HIV Prevention, Treatment, Care and Support - A Training Package for Community Volunteers

Module 2

TREATMENT LITERACY

SAfAIDS Southern Africa HIV/AIDS Information Dissemination Service

World Health Organization

International Federation of Red Cross and Red Crescent Societies

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The professionals at SAfAIDS were responsible for the research, content development, layout and design of the training package. Those who played key roles include:

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Field testing of the modules

The following independent evaluators conducted pre-testing activities:

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Introduction

Module Two: Treatment Literacy aims to provide CBVs with the knowledge and skills to provide accurate information to their client and their families related to:

- Introduction to ART
- Basic Facts About ARVs
- Special Considerations for ART

Materials to be used in this module:

1. Module Two: Treatment Literacy (this module)
2. Participants Manual
3. Facilitator's Guide
4. Evaluation Tools Manual

Training time for this module is approximately 10 hours 30 minutes.

If the topics in this module represent new information to participants, facilitators may need to provide additional time during role-plays to ensure appropriate and accurate information is provided on topic areas. When developing training schedules, facilitators should take this point into consideration.

There are many important new terms related to ART Treatment Literacy that are important for CBVs to recognise and understand. As you come across each highlighted word, go back to the Facilitator's Guide and review its definition if necessary.

For a detailed discussion on the training methodology and evaluation techniques used for this module, facilitators should refer to the Facilitator's Guide.

The evaluation tools used in this module include:

<u>Evaluation of Module Content</u>

1. Participants Evaluation
2. Facilitator Evaluation

<u>Participant Evaluation Tools:</u>

1. Pre and Post Test Questionnaire
2. Demonstration of Core Skills

Upon completion of this module, participants should demonstrate the following core skills:

1. Provide clients with important links with health facilities and information they should know before beginning ART. **Session One; Tool 3**
2. Effectively explain ART to clients using the Flipchart for Client Education and Client Education Cards. **Session Two; Tool 2**
3. Assist clients and client families to manage and record side effects to ARVs **Session Two; Tool 4**
4. Effectively inform clients about TB, identify clients with TB and refer clients with TB to HIV Testing and Counselling Services using the 5 As. **Session Three; Tool 2**
5. Assist women in their community to overcome identified challenges to ART. **Session Three; Tool 3**

Table of Contents

1 Session One : Introduction to ART

Purpose: The purpose of Session One is to develop an understanding of what ART means, the goals and benefits of ART and the role of CBVs during each stage of HIV infection.

Objectives:
By the end of this session, CBVs should be able to:

1. Provide clients with an overview of ART, its goals and benefits.
2. Understand the roles and responsibilities of CBVs through each stage of HIV infection.
3. Provide clients with important links to with health facilities and information they should know before beginning ART

Duration: 2 hours 30 minutes

Required Materials: Flipchart, markers.

Recommended Preparation:

- Arrange for an on site visit to local health facilities and/or invite clinical team staff involved in managing clients on ART to provide a presentation to CBVs on their role in ART at local health facilities.
- Prepare copies of handout 2-1 for use in Tool 1
- Prepare copies of handout 2-2 and 2-3 for use in Tool 2
- Prepare copies of country protocols on ART, if any, for use in Tool 4.

Objective	Content	Time	Methodology
Provide clients with an overview of ART, its goals and benefits.	1. ART Basics	1 hour	Mini Lecture Tool One (ST): Case Study and Role Play
Understand the roles and responsibilities of CBVs through each stage of HIV infection.	2. When to start ART	1 hour 30 minutes	Mini Lecture Tool Two (K): Group Activity
Provide clients with important links with health facilities and information they should know before beginning ART			Mini Lecture Tool Three (ST): Group Role Play

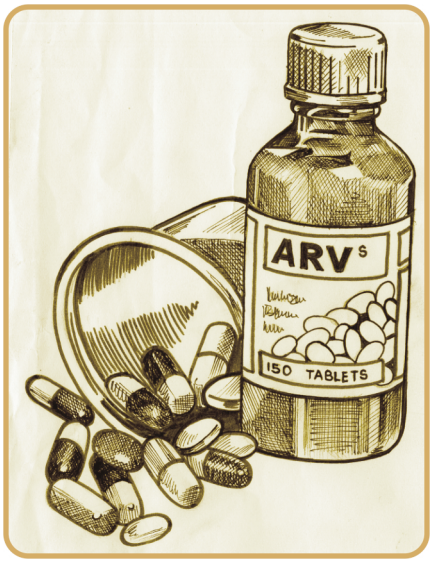
1. ART Basics (1 hour)

a) What is ART? (10 minutes)

Antiretroviral Therapy (**ART**) is a term used to describe giving ARV drugs in the correct way, with adherence support.

