ADHERENCE SUPPORT WORKER TRAINING

PARTICIPANT'S GUIDE

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ADHERENCE SUPPORT WORKER TRAINING
PARTICIPANT'S GUIDE

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ACRONYMS/GLOSSARY

AIDS	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^3 or they have experienced certain illnesses (called AIDS-defining illnesses).
ART	Antiretroviral therapy – a treatment for HIV using antiretroviral drugs (see ARV).
ARV	Drugs used to fight the HIV virus by making it difficult for them to multiply.
ARV drug classes	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.
ASW	Adherence support worker.
CD4 cells	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.
CT	Counseling and testing for HIV. Also called voluntary counseling and testing (VCT).
First-line	The combination of drugs that is usually used first with ART.
FTC	Emtricitabine.
HIV	Human Immunodeficiency Virus – the virus that causes AIDS.
Immune system	The systems in the body that work to fight off infection.
Infection	An infection is caused by a bacteria or virus entering the body. The body can naturally fight off some infections, while others cause illnesses.
Opportunistic infection (OI)	An infection that occurs in a person with a weak immune system.
PLHA	People living with HIV/AIDS.

Resistance	The ability of the HIV virus to change and resist the capacity of some drugs to work against it.
Second-line	The combination of drugs that is usually used to treat HIV once first-line drugs have failed.
Side effects/ toxicities	Symptoms or problems caused by taking drugs; they can range from minor to major.
TB	Tuberculosis.
TB/HIV co-infection	Infection with both TB and HIV.
Viral load	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.
Viral replication	A virus makes more copies of itself by viral replication.
Window period	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 you to work alongside nurses and doctors as part of the clinical team at ART clinics. As an adherence support worker (ASW), you will work with patients both in the clinic and community to provide HIV education, treatment support, and ART adherence counseling. You 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. You will be assigned to work with patients in the clinic and, if the patients desire, in the home. You 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 to help you improve your relationship build ing and counseling skills. The modules include didactic sessions as well as role plays and group exercises. Since this is a long training, you will frequently be asked to work in pairs or groups. To help you begin to feel comfortable sharing ideas and practicing new techniques with your fellow participants, there will be some team-building and icebreaker activities. Since you may not have a background in HIV/AIDS, the facilitator may modify the content or speed of the presentations to suit your needs. The facilitator will also be available to answer questions between sessions.

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.

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.

DISCUSSION OF HIV STIGMA AND DISCRIMINATION

PURPOSE

- This session discusses stigma and discrimination people living with HIV/AIDS face. It provides a good way for you to understand values and beliefs about HIV, which can be "corrected" with the basic technical information provided 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.

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.

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 your 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 you do.

UNIT B: TECHNICAL BACKGROUND FOR ADHERENCE SUPPORT WORKERS

UNIT B: TECHNICAL BACKGROUND FOR ADHERENCE SUPPORT WORKERS

These technical background sessions will give you the basic knowledge you will need in your work with patients. This technical information will be presented by the facilitator and applied in the exercises and will continue to be applied in content and exercises throughout the rest of the training.

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.

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^3 of blood.

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.

