside the clinic.

### Confidentiality (Slide 2)

- The ASW must follow protocols for maintaining confidentiality in the storage and disposal of patient records.
- The ASW will breach confidentiality only if there are sound reasons, and after consulting with a supervisor and informing the patient. Sound reasons include the following:
  - On instruction by a court.

- When you believe the patient is no longer able to take responsibility for his or her own decisions and actions.
- When you believe the patient will cause serious harm to himself or herself or to other persons, or if the patient may be harmed by someone else.
- When you believe the patient infected with HIV may infect specified third parties because of nondisclosure of status (after all avenues have been explored and assistance offered).

### Consent

- Consent is defined as giving permission.
- Since the patient is autonomous (that is, makes his or her own decisions), he or she must give informed permission for any clinical activity, including testing, counseling, home visits, referrals, or sharing of information with others.
- Sometimes this consent is verbal, and other times it is written.
- Clinical protocols will guide ASWs in deciding when they need written consent from a patient; ASWs should consult with a supervisor for clarification.

### Professional behavior

- ASWs are considered an important part of the clinical team and are expected to behave professionally, both in the clinic and on home visits.
- Professional behavior builds trust for you and other ASWs among your patients, their families, and the community.

### Examples of professional behavior (Slide 1)

#### An ASW must

- Follow clinical protocols.
- Attend clinical meetings as requested.
- Participate as part of the clinical team.
- Monitor his or her own competence and limitations.

- Seek support from a supervisor and other members of the clinic team when needing help.
- Discuss any unprofessional behavior on the part of other ASWs with a supervisor.

#### Examples of professional behavior (Slide 2)

- Strictly adhere to confidentiality standards.
- Be on time for appointments and home visits.
- Be prepared for work at the ART clinic and have all necessary tools available (such as forms and guides).
- Be prepared for home visits and have all necessary tools available (such as forms and guides).
- Be responsible for your own physical safety.
- Treat all patients equally (no favorites).
- Don't make promises that cannot be kept.

#### Examples of professional behavior (Slide 3)

- If you do not know something, admit you do not know and go find the answer.
- Don't advise patients about matters that are beyond the scope of your expertise.
- Maintain professional boundaries — patients are clients, not friends.
- Maintain good personal hygiene and presentation.

## Exercise: Ethics and Professional Behavior (60 minutes)

- Ask participants to form pairs.
- Pass out one copy of the exercise to each pair (page 204).
- Ask the pairs to work together on the exercises with the following steps:
  - Read each scenario.
  - Define the ethical or professional problem.
  - Discuss how the situation could be handled so it adheres to the ethical and professional behavior guidelines previously presented.
  - Discuss how the ASW should work in the scenario to maintain a good relationship with the patient.
- After the pairs have gone through all of the exercises, review them as a group.
  - Ask for pairs to read the situation and discuss their answers.
  - Review answers for appropriateness.
  - Ask the group, “Is there another way to change this situation to make it more ethical and professional?”

## MODULE 12: PROBLEM-SOLVING

### PURPOSE

The purpose of this session is to introduce the three-stage problem-solving model and demonstrate how it can be applied to improve patient adherence.

### OBJECTIVES

- Understand the three stages of problem-solving management.
- Be able to use the model to help patients with adherence challenges, as presented in case studies.

### TIME

Review objectives	5 minutes
Present content	35 minutes
Activities	50 minutes
Total time	1 hour 30 minutes

### SESSION PLAN

- Present purpose and objectives of session.
- Present the following content and activities.

### CONTENT

#### Three Stages of Problem-solving

ASWs can use these methods to help patients identify and overcome their problems with adherence:

- Stage 1: Understanding the present scenario.
- Stage 2: Understanding the preferred scenario.
- Stage 3: Making a plan.

### Stage 1: Understanding the present scenario (Slide 1)

- Assess the problem.
  - Help patients tell their stories.
    - › Use appropriate communication and relationship skills. For example: “Tell me about your home situation.”
  - Determine the following:
    - › The nature and severity of the problem.
    - › Other problems that are not being discussed.
    - › The impact of the patient’s environment on his or her problems.
    - › Personal and interpersonal resources belonging to the patient.
    - › Ways in which problems could be opportunities.

### Stage 1: Understanding the present scenario (Slide 2)

- Develop new perspectives.
  - Help the patient overcome blind spots and develop new perspectives on his or her problem situation.
  - Use imagination and help find new ideas to empower patients.
  - Help patients see themselves, others, and the world in a more creative way.
  - Work with patients but do not tell them how to act or feel. For example, “Some people have tried working with their spiritual leader when they are worried about disclosing to their family. Would this be an option for you?”

### Stage 1: Understanding the present scenario (Slide 3)

- Help patients search for direction.
  - Help patients identify and work on problems, issues, concerns, or opportunities that will make a positive difference through the following:
    - › Determine the cost of the problem in terms of effort and time to be spent on it.

- › If there are a number of problems or a complex problem, help the patient determine which concern to address first.
- › Together with the patient, clarify the problem, issue, or concern in terms of specific experiences, behavior, feelings, or emotions.

### Exercise: Problem-Solving Stage 1 (20 minutes)

- Discuss the following case study with the group.
- Ask one participant to play the role of Charity (ask that person to come to the front of the room). That person will answer questions and participate as needed.
- The rest of the group will participate in the discussion and use the techniques in Stage 1 to demonstrate how an ASW can use problem-solving stages to help a patient.
- Charity is a 35-year-old woman living in Lusaka. She operates a small snack shop to support her five children (ages 2 through 8). Her husband died of AIDS one year ago. She tested positive for HIV shortly after he died and has been taking ART for six months. Her ASW made a home visit because she missed an appointment. She reported missing several doses of her ART medications over the last month. She also said she has been ill with pneumonia for the past few weeks and has been unable to work.
- Stage 1: Understand the patient's present scenario.
  - Assess the problem.
    - › What questions would an ASW ask Charity to determine what influences her health and adherence to ART?
    - › What is the impact of her home and situation? Does she have any resources or opportunities to help her?
  - Develop a new perspective.
    - › How would you help Charity develop a new perspective? Is there any part of her problem that you think she can't recognize?
  - Help Charity search for direction.
    - › What is her non-adherence costing her (in time, money, or relationships)?
    - › Which problem should she address first?