Antiretroviral drugs (**ARVs**) are drugs used to treat HIV. Because HIV is a retrovirus, drugs used against HIV are called anti-retroviral.

ARVs help to stop HIV from making copies of itself (replicating) within the immune system of PLWHA. If HIV cannot replicate, the damage to the system is reduced and the risk of getting opportunistic infections is decreased.



Important things to know about ART:

- People use many different terms to talk about ART.
- ART involves a combination of antiretroviral drugs.
- **ART is NOT a cure** for HIV and AIDS
- While on ART, people living with HIV or AIDS **can still transmit HIV** and can still become re-infected with HIV
- ARVs are **taken for life**
- ARVs are only given to PLWHA who are eligible to take the drugs (**not all PLWHA need to take ARVs**).

b) Goals of ART in PLWHA (10 minutes)

The goal of ART is to reduce the amount of HIV in the blood and to increase the number of CD4 cells in the blood as much as possible. ART improves the quality of life of PLWHA.

Goals of ART:

- To stop HIV from making copies of itself (replicating) in the body.
    - ART halts viral replication (stops the virus from increasing) thus preventing further disease progression and immune system damage.
    - The body's defense (immune system) gets a chance to recover and less opportunistic infections occur.

c) Benefits of ART (40 minutes with Tool 1)

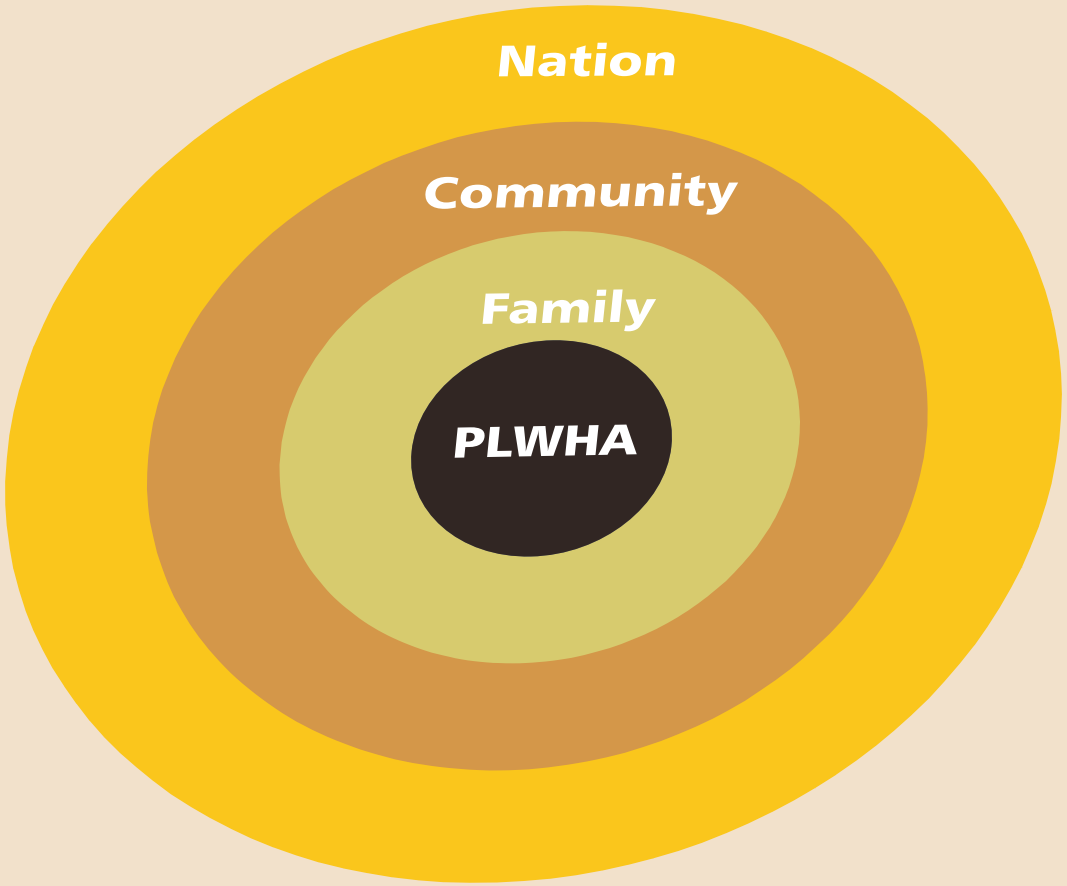
By helping fight HIV and AIDS, ART has benefits for everyone and not just PLWHA.