HIV Myths and Realities

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

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

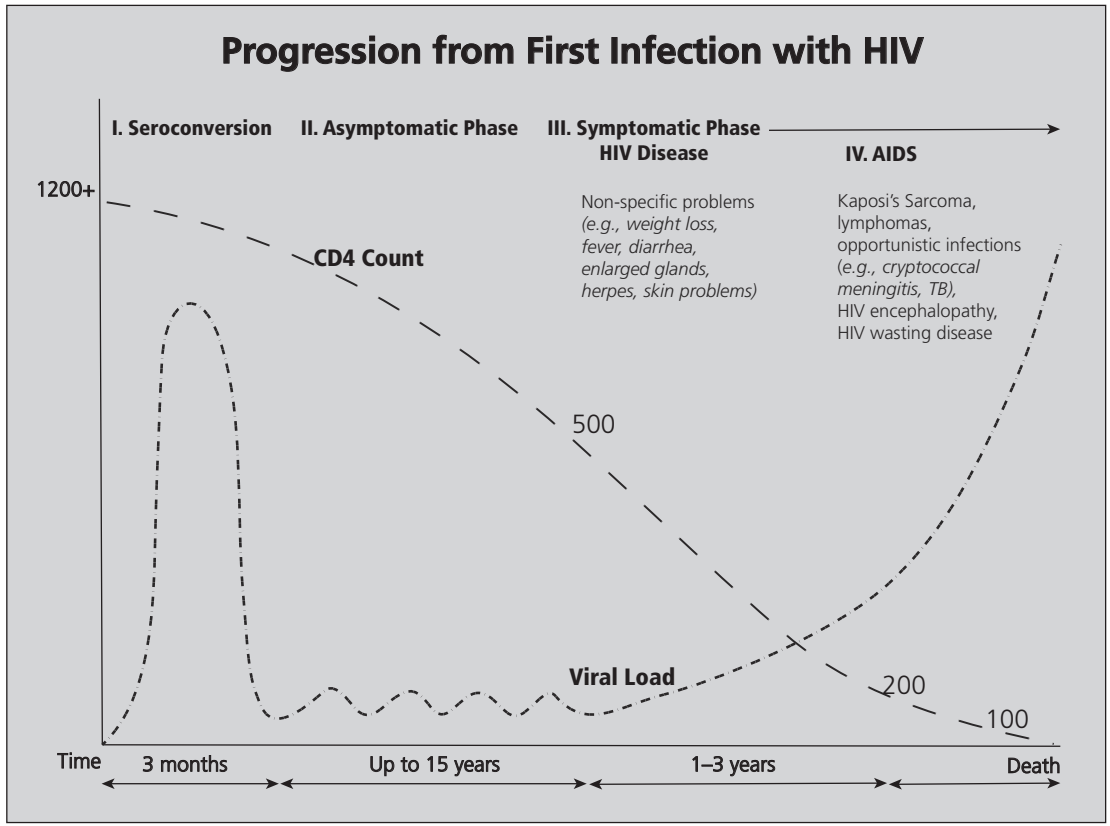
- As an ASW, you will be working with patients and their families.
  - There is no need to memorize these phases, just become familiar with how HIV progresses.
- Take-home messages:
  - HIV progresses from initial infection to AIDS in a predictable fashion.
  - The length of time for this progression 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.

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.

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.

MODULE 3: BASICS OF COUNSELING AND TESTING (CT)

PURPOSE

This session will familiarize you 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

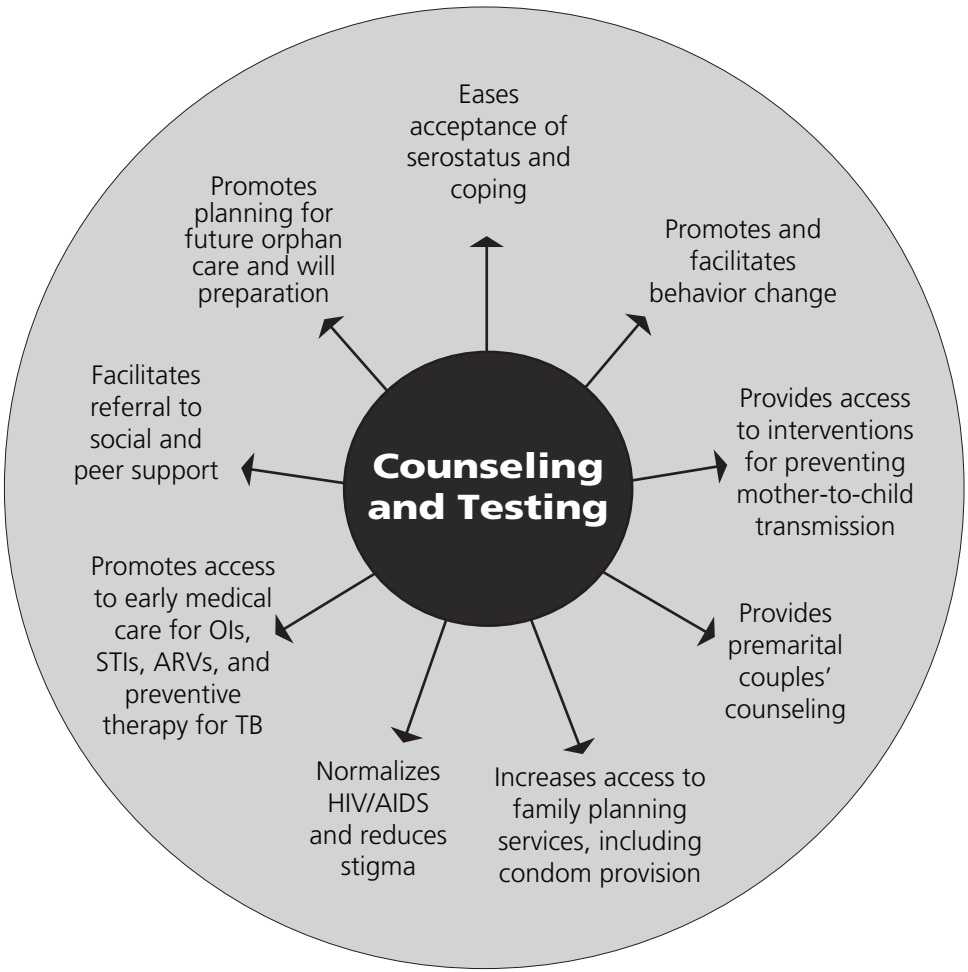
- Become familiar with the practice and basic principles of CT.
- Feel confident describing, recommending, and referring people to CT services.