## Stage 2: Understanding the preferred scenario

- Help each patient develop a range of possibilities for the future, or picture a new state of affairs.
- Help each patient translate the preferred scenario possibilities into possible solutions.
  - Goals should make sense and be specific, measurable, attainable, and realistic.
  - Set a deadline for reaching goals.
- Help patients identify the kinds of incentives that will enable them to commit themselves to their goals. Focus on ways to reduce the patient’s crisis or pain.

### Exercise: Problem-Solving Stage 2 (15 minutes)

- Instruct the class to continue with the previous role play and discuss the following:
- How would you help Charity to identify some preferred scenarios? How would she like her life to be? Could referrals to any services help her?
- Help her set goals that are in line with her preferred scenarios.
- What rewards will she receive if she accomplishes the goals?

## Stage 3: Making a plan

- A plan is a set of actions that will achieve a goal.
  - ASWs can help patients brainstorm and develop numerous strategies for reaching their goals. Ask them: “How can you get where you want to go?”
  - Remember to help patients choose a set of strategies that best fit their environment and resources.
  - In addition, help patients formulate a plan (a step-by-step procedure) for accomplishing each goal.

### Exercise: Problem-Solving Stage 3 (15 minutes)

- Tell the class to continue with the previous role play and discuss the following.
  - How can the ASW help Charity accomplish her goal?
  - What strategies can she use that fit her lifestyle?
  - How can she implement these strategies? Detail each step.
  - How will you, as an ASW, help her implement these strategies?

### Problem-solving

- The model presented in this training can help patients identify and overcome their problems.
- More specifically, ASWs can use the methods presented to help patients overcome any problems with adherence.

## MODULE 13: DATA COLLECTION AND MONITORING

### PURPOSE

This session will introduce the processes for data collection and monitoring and give participants the opportunity to practice completing the necessary forms and processes.

### OBJECTIVES

- Understand the types of patient data to be collected.
- Be familiar with standardized data-collection tools.
- Practice using the tools.

### TIME

Review objectives	5 minutes
Present content	1 hour 25 minutes
Activities	1 hour 30 minutes
Total time	3 hours

### SESSION PLAN

- Present the purpose and objectives of session.
- Present the following content and activities.

### ADDITIONAL PREPARATION/SUPPLIES NEEDED

- One set of copies of the ASW forms for each participant (see pages 209–215).

### CONTENT

Documenting your work is important

- It helps guide good practice.
- It collects information on patients for future visits.
- It collects information that the clinic needs to provide quality patient care and reports for program monitoring.

## Forms for ASWs

- Pre-treatment adherence form.
- ART adherence form.
- ASW register.
- Referral form.
- Referral register.

## Pre-treatment adherence form (Slide 1)

- The pre-treatment adherence form should be completed during the first ASW and patient visit.
- Goal:
  - Guide ASWs in their work with patients.
  - Document the evaluation of a patient's readiness to start ART.
- Types of data collected:
  - Consent for home visits.
  - Evaluation for probable adherence issues.
  - Patient education.
  - Referrals.

## Pre-treatment adherence form (Slide 2)

- Special instructions:
  - Use the form as a guide in your discussion with the patient. Be sure to discuss all topics listed.
  - The form uses yes/no ticks and has space for explanations or comments. Use the explanation/comment column whenever necessary.
  - Be sure to document the patient's consent for home visits.
  - Be sure to date the form and sign your name.
  - Attach the form to the patient's chart when you are finished.

### Exercise: Pre-Treatment Adherence Form (40 minutes)

- Ask the participants to get into pairs and perform a role play. The scene is between a woman who will be starting ART and an ASW newly assigned to her case.
  - ASW: Using the technical information and communication/counseling skills you have developed, discuss adherence to ART with her. Fill out the pre-treatment adherence form.
  - Patient: Participate in the discussion as appropriate.
- Ask participants to switch roles so both partners have a chance to practice filling out the form.
- Ask one group to share their form. Correct any errors.

### Follow-up adherence form (Slide 1)

- Goal:
  - Guide ASWs in their work with patients.
  - Document the evaluation of the patient's adherence.
- Type of data collected:
  - Patient education.
  - Adherence evaluation.
  - Physical symptoms.
  - Referrals.
- The follow-up adherence form is completed at all visits after a patient starts ART.

### Follow-up Adherence Form (Slide 2)

- Special instructions:
  - The form will be filled out multiple times and kept with the patient's chart.

- It is important to indicate the type of visit (clinic or home) and mark the date at the top.
- Use the form as a guide in your discussion with the patient. Be sure to discuss all the topics listed.
- The form uses yes/no ticks and has space for explanations or comments. Use the explanation/comment column whenever necessary.
- Notify the ART adherence counselor if information needs to be reported right away.
- Attach the form to the patient’s chart when you are finished.

### Exercise: Follow-Up Adherence Form (40 minutes)

- Ask the participants to continue the previous role play with their partners.
- In this scene, the same patient has been on ART for two months.
  - ASW: Using the technical information and communication/counseling skills you have learned, discuss adherence to ART with her. Fill out the ART treatment adherence form.
  - Patient: Participate in the discussion as appropriate.
- Ask participants to switch roles so both partners have a chance to fill out the form.
- Ask one group to share their form. Correct any errors.