Tool 1: Benefits of ART

Divide participants into four groups and ask them to list the benefits of ART for individuals in the category to which they have been assigned.

1. PLWHA
2. Family
3. Community
4. Nation

Have each group present their list and discuss how benefits of ART may overlap between categories. Finally, review the information below by recreating the diagram on a flip chart and add in any additional benefits not mentioned by participants.



Benefits of ART include:

	PLWHA	Family	Community	Nation
Prolongs life and improves the quality of life of PLWHA	☑			
Reduces mother to child transmission of HIV		☑		
Helps households stay together by reducing illness and death caused by HIV and AIDS		☑		
Increases number of people to accept HIV testing and counselling			☑	
Increases awareness of HIV and AIDS in the community as more people use HIV testing and counselling services			☑	
Increases motivation of CBV who can better help PLWHA			☑	
Overall development of country is dependent on the ability of its people benefits by remaining productive and healthy				☑
Reduced burden on health facilities				☑
Reduces stigma associated with HIV by proving HIV is a chronic, manageable illness and NOT a death sentence	☑	☑	☑	☑
Less time and money spent treating opportunistic infections and providing palliative care	☑	☑	☑	☑
Decreased number of children orphaned by AIDS	☑	☑	☑	☑
Has the potential to help prevent the spread of HIV by: Increased exposure to information on HIV prevention while accessing treatment* More people are encouraged to know their HIV status when treatment is available.	☑	☑	☑	☑

Tool 1: Explaining ART, its Goals and Benefits

CBVs play an important role in helping PLWHA and their families to understand what ART is and the goals and benefits of ART. Divide participants into pairs and distribute copies of the case study in Handout 2-1, or write down the case study on a flipchart where all participants can see it. Ask each person to take turns being both the client and the CBV.

Lucy, your client, is living with HIV. During a home visit, Lucy tells you she has heard that ARV treatment has become available, but that she doesn't really understand what this means or how this would affect her life. Lucy says that her husband is sceptical of the benefits of ART and she wants to be able to explain to him what it is and how it will help the family.

What do you tell Lucy?

Facilitator's Note: To assess competency in providing this information, ensure that role-plays conducted include the following important information:

- ☐ An accurate explanation of the meaning of ARVs and what ART is
- ☐ Important things Lucy should know about ART including:
  - ○ ART is not a cure for HIV
  - ○ Not everyone that is HIV positive needs to be on ART
  - ○ ART is a life long commitment
  - ○ HIV can still be transmitted by PLWHA on ART
- ☐ The goals and benefits of ART.