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.
- 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.

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 you can counsel people living with HIV/AIDS on positive living.

OBJECTIVES

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

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, you should 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.
- You 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.

MODULE 4B: SAFER SEX

PURPOSE

This session will discuss safer sex, inviting you to reflect on your 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 you the opportunity for self-awareness in how you communicate about sensitive subjects, ones that may challenge your 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.

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 (are 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.

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 a 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 you make and nurture relationships with patients, including values and beliefs, problem-solving, and communication. Exercises in these sessions will ask you 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 you to examine your own values and beliefs. It will pick up on themes from the earlier technical session in activities and explore how awareness of our own values is important in dealing with people.

OBJECTIVES

- Think about your own values and beliefs and how these might help or hinder your helping relationships.
- Think about ways you might put those values aside in your professional work and be less judgmental and, therefore, more helpful.

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.

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 you 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.

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 to 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.

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."

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.

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 roles and responsibilities.

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 ASW 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 ASW behaviors (Slide 2).

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

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 each patient's welfare.
- See each patient as unique.

- Help patients identify and cultivate their own resources.
- Provide encouragement and support.

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.

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."

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.

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.

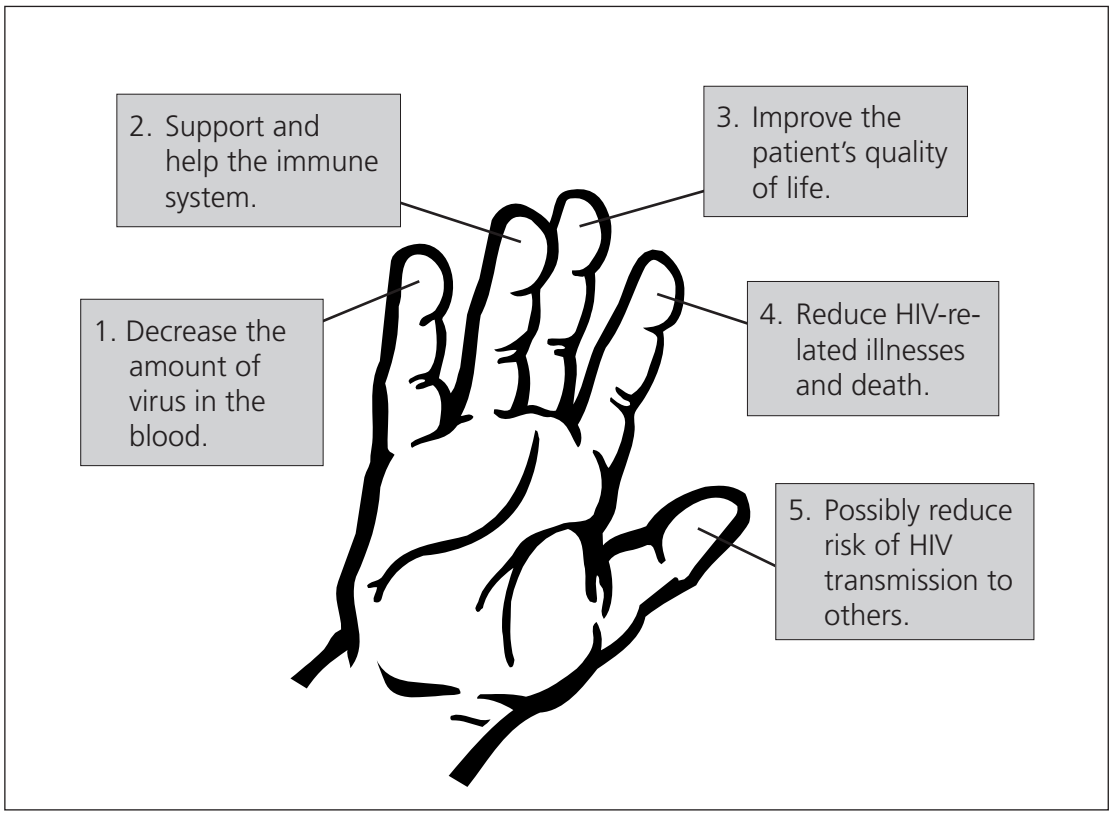
Who needs to take ART?