### ASW Register (Slide 1)

- Goal: Collect brief information about ASW activities for data reporting and patient tracking.
- Types of data collected:
  - Patient information.
  - Services provided.

- Services planned.
- Complete this form after each patient visit.

### ASW Register (Slide 2)

- Special instructions:
  - Check services provided.
  - Be sure to include the date of the next scheduled appointment.
  - Include your initials.

### Exercise: ASW Register (20 minutes)

- Ask participants to continue the previous role play with their partners.
  - Fill out the ASW register for the two previous appointments.
- Ask one group to share their form. Correct any errors.

### Referral Form (Slide 1)

- Goal: To provide patients with information needed for their referral to services and to document those services to guide further referral needs.
  - Complete this form at the time of referral.
- Types of data collected:
  - Name of the organization to which the patient is referred.
  - Needs of the patient.
  - Documentation of services (filled out by organization that provides the services).

### Referral Form (Slide 2)

- Special instructions:
  - Information on local agencies/resources can be found in the referral directory.

- Include a comprehensive description of the reason for the referral.
- When the patient returns Part B, review it and discuss his or her experience. Were the patient’s needs met?
- If his or her needs were not met, refer the patient again. If possible, refer the patient to a different organization providing the same service.

### Exercise: Referral Form (30 minutes)

- Ask participants to continue the role play with their partners.
- In this scene, the patient tells you that he or she does not have enough food for the family and needs a referral for food support.
  - ASW: Talk to the patient about his or her needs. Fill out the referral form for a referral to the local church food bank.
  - Patient: Participate in the discussion as appropriate.
- Ask one group to share their form. Correct any errors.

### Referral Register (Slide 1)

- Goal: To collect brief information about referral activity for data reporting and patient tracking
- Types of data collected:
  - Patient information.
  - Services provided.
  - Services still needed.
- Complete this form after making referrals or when patients report back on their referral experience.

### Referral Register (Slide 2)

- Special instructions:

- The “referred by” organization will always be the ART clinic.
- The “referred to” organization will be the organization that the patient will go to for services.
- Fill out the “services completed and follow-up needed” boxes after the patient has gone for services.

### Exercise: Referral Register (20 minutes)

- Ask participants to finish the previous role play with their partners.
- In this scene, the patient tells the ASW that she has registered to receive food from the local church. She will receive food from them on a regular basis. She gives the ASW Part B of the referral form.
  - Complete the referral register.
- Ask one group to share their form. Correct any errors.



## UNIT F: PRACTICUM IN FACILITIES



# UNIT F: PRACTICUM IN FACILITIES

## PURPOSE

The purpose of the practicum is to allow ASWs to apply the skills they obtained in the training by observing trained counselors and working with real patients. It also allows training staff to give feedback to the ASWs on their implementation of the role.

## OBJECTIVES

- To acquaint ASWs with their roles and responsibilities in the health facility setting using real patients and tools.
- To assess the technical knowledge and relationship/counseling skills gained in the training by supervising the ASW meeting with patients.
- To provide feedback to ASWs in their exchanges with patients.

## TIME

Review objectives	5 minutes
Observe an ART adherence counselor	Day 1: Two morning sessions
Discuss observations	Day 1: One afternoon session
Make supervised visits with patients	Day 1: One afternoon session Day 2: Two morning sessions
Receive feedback from supervisor	Day 2: One afternoon session
Total time	2 days

## SESSION PLAN

- See content section below.

## ADDITIONAL PREPARATION/SUPPLIES NEEDED

- ASW supervision form (see page 175).

## CONTENT

### Procedures for observations

- The ASW will work with an ART adherence counselor to observe the counselor's work.
- After observations, the facilitator will lead a discussion including both the ASWs and their supervisors.
  - What did the ASWs observe?
  - What did they think was important?
  - What did they learn?

### Procedures for supervised visits and feedback

- The ASW will meet with patients while supervised by his or her assigned ART adherence counselor.
- The ASW will meet with his or her supervisor for feedback.
  - Supervisors should work with ASWs in a patient and nonjudgmental way.
  - After observing the ASWs interactions with patients, supervisors will fill out one ASW supervision form for each ASW. They will discuss their responses on the form with the ASW in the feedback session. They will return the forms to the facilitator.

## ASW Supervision Form

After observing the ASWs in their meetings with patients, please fill out the following form and discuss it with the ASWs in the feedback sessions. After the feedback sessions, please return the form to the ASW training facilitator.

Supervisor's name: \_\_\_\_\_

ASW's name: \_\_\_\_\_

### PLEASE RATE THE ASW ON THE FOLLOWING (CIRCLE ONE):

#### 1. TECHNICAL KNOWLEDGE

The ASW provided correct technical knowledge on HIV/AIDS and ART.

Always                      Sometimes                      Never

The ASW gave the technical information in a way the patient could understand.

Always                      Sometimes                      Never

The ASW answered questions slowly and clearly.

Always                      Sometimes                      Never

#### 2. COMMUNICATION AND COUNSELING

The ASW helped the patient feel comfortable.

Always                      Sometimes                      Never

The ASW encouraged patients to ask questions.

Always                      Sometimes                      Never

#### 3. NEEDS OF PLHA

The ASW asked the patient about other needs beyond medical care.

Always                      Sometimes                      Never

The ASW provided referrals when necessary.

Always                      Sometimes                      Never

#### 4. PROFESSIONAL BEHAVIOR AND ETHICS

The ASW exhibited appropriate professional and ethical behavior.

Always                      Sometimes                      Never

#### 5. DOCUMENTATION

The ASW filled out the forms appropriately.