2. When to start ART

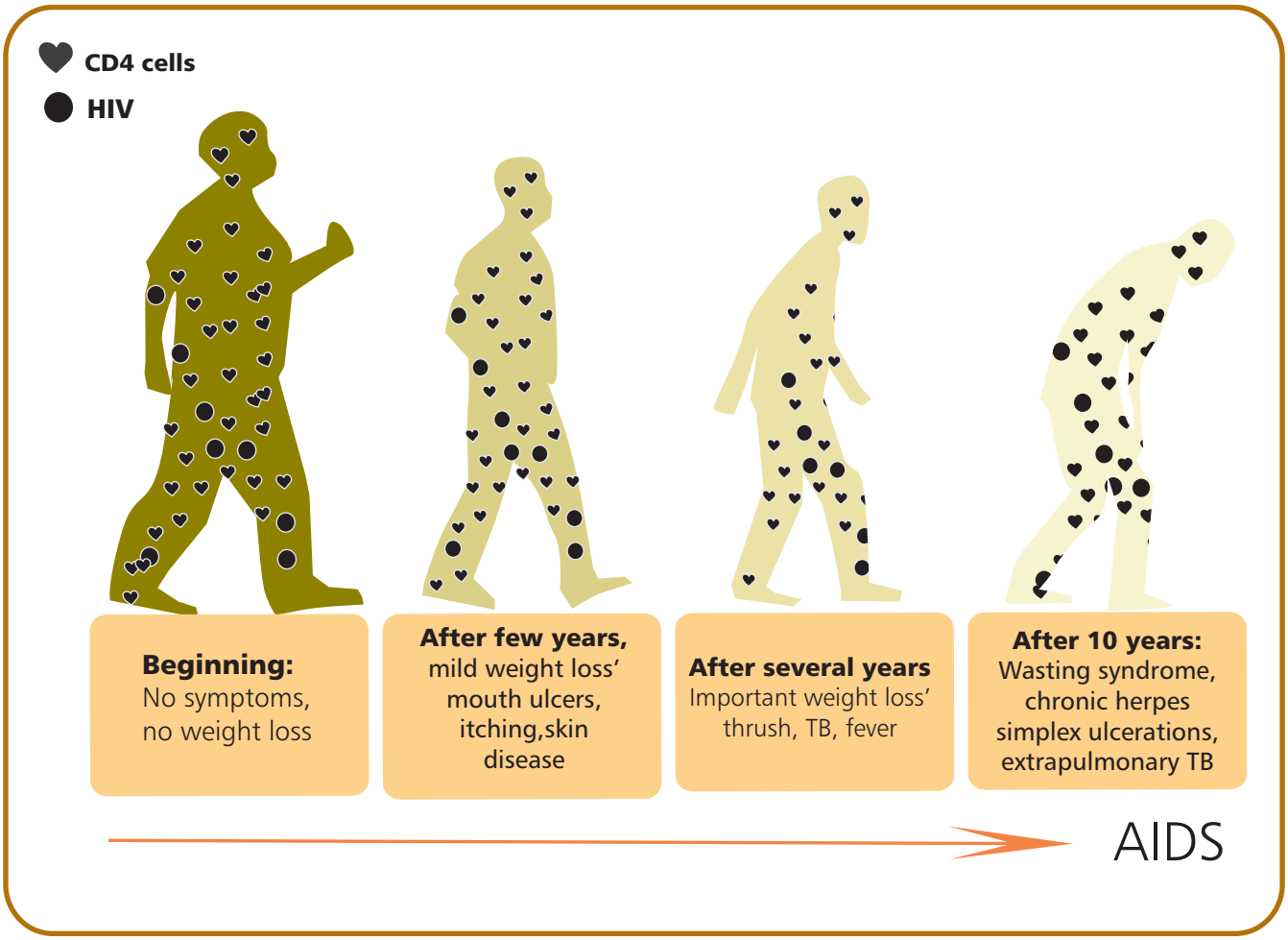
(1 hour 25 minutes)

a) Clinical Staging of HIV and ART (30 minutes with tool 2)

Not everyone who is HIV positive needs to start ART. Different countries have different protocols or guidelines on when ART should begin for PLWHA. Therefore, the clinical team determines when a client should begin treatment based on these guidelines. The clinical team will refer these clients to the CBV for additional support. For this reason, it is important that CBVs understand the Clinical Staging of HIV and their role at each stage.

CBVs can think of the staging system as a different way of understanding the Progression of HIV infection to AIDS discussed in Module One, which describes how HIV progresses in the body over time without treatment. Clinical staging however, uses a list of signs and symptoms to help doctors and other health professionals determine how far HIV infection has progressed in PLWHA.

Progression of HIV



KNOWLEDGE

Tool 2: Charting the Timeline of HIV and AIDS

Distribute copies of Handout 2-2 and 2-3. Ask for four volunteers from the class. Give each participant a flipchart and assist each individual with Stage I, II, III or IV. Ask each participant to draw an illustration similar to the one on the handout according to the stage they have been assigned.