- 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).

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).

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.

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/Entriva (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^3 every 12 hours OR 90-180 mg/m^3 every 8 hours ; neonatal: 2 mg/m^3 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^3 once daily. If no major side effects, then 120-200 mg/m^3 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:

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

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	Protect hair from damage. Don't dye, straighten, or plait. Don't buy products that promise to grow hair back.	
Anemia	Increase foods such as fish, meat, chicken, spinach, asparagus, dark leafy greens, and lima beans.	The patient has been feeling tired for three to four weeks and it is worsening. Both of the patient's feet are swelling.

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.

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 you 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.

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.

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).

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.

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.

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.

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 your roles and responsibilities as an ASW in both the facility and community settings. These modules will teach you exactly what they you will be expected to do in your roles as ASWs and prepare you for the practicum. Substantial role plays and other exercises will allow you to learn to implement the skills and knowledge you have obtained in previous sessions in your 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.

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.

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, iIf the regular dose is to be taken at 7 AM, the missed dose can be taken up to 1 PM.

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?"

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.

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.

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.

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.

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 people living with HIV/AIDS and how you 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.

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.

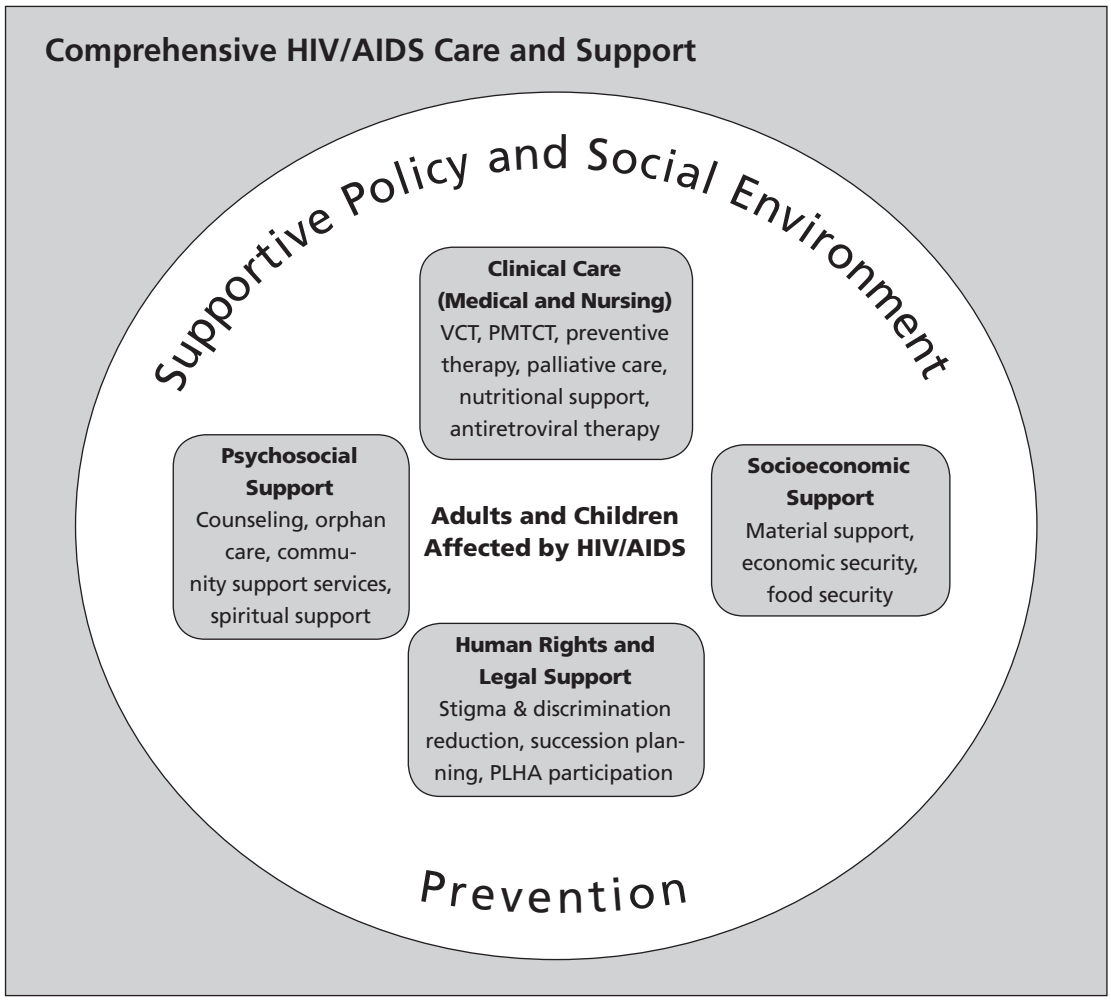
Needs may change

- 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.)

MODULE 10: ROLES AND RESPONSIBILITIES OF ASWS IN THE COMMUNITY

PURPOSE

This session will introduce your roles and responsibilities 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.

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).

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).

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 you 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.

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.

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.

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.

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.

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.

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 you 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.

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.

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.

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.

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.

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.

AGENDA

Agenda: Adherence Support Worker Training	