Always                      Sometimes                      Never





## UNIT G: COURSE WRAP-UP AND EVALUATION



# UNIT G: COURSE WRAP-UP AND EVALUATION

## PURPOSE

The purpose of this session is to wrap up the training by reviewing goals and assessing the participants' learning with the post-training knowledge assessment.

## OBJECTIVES

- Review goals from the beginning of course.
- Assess which goals were achieved and which were not met.
- Evaluate learning by reviewing the “What I Know and Don’t Know about HIV” cards and post-training knowledge assessment.
- Provide feedback on the training via the training evaluation form.

## TIME

Total time	40 minutes
------------	------------

## SESSION PLAN

- See content session below.

## ADDITIONAL PREPARATION/SUPPLIES NEEDED

- Participant goals from the “Why Are We Here?” session.
- Cards from the “What I Know and Don’t Know about HIV” exercise.
- Post-training knowledge assessment forms.
- Training evaluation forms.

## CONTENT

### Course completion

- The ASW will receive his or her certification after attending the training and demonstrating sufficient knowledge and skills in the sessions.

- A certified candidate will be allowed to practice as an ASW at both the facility and community level.

### Exercise: Did We Meet Our Goals? (10 minutes)

- Using the flip chart paper from the “Why Are We Here?” exercise, review the goals identified by the participants on the first day.
- Ask participants to discuss which goals were met and which were not.

### Exercise: What I Learned from This Training (10 minutes)

- Ask for volunteers to share the most important thing they learned from the training.
- As appropriate, share the “What I Don’t Know about HIV” cards that pertain to content in the training.
- Read each card and then review information from the appropriate training.

### Exercise: Post-Test Knowledge Assessment (10 minutes)

- Ask the participants to fill out the post-test knowledge assessment form to the best of their ability.
- Collect the forms.

### Exercise: Evaluation (10 minutes)

- Ask participants to fill out the evaluation form.
- Collect the forms.

# AGENDA

<b>Agenda: Adherence Support Worker Training</b>	
<b>Introductions and Expectations: Day One</b>	
8:30–10:00	Opening and introductions
10:00–10:30	Tea break
10:30–12:00	Goals/expectations of training/pre-course assessment
12:00–1:30	Lunch
1:30–3:00	Goals/expectations of training/pre-course assessment, continued
3:00–3:30	Tea break
3:30–5:00	Stigma and discrimination discussion
<b>Technical Background for ASWs: Day Two</b>	
8:30–10:00	Module 1: Basics of HIV and HIV disease progression
10:00–10:30	Tea break
10:30–12:00	Module 1: Basics of HIV and HIV disease progression, continued
12:00–1:30	Lunch
1:30–3:00	Module 2: HIV/TB
3:00–3:30	Tea break
3:30–5:00	Module 2: HIV/TB, continued
<b>Technical Background for ASWs: Day Three</b>	
8:30–10:00	Module 3: Basics of counseling and testing
10:00–10:30	Tea break
10:30–12:00	Module 3: Basics of counseling and testing, continued
12:00–1:30	Lunch
1:30–3:00	Module 4A: Positive living
3:00–3:30	Tea break
3:30–5:00	Module 4B: Safer sex
<b>Technical Background for ASWs: Day Four</b>	
8:30–10:00	Module 5A: Building helping relationships: Step 1
10:00–10:30	Tea break
10:30–12:00	Module 5B: Building helping relationships: Step 2

<b>Agenda: Adherence Support Worker Training</b>	
12:00–1:30	Lunch
1:30–3:00	Module 5C: Building helping relationships: Step 3
3:00–3:30	Tea break
3:30–5:00	Module 6: Basics of ART
<b>Technical Background for ASWs: Day Five</b>	
8:30–10:00	Module 6: Basics of ART, continued
10:00–10:30	Tea break
10:30–12:00	Module 6: Basics of ART, continued
12:00–1:30	Lunch
1:30–3:00	Module 6: Basics of ART, continued
3:00–3:30	Tea break
3:30–5:00	Module 6: Basics of ART, continued
<b>Qualities of a Good ASW: Day Six</b>	
8:30–10:00	Module 7A: Adherence
10:00–10:30	Tea break
10:30–12:00	Module 7A: Adherence, continued
12:00–1:30	Lunch
1:30–3:00	Module 7A: Adherence, continued
3:00–3:30	Tea break
3:30–5:00	Module 7B: Pediatric adherence
<b>Roles and Responsibilities of ASWs: Day Seven</b>	
8:30–10:00	Module 8: Roles and responsibilities of ASWs in health facilities
10:00–10:30	Tea break
10:30–12:00	Module 8: Roles and responsibilities of ASWs in health facilities, continued
12:00–1:30	Lunch
1:30–3:00	Module 9: Needs of PLHA
3:00–3:30	Tea break
3:30–5:00	Module 10: Roles and responsibilities of ASWs in the community, continued

## Agenda: Adherence Support Worker Training

### Roles and Responsibilities of ASWs (continued): Day Eight

8:30–10:00	Module 10: Roles and responsibilities of ASWs in the community
10:00–10:30	Tea break
10:30–12:00	Module 11: Ethics and professional behavior
12:00–12:30	Module 12: Problem-solving
12:30–1:30	Lunch
1:30–3:00	Module 13: Data collection and monitoring
3:00–3:30	Tea break
3:30–5:00	Module 13: Data collection and monitoring, continued

### Practicum in Facilities: Day Nine

8:30–10:00	Practicum in facilities: Observe ART adherence counselor
10:00–10:30	Tea break
10:30–12:00	Practicum in facilities: Observe ART adherence counselor, continued
12:00–1:30	Lunch
1:30–3:00	Practicum in facilities: Discuss observations
3:00–3:30	Tea break
3:30–5:00	Practicum in facilities: Supervised meetings with patients