As you review each stage, ask participants to write down important facts about the stage they have been assigned under their illustration.

Facilitator's note: Facilitators should end this activity by reviewing Handout 2-3: The Role of CBVs in Each Stage of HIV Infection and ensure that CBVs understand their roles and responsibilities in each stage.

Facilitators should re-emphasise that the clinical team at the health facility will decide when to start ART. This decision is based on different reasons: the clinical stage of HIV, absence/stabilisation of opportunistic infections, preparation of the client for adherence.

Understanding the Clinical Staging for HIV and AIDS

Stage One: HIV positive and feeling healthy

- During Stage One, the immune system of PLWHA is still strong and the CD4 count is high
- Stage One is a good time for PLWHA to begin to live positively by seeking access to medical facilities they will need in the future, treating OIs immediately should then begin to occur, preventing the transmission of HIV to others and ensuring proper nutrition and emotional support by joining a support group for PLWHA
- During Stage One, PLWHA may want to disclose their status to family and friends and discuss options for future health and care.
- ***A person with Stage One HIV infection does not need to begin ART***

During this Stage, the CBVs role is to:
Link:
- Clients to facilities for OI management
- Clients to routine clinical care
- Clients to community support

Provide:
- Client education
- Ongoing support
- Peer support

Stage Two: HIV positive and beginning to get sick more often

- During Stage Two, HIV begins to damage the immune system of PLWHA and they begin to become sick more often
- PLWHA will begin to suffer from opportunistic infections and may lose weight, and/or develop skin or chest infections
- During Stage Two, it is very important that PLWHA go to a clinic or hospital early to treat OIs as they occur
- ***If possible, PLWHA should take a CD4 blood test at this time to determine the need to start ART.***

During this Stage the CBVs role is to:
Link:
- Clients to facilities for OI management
- Clients to routine clinical care
- Clients to community support

Provide:
- Client education
- Ongoing support
- Peer support

Stage Three: HIV positive and becoming increasingly sick

- During stage three, the immune system is becoming increasingly weak because of HIV
- PLWHA will begin to lose more weight and may suffer from long lasting OIs such as diarrhoea, fever, thrush or TB
- Illnesses may return after treatment and PLWHA should seek medical attention as soon as they begin to get sick or notice that an OI has returned
- ***PLWHA should request to have a CD4 blood test during Stage Three, as during this stage ARVs are often required.***

During this Stage the CBVs role is to:
Link:
- Clients to facilities for OI management
- Clients to routine clinical care
- Clients to community support

Provide:
- Client education
- Ongoing support
- Peer support
- Prophylaxis support
- ART support

**The simplified WHO Clinical Staging System has been adapted from Namibia Red Cross' 'HIV/AIDS and Antiretroviral Treatment' booklet, November 2004.*

Stage Four: HIV positive and very sick with AIDS

- During Stage Four, the immune system has been severely damaged by HIV and PLWHA may no longer be able to fight off infection
- PLWHA may become bedridden and need others to care for them
- PLWHA will experience severe OIs, such as chest infections (TB), diarrhoea, skin infections, skin cancer and others
- ***People in Stage Four need ART and should receive immediate treatment for any illness.***

During this Stage the CBVs role is to:
Link:

- Clients to facilities for OI management
- Clients to routine clinical care
- Clients to community support

Provide:

- Client education
- Ongoing support
- Peer support
- Prophylaxis support
- ART support

b) Review of CD4 and Viral Load (15 minutes)

CD4 and viral load counts are two terms that CBVs may hear a lot about when implementing ART interventions in areas where laboratory testing is used. It is important to review these terms and ensure CBVs have a sound understanding of what they mean, particularly with reference to antiretroviral therapy.

Viral Load is essentially the amount of HIV in a person's blood.
A viral load test will tell a person living with HIV or AIDS:

- How much HIV he or she has in their system
- Whether antiretroviral therapy is working. ARVs act to decrease the amount of HIV in a person's system. So, if a person on ART has a low viral load, the medications are doing their job.

CD4 cells are a type of white blood cell in your body (called a lymphocyte or T4 cell) that fights infection. The more CD4 cells a person has, the healthier he or she is.