Introductions and Expectations: Day One	
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
Technical Background for ASWs: Day Two	
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
Technical Background for ASWs: Day Three	
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
Technical Background for ASWs: Day Four	
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

Agenda: Adherence Support Worker Training	
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
Technical Background for ASWs: Day Five	
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
Qualities of a Good ASW: Day Six	
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
Roles and Responsibilities of ASWs: Day Seven	
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

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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.aidsinfonet.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.

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: • Virus • Transmission			
Patient understands what ART does: • Improves immune function • Fewer OIs • ART is not a cure • ART is continuous and lifelong treatment			
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): • Lack of transportation • Insufficient food • Lack of social support • Alcohol and drug use • Travel • Mental Illness • Other: _____			
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.			
ART adherence counselor was notified of missed visit.			
Patient understands his or her serostatus well.			
Patient understands the HIV: • Virus • Transmission			
Patient understands what ART does: • Improves immune function • Fewer OIs • ART is not a cure • Continuous and lifelong treatment			
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: _____			
ART adherence counselor was notified of missed doses (if >3 notify immediately, if 1-2 notify on same day).			

Minimum Required Steps	Yes	No	Explanation and Comments
If doses missed, circle adherence barriers and note patient's strategies to overcome them in comments section. • Lack of transportation • Insufficient food • Lack of social support • Alcohol and drug use • Travel • Mental Illness • Other: _____			
New symptoms/side effects to report:			
New symptoms reported to ART adherence counselor.			
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.)			
If a referral was provided on last visit, were needs met? (Note in referral register.)			

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

1. Good 2. Poor 3. Indeterminate

_____

ASW Name

PATIENT REFERRAL FORM

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

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	

REFERRAL REGISTER

Date	Client name	Registration/ ART number	Client on ART? (yes/no)	Referred by (organization name)	Services referred for: (use codes below)	Referred to (organization name)	Services provided: (use codes below)	Services completed (yes/no)	Follow-up needed: (yes/no)

For services use the following codes:

1. Adherence counseling	8. Food support	15. Nutrition counseling	22. Post-test clubs	29. Support for domestic violence victims
2. Antiretroviral therapy	9. HIV counseling and testing	16. OB/GYN services	23. Prevention services	30. Treatment support
3. Child care	10. Home-based care	17. Peer counseling	24. Psychosocial support	31. TB services
4. Clinical care	11. Legal support	18. PEP services	25. Social services	32. Youth support groups
5. Education/schooling	12. Material support	19. Pharmacy	26. Spiritual support	33. Other_____
6. Family planning	13. Mental health services	20. PLHA support	27. STI services	34. Other_____
7. Financial support	14. Microfinance	21. PMTCT services	28. Substance abuse management	

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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