### Course Wrap-Up and Evaluation: Day Ten

8:30–10:00	Practicum in facilities: Supervised meetings with patients, continued
10:00–10:30	Tea break
10:30–12:00	Practicum in facilities: Supervised meetings with patients, continued
12:00–1:30	Lunch
1:30–3:00	Practicum in facilities: Feedback from supervisor
3:00–3:30	Tea break
3:30–5:00	Course wrap-up and evaluation

# QUESTIONNAIRE: PRE-TRAINING KNOWLEDGE ASSESSMENT

## Adherence Support Worker Training

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Use this knowledge assessment to evaluate the success of information and knowledge transfer provided by this course. This assessment includes two types of questions: 1) true/false and 2) multiple choice. You will receive your pre-training and post-training results at the end of the training. READ EACH QUESTION THOROUGHLY, then circle the correct answer.

### 1. What is stigma?

- a. Being HIV-positive.
- b. Having no friends to look after you when you are sick.
- c. A mark of shame or discredit on a person or group.
- d. Being dependant on others for everything.

### 2. Discrimination happens when a person is treated unfairly because of

- a. Race.
- b. Religious affiliations.
- c. Health status.
- d. Any the above.

### 3. HIV is a virus that can be spread

- a. By having unprotected sex with an HIV infected person.
- b. During pregnancy or childbirth.
- c. By mosquitoes.
- d. By a handshake.
- e. Both a and b.

**4. HIV and AIDS are the same.**

True                  False

**5. TB in an HIV-positive patient can be cured.**

True                  False

**6. All TB patients are HIV-positive.**

True                  False

**7. Benefits of testing are**

- a.      Knowing one's HIV status.
- b.      Entry point to care and treatment.
- c.      Prevention of infection transmission.
- d.      All of the above.

**8. Positive living involves all that is listed below except**

- a.      Making positive choices.
- b.      Avoiding risky behaviors.
- c.      Having a positive outlook on life.
- d.      Stopping ARVs when feeling well.

**9. The following are safer sex practices in transmission of HIV except**

- a.      Condom use.
- b.      Masturbation.
- c.      Non-penetrative sexual activities.
- d.      Sex without a condom.

**10. ASWs should avoid expressing their own values when working with patients and use their technical knowledge to guide interactions with patients.**

True    False

**11. Communication includes sharing of**

- a. Information.
- b. Ideas.
- c. Beliefs and opinions.
- d. Feelings and emotions.
- e. All the above.

**12. Antiretroviral therapy (ART) should always include a combination of three drugs.**

True            False

**13. ART drugs work by**

- a. Making a person immune to HIV.
- b. Giving the patient extra nutrition.
- c. Completely eliminating the virus from the patient.
- d. Slowing down the multiplication rate of the virus.

**14. To succeed on ART the patient must always take the correct number of pills at the correct time.**

True            False

**15. Adherence education and support must be provided before starting ART and throughout the life of treatment.**

True            False

**16. There are many reasons why a patient may not adhere to ART, including**

- a. Side effects from the drugs.
- b. Feeling well and not wanting to take drugs any more.
- c. Feeling depressed.
- d. Forgetting to take drugs.
- e. All of the above.

**17. Ways that people living with HIV/AIDS (PLHA) can live more positively include**

- a. Getting regular medical care.
- b. Avoiding stress.
- c. Maintaining good nutrition.
- d. All of the above.

**18. If PLHA face difficulties outside of medical care, the ASW can help them by providing referrals to services and following up to see if their needs were met.**

True                  False

**19. A good way to get patients to adhere to treatment is to lecture them on what to do.**

True                  False

**20. Important features of each clinical visit after a patient has started ART include all of the following except**

- a. Assessing the patient's adherence.
- b. Determining the patient's side effects.
- c. Discussing barriers to adherence.
- d. Lecturing the patient about proper behaviors.



# QUESTIONNAIRE: POST-TRAINING KNOWLEDGE ASSESSMENT

## Adherence Support Worker Training

Name: \_\_\_\_\_ Date: \_\_\_\_\_

The purpose of this knowledge assessment is to evaluate the success of information and knowledge transfer provide by this course. This assessment includes two types of questions: 1) true/false and 2) multiple choice. You will receive your pre-training and post-training results at the end of the training. READ EACH QUESTION THOROUGHLY, then circle the correct answer.

### 1. What is stigma?

- a. Being HIV-positive.
- b. Having no friends to look after you when you are sick.
- c. A mark of shame or discredit on a person or group.
- d. Being dependant on others for everything.

### 2. Discrimination happens when a person is treated unfairly because of

- a. Race.
- b. Religious affiliations.
- c. Health status.
- d. Any the above.

### 3. HIV is a virus that can be spread

- a. By having unprotected sex with an HIV infected person.
- b. During pregnancy or childbirth.
- c. By mosquitoes.
- d. By a handshake.
- e. Both a and b above.

**4. HIV and AIDS are the same.**

True                  False

**5. TB in an HIV-positive patient can be cured.**

True                  False

**6. All TB patients are HIV-positive.**

True                  False

**7. Benefits of testing are**

- a.      Knowing one's HIV status.
- b.      Entry point to care and treatment.
- c.      Prevention of infection transmission.
- d.      All of the above.

**8. Positive living involves all that is listed below except**

- a.      Making positive choices.
- b.      Avoiding risky behaviors.
- c.      Having a positive outlook on life.
- d.      Stopping ARVs when feeling well.

**9. The following are the safer sex practices in transmission of HIV except**

- a.      Condom use.
- b.      Masturbation.
- c.      Non-penetrative sexual activities.
- d.      Sex without a condom.