A CD4 count will tell a person living with HIV or AIDS:

- How weak or strong his or her immune system is (a high CD4 count means the immune system is strong)
- Whether to start antiretroviral therapy: PLWHA with CD4 counts below 200 should start ART if it is available, though this figure may change depending on country protocols.
- Whether to change antiretroviral therapy: If a person is on ART and the CD4 counts begin to drop, the ARVs he or she is taking may have stopped working. He or she may need to take different ARVs.

c) What Clients Should Know Before Starting Treatment (45 minutes with Tool 3)

Preparing clients for treatment is a very important factor in the success of ART. It is so important that the next module is devoted entirely to issues surrounding treatment preparedness. For now, it is important for CBVs to understand that it is not only the client's physical condition that determines when to start ART. The decision to start ART is also based upon how prepared they are to make the commitment for life long treatment.

Types of information that CBVs should review with their clients before they start ART include:

- Clients should understand what ART means and how it will affect their life. Any questions clients have about ART should be answered in a way they find acceptable before starting treatment.
- Once beginning ART, ARV tablets must be taken as ordered by the doctor every day, at the same time, for the rest of your life.
- Clients may have to avoid certain foods and eat and drink at certain times of the day while on ART.
- It is important for clients to disclose their HIV status to at least one person before starting ART (such as a CBV, family member or friend), so that this person can support them to take the drugs properly.
- If clients miss taking their ARV tablets, HIV will begin replicating again and the ARV medicine may no longer be able to work properly, causing multiplication of HIV and illness and infection to return.
- Clients should be linked with all people at local health facilities that will be part of their HIV care team. CBVs are there to assist clients to make these links.
- Clients should understand the importance of regular clinic visits and being able to speak openly and honestly with doctors, nurses and other health professionals about their life and health.

Tool 3: Group Role Play on when to start ART.

Facilitator's Note: Prior to conducting this activity, it is important that facilitators introduce CBVs to the clinical team staff that will be responsible for managing clients on ART. Such introductions would best be conducted on site at local health centres. If this is not possible, facilitators should invite the clinical team staff to join the training session and provide short presentations on their role in supporting clients on ART.

This section has provided participants with important information on when ART is started for people in their community and the role of CBVs in ART. It is now important that CBVs can provide this information to clients in a way that is easily understood using **Section 4: Basic Facts about ART from the Flipchart for Client Education** pages 4-1 to 4-5 and **Chapter 4: Client Self Management and Caregiver Booklet for HIV Management** as learning tools.

Divide the class into two groups. Provide each group with the following topics:
1. Health facilities clients should be linked with before starting ART.
2. Important things clients should know before starting ART.

Ask each group to present a role play on their topic as though they are talking to a client.

Have remaining participants think of additional questions clients might have about local health facilities and pose these questions to the clinical team.

2 Session Two: Basic Facts About ARVs

Purpose: The purpose of Session Two is to provide some basic facts about ARVs, including the major classes of ARV drugs and the drugs commonly used in first and second line ARV regimens. Side effects of ARVs will also be covered.

Objectives:

By the end of this session, CBVs should be able to:

1. Describe how ARVs work to clients in a clear and accurate manner
2. Use the Client Education Cards for First-line regimens to educate clients on important considerations of the medications they are taking.
3. Effectively explain ART to clients using the Flipchart for Client Education and Client Education Cards.
4. Demonstrate the ability to distinguish between mild and major side effects to ARVs.
5. Assist clients and client families to manage and record side effects to ARVs.

Duration: 4 hours

Required Materials: Flipchart, cards, pens and markers.

Recommended Preparation:

- If possible, bring samples of drugs used in first line regimens for use in Tool 1.
- Write out minor and major side effects of ARVs on separate cards in preparation for Tool 3.
- Make copies of handouts 2-4, 2-5, 2-6 and 2-7 for distribution to participants during the Session.