**10. ASWs should try to avoid expressing their own values when working with patients and use their technical knowledge to guide interactions with patients.**

True      False

**11. Communication includes sharing of**

- a. Information.
- b. Ideas.
- c. Beliefs and opinions.
- d. Feelings and emotions.
- e. All the above.

**12. Antiretroviral therapy (ART) should always include a combination of three drugs.**

True                  False

**13. ART drugs work by**

- a. Making a person immune to HIV.
- b. Giving the patient extra nutrition.
- c. Completely eliminating the virus from the patient.
- d. Slowing down the multiplication rate of the virus.

**14. To be successful on ART the patient must always take the correct number of pills at the correct time.**

True                  False

**15. Adherence education and support must be provided before starting ART and throughout the life of treatment.**

True                  False

**16. There are many reasons why a patient may not adhere to ART. These reasons include**

- a. Side effects from the drugs.
- b. Feeling well and not wanting to take drugs any more.
- c. Feeling depressed.
- d. Forgetting to take drugs.
- e. All of the above.

**17. Ways that people living with HIV/AIDS (PLHA) can live more positively include**

- a. Getting regular medical care.
- b. Avoiding stress.
- c. Maintaining good nutrition.
- d. All of the above.

**18. If PLHA face difficulties outside of medical care, the ASW can help by providing referrals to services and following up to see if their needs were met.**

True                  False

**19. A good way to get patients to adhere to treatment is to lecture them on what to do.**

True                  False

**20. Important features of each clinical visit after a patient has started ART include all of the following except**

- a. Assessing the patient's adherence.
- b. Determining the patient's side effects.
- c. Discussing barriers to adherence.
- d. Lecturing the patient about proper behaviors.

# TRAINING EVALUATION

## Adherence Support Worker Training

Please complete this form to give us your evaluation of this training. The focus is on the content of the sessions and the methods used to present it.

Please check one. Feel free to comment.

**1. Sequence: The topics were presented in a logical order in relation to the other topics of the day.**

Agree

Disagree

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**2. Length: The sessions and the training overall lasted the right amount of time.**

Agree

Disagree

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**3. Level: The sessions were taught at an appropriate level.**

Agree

Disagree

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**4. Content relevance: The content of the training was relevant.**

\_\_\_\_\_ Agree

\_\_\_\_\_ Disagree

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**5. Methodology: The training methods were useful.**

\_\_\_\_\_ Agree

\_\_\_\_\_ Disagree

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Other Comments: Please tell us what you think would have made the training more useful, clear or relevant. \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## REFERENCES

African Network for the Care of Children Affected by AIDS (ANECCA). *Handbook on Paediatric AIDS in Africa*. ANECCA. Kampala, Uganda, 2005.

Frank, L. and H. Miramontes. *AIDS Education and Training Center Adherence Curriculum Principles*, 1997. Accessed May 4, 2005 at [hivinsite.ucsf.edu](http://hivinsite.ucsf.edu).

Horizons/Population Council International Centre for Reproductive Health, Coast Provincial General Hospital, Mombasa, Kenya. *Adherence to Antiretroviral Therapy in Adults: A Guide for Trainers*. Population Council, Nairobi, Kenya, 2004.

Kidd, R. and S. Clay. *Understanding and Challenging HIV Stigma: Toolkit for Action*. CHANGE Project. Washington D.C., 2003.

National Aids Manual (NAM). *Adherence: Information Series for HIV-Positive People*, 2004. Accessed May, 4, 2005 at [www.aidsmap.org](http://www.aidsmap.org).

Project Concern International. *Adherence Support for Patients on Antiretroviral Therapy*. Project Concern. Lusaka, Zambia, 2004.

Project Concern International, Center for Infectious Disease Research, Zambia, Kara Counseling Trust, and Training and Counseling Resources Center. *Basic Counseling and Adherence Support Skills for Antiretroviral Therapy*. Training and Counseling Resources Center. Lusaka, Zambia, 2004.

Regional Center for Quality of Healthcare (RCQHC). *Nutrition for PLWHA-Counseling Cards*. RCQHC. Kampala, Uganda, 2005.

US National Institutes of Health (NIH). *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection*, 2005. Accessed May 5, 2005 at [www.aidsinfo.nih.gov](http://www.aidsinfo.nih.gov).

Winiarski, M. *Community-Based Counseling for People Affected by HIV and AIDS*. Longman and Catholic AIDS Action, 2004.

World Health Organization (WHO). *Facilitator Guide for the WHO ART Aid Training Course*. WHO. Geneva, Switzerland, 2004.

## Internet Resources

**www.aids-ed.org:** The AIDS Education and Training Center (AETC) National Resource Center website includes adherence information within treatment guidelines as well as information for providers who work with special populations.

**www.aidsmeds.com:** This website includes treatment information geared toward PLHA. It includes lessons on drugs, conditions and treatments that are designed for patient education.

**www.aidsinonet.org:** AIDS InfoNet is a project of the New Mexico AIDS Education and Training Center in the Infectious Diseases Division of the University of New Mexico School of Medicine. The website includes single-topic fact sheets written in a non-technical fashion.

# TRAINING MATERIALS

## A. NAMING STIGMA THROUGH PICTURES

Drawings based on illustrations by Petra Röhr Rouendaal in *Understanding and Challenging HIV Stigma: Toolkit for Action*. CHANGE Project. Washington, D.C., 2003.













## B. CARDS FOR BODY LANGUAGE EXERCISE

Photocopy this page and cut the squares into cards:

<p><b>Verbal message:</b> I am so happy to see you.</p> <p><b>Nonverbal message:</b> You are honestly happy to see the person.</p>	<p><b>Verbal message:</b> I am so happy to see you.</p> <p><b>Nonverbal message:</b> You really dislike the person.</p>
<p><b>Verbal message:</b> I am so happy to see you.</p> <p><b>Nonverbal message:</b> You are in a big hurry.</p>	<p><b>Verbal message:</b> I am so happy to see you.</p> <p><b>Nonverbal message:</b> You strongly distrust the person.</p>

### C. ETHICS AND PROFESSIONAL BEHAVIOR EXERCISE

- Read each scenario.
- Discuss the ethical or professional problem presented.

1. An ASW tells a patient, "I really like working with you. You are the best patient I have!"
2. An ASW is approached by her cousin on the street. The cousin states, "I am so worried about Mrs. K. I know she is your patient. How is she doing?"
3. An ASW tells a patient, "You really should do something about your life."
4. A patient has missed an appointment. The ASW checks the patient's chart and sees that the patient did not give permission for home visits. Should the ASW go to the patient's home?
5. A family member asks an ASW, "I know you are busy. But your visits really help us. If I gave you some extra money, would you come to the house more often?"
6. An ASW does not come to the clinic for a scheduled clinical team meeting. When asked why he states, "I am just an ASW, my work is not important to the team."
7. On a home visit, a family member tells the ASW she is confused about which foods to give to her daughter when she is nauseated. The ASW cannot remember which foods would help, but makes up something anyway.
8. When a patient states, "I have taken all doses of my medications this month," the ASW says, "You could not have taken all of them, I don't believe you."
9. When a patient asks for a special favor, the ASW states, "We are not supposed to do this, but I will do it for you because I like you."
10. A patient confides in the ASW that he or she is registered at two clinics. The patient takes the drugs that he picks up at one clinic and sells the drugs he picks up at the other clinic to have money for food.

## Answers to Ethics and Professional Behavior Exercise

1. An ASW tells a patient, “I really like working with you. You are the best patient I have!” (Treat all patients equally.)
2. An ASW is approached by her cousin on the street. The cousin states, “I am so worried about Mrs. K. I know she is your patient. How is she doing?” (Do not violate confidentiality.)
3. An ASW tells a patient, “You really should do something about your life.” (Show respect and do not judge.)
4. A patient has missed an appointment. The ASW checks the patient’s chart and sees that the patient did not give permission for home visits. Should the ASW go to the patient’s home? (No, it is not appropriate because the patient did not give consent.)
5. A family member asks an ASW, “I know you are busy. But your visits really help us. If I gave you some extra money, would you come to the house more often?” (ASWs cannot accept money or favors and should not treat one patient better than another.)
6. An ASW does not come to the clinic for a scheduled clinical team meeting. When asked why he states, “I am just an ASW, my work is not important to the team.” (ASWs are an important part of the clinic team.)
7. On a home visit, a family member tells the ASW she is confused about which foods to give to her daughter when she is nauseated. The ASW cannot remember which foods would help, but makes up something anyway. (If you don’t know something, tell the patient you don’t know and get the information later.)
8. When a patient states, “I have taken all doses of my medications this month,” the ASW says, “You could not have taken all of them, I don’t believe you.” (Trust what the patient says.)
9. When a patient asks for a special favor, the ASW states, “We are not supposed to do this, but I will do it for you because I like you.” (Treat all patients equally.)

10. While standing outside the clinic on a break, two ASWs discuss the health status of a patient. (This scenario is complex — it is intended to start a discussion about many ethical/professional behavior issues such as confidentiality, do not harm, and professional responsibilities of the ASW. It is likely that the participants will discuss various principles of ethics and professional behavior. Encourage their discussion and tell them that many times questions may arise that cannot be answered easily.)

## **D. SUGGESTED ICEBREAKER OR TEAM-BUILDING EXERCISES**

Facilitators can use icebreakers or team-building exercises to keep participants interested and motivated. Since this is a long training, facilitators may want to start off each morning with a quick exercise.

### [Some suggested exercises:](#)

- Ask participants to share a nickname they have been called and explain the meaning.
- Ask participants to share something about themselves that no one in the group knows.
- Hand out coins with dates in the last 15 years. Ask participants to tell the others what significance (if any) the year on the coin holds for them.
- Ask participants to each answer one provocative question about themselves. For example:
  - What is your greatest achievement?
  - What was the best day of your life?
  - If you could have a T-shirt printed with a message, what would it say?
- Ask participants for ideas for other exercises.

## **E. SOME IDEAS FOR FORMING GROUPS**

Most of the exercises in this training require forming pairs or groups. The following are some ideas for forming groups to ensure that participants work with different people, making their group work more enriching.

- Distribute playing cards to each participant and match people with the same numbers, suits, or cards.
- Pair people by attributes, such as similar birthdays, ages, or hometowns.
- Pair those sitting the farthest apart or closest together.
- Ask participants to count off; create groups of odds and evens or pair those with the same number.
- Pair up people who have not spoken or worked together yet.

## F. ASW FORMS

### PRE-ART TREATMENT ADHERENCE FORM

Patient's Name: \_\_\_\_\_ ID No.: \_\_\_\_\_ Date: \_\_\_\_\_

Minimum Required Steps	Yes	No	Explanation and Comments
Patient came on the appointment date.			
Patient understands his or her serostatus well.			
Patient has disclosed serostatus to his or her spouse or partner.			
Spouse or partner serostatus known and linked with care and treatment.			
Children's serostatus known and linked with care and treatment.			
Patient has disclosed to at least one friend or relative.			
Patient has identified a treatment assistant.			
Patient understands the HIV: <ul style="list-style-type: none"> <li>• Virus</li> <li>• Transmission</li> </ul>			
Patient understands what ART does: <ul style="list-style-type: none"> <li>• Improves immune function</li> <li>• Fewer OIs</li> <li>• ART is not a cure</li> <li>• ART is continuous and lifelong treatment</li> </ul>			
Patient understands the importance of adherence.			
Patient understands drug side effects and what to do about them.			
Patient understands not to share ARVs with anyone.			
Patient understands what to do if he or she misses a dose.			

Minimum Required Steps	Yes	No	Explanation and Comments
Presence of adherence barriers (note strategies in comments section): <ul style="list-style-type: none"> <li>• Lack of transportation</li> <li>• Insufficient food</li> <li>• Lack of social support</li> <li>• Alcohol and drug use</li> <li>• Travel</li> <li>• Mental Illness</li> <li>• Other: _____</li> </ul>			
The patient consumes alcohol. Quantity: _____			
The patient is willing to start ARVs.			
The patient consents to home visits by the ASW. (If yes, include best day/time for visits and date of first visit in comments section.)			
The patient needs a referral for additional assistance right now. (If yes, fill out the referral form and referral register.)			

**Generally, how do you judge the patient’s (1) readiness and (2) commitment to adhere to treatment?**

1. Good      2. Poor      3. Indeterminate

---

ASW Name

## ART TREATMENT ADHERENCE FORM

Patient's name: \_\_\_\_\_ ID no.: \_\_\_\_\_ Date: \_\_\_\_\_

Type of visit (tick one): \_\_\_ Scheduled clinic visit \_\_\_ Unscheduled clinic visit \_\_\_ Home visit

Minimum Required Steps	Yes	No	Explanation and Comments
Patient came on the appointment date/was available for home visit.			
<i>ART adherence counselor was notified of missed visit.</i>			
Patient understands his or her serostatus well.			
Patient understands the HIV: <ul style="list-style-type: none"> <li>• Virus</li> <li>• Transmission</li> </ul>			
Patient understands what ART does: <ul style="list-style-type: none"> <li>• Improves immune function</li> <li>• Fewer OIs</li> <li>• ART is not a cure</li> <li>• Continuous and lifelong treatment</li> </ul>			
Patient understands the importance of adherence.			
Patient understands drug side effects and what to do about them.			
Patient understands not to share ARVs with anyone.			
Patient understands what to do if he or she misses a dose.			
Number of doses missed since last visit: _____			
<i>ART adherence counselor was notified of missed doses (if &gt;3 notify immediately, if 1-2 notify on same day).</i>			

Minimum Required Steps	Yes	No	Explanation and Comments
<p>If doses missed, circle adherence barriers and note patient's strategies to overcome them in comments section.</p> <ul style="list-style-type: none"> <li>• Lack of transportation</li> <li>• Insufficient food</li> <li>• Lack of social support</li> <li>• Alcohol and drug use</li> <li>• Travel</li> <li>• Mental Illness</li> <li>• Other: _____</li> </ul>			
New symptoms/side effects to report:			
<i>New symptoms were reported to ART adherence counselor.</i>			
The patient consumes alcohol. Quantity: _____			
The patient or family needs a referral for additional assistance right now. (If yes, fill out the referral form and referral register.)			
<i>If a referral was provided on last visit, were needs met? (Note in referral register.)</i>			

**Generally, how do you judge the patient's adherence?**

1. Good      2. Poor      3. Indeterminate

---

ASW Name

## PATIENT REFERRAL FORM

PATIENT REFERRAL FORM	
<b>Part A: Referral:</b> To be filled out by the organization making the referral	
<b>Date:</b>	
<b>Patient name:</b>	<b>Date of birth/age:</b>
<b>Referred to:</b>	
Organization/health facility:	Name of contact:
Address/phone number:	
<b>Reason for referral/patient's need(s):</b>	
<b>Referred by:</b>	
Organization/health facility:	Referral focal person:
Address/phone number:	
Part B: FEEDBACK	
<b>Services provided:</b> To be filled out by the organization providing the requested service	
<b>Date:</b>	
<b>Patient name:</b>	<b>Date of birth/age:</b>
<b>Services:</b>	
<input type="checkbox"/> Services provided: _____	
<input type="checkbox"/> Services completed as requested ____ Yes ____ No	
<input type="checkbox"/> Follow-up needed: services: _____ Date for follow-up: _____	
<b>Additional comments:</b>	
<b>Name of organization/health facility:</b>	

## ASW REGISTER

Date	Client name	Registration/ ART number	Adherence services provided:			Date of next appointment	Type of next visit (tick one)		ASW initials
			Pre-ART support	ART support	Referral		Home visit	Clinic visit	





Adherence support workers, or ASWs, are important members of the ART clinical team. They help improve patient adherence, knowledge, and understanding; provide education and counseling in the patient's own language; and free up nurses and doctors to focus on other clinical needs. Developed by Family Health International through the Zambia HIV/AIDS Prevention, Care and Treatment Partnership, this two-week intensive course teaches community volunteers to work alongside nurses and doctors. ASWs learn to interact with patients in clinical, community, and home settings where they provide HIV education, treatment support, and ART adherence counseling. They also are trained to participate in the referral network and to reengage treatment defaulters by tracking patients who miss appointments. The facilitator's guide and participant's manual include technical information and techniques for relationship building and counseling. Modules include didactic sessions, role plays, and group exercises. A CD with PowerPoint presentations is included in the facilitator's guide.

**Modules include the following:**

- Introduction and Assessment
- Technical Background for Adherence Support Workers
- Building Helpful Relationships for Adherence Support Workers
- Roles and Responsibilities of Adherence Support Workers
- Qualities of a Good Adherence Support Worker
- Practicum in Facilities



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ISBN 1-933702-10-9

PN-ADI-823

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