Objective	Content	Time	Methodology
Describe how ARVs work to clients in a clear and accurate manner	1. Basic Facts on ARVs	20 minutes	Mini Lecture *Assessed in Tool Two (ST): Role Play
Use the Client Education Cards for First Line Regimens to educate clients on important considerations of the medications they are taking.	2. First-line ARV regimens	1 hour	Mini Lecture Tool One (ST): Case study and Role Play
Effectively explain ART to clients using the Flipchart for Client Education and Client Education Cards.	3. Second-line ARV regimens	35 minutes	Mini Lecture Tool Two (ST): Case Study and Role Play
Demonstrate the ability to distinguish between mild and major side effects to ARVs.	4. Side Effects of ARVs	45 minutes	Mini Lecture Tool 3 (ST): Matching Game
Assist clients and client families to manage and record side effects to ARVs.	5. Managing Side Effects	1 hour	Mini Lecture Tool 4 (ST): Role Plays

1. Basic Facts on ARVs (10 Minutes)

a) How do ARVs work? (5 minutes)

- ARVs stop HIV from multiplying within the immune system of PLWHA (reducing viral load)
- When HIV is stopped or slowed, the immune system is allowed to recover (increasing CD4 Cells)
- The better a person's immune system is (more CD4) and the less HIV present (viral load), the better that person is able to fight infections that can lead to AIDS.

b) Three Categories of ARV Drugs (5 minutes)

- There are currently three main classes, or categories, of antiretroviral drugs. Research on HIV and AIDS is constantly seeking to create more effective ARVs. This means that the number of categories of ARV drugs, and the types of drugs in each category, will probably change in the future.
- CBVs are NOT expected to memorize the major classes of ARV drugs and the names of types of drugs found in each class. Rather, the purpose of this section is to help CBVs to become familiar with the names of drugs so that they may become familiar with the 'language of ARVs'.
- As a CBV it is always important to ask questions about drugs you are not familiar with. As we have stated before, HIV is a constantly changing epidemic, and requires us to learn and change with it.

c) PEP and ART

As discussed in Module One, Post Exposure Prophylaxis (PEP) is a type of ARV that is provided to people who have been exposed to transmission. PEP prevents the uptake of HIV in the body after exposure to the virus through blood or fluid contact with an HIV infected person.

PEP is not only for caregivers or medical professionals who have been exposed to HIV transmission. Hold a brief discussion on instances in which individuals in the community may need PEP.

Examples include:

- Medical exposure (during caring activities)
- Crime-related exposure (rape)
- Contact with blood in an accident situation (such as a car accident).

Facilitator's Note: Hold a brief discussion of any additional situations in which individuals in the community may require PEP. PEP will be discussed again in Module 7: Palliative Care, facilitators not planning to conduct this module should conduct Tool 2 in Session Three: Availability of PEP in Your Community now.

2. First-line ARV regimens (1 hour)

a) What is a 'First-line regimen'? (5 minutes)

A **First-line regimen** is the name of a combination of ARV drugs used 'first' to treat HIV and AIDS. ART is always taken as a combination of THREE antiretroviral drugs since:

- It takes a lot of force stop HIV

- Anti-HIV drugs from different drug groups are needed to attack the different enzymes of the virus
- Combinations of anti-HIV drugs may overcome or delay resistance.

b) What is Resistance? (10 minutes)

Resistance is the ability of HIV to change its structure in ways that make drugs less effective. HIV has to make only a single, small change to resist the effects of some drugs. If three drugs are given, it takes longer to make those changes. If the drugs are always taken as prescribed, it is unlikely that those changes will happen at all. If the three drugs are not taken properly, the HIV virus can still develop resistance.

c) Names of drugs used in First-line regimens (10 minutes)

Facilitator's Note: Distribute copies of Handout 2-4 'Client Education Cards for First-line Regimens'.

Some names of drugs used in First-line regimens include:

- Zidovudine (AZT or ZDV)
- Lamivudine (3TC)
- Stavudine (d4T)
- Nevirapine (NVP)
- Efavirenz (EFZ)

ARV REGIMENS

ARV REGIMEN	Use in women in childbearing age or pregnant?	Use in PLWHA with TB?
ZDV + 3TC +NVP	Yes	Yes*but with caution in Rifampicin based regimens
d4T + 3TC + NVP	Yes	Yes*but with caution in Rifampicin based regimens
ZDV + 3TC +EFV	No	Yes *but not pregnant women
d4T + 3TC + EFV	No	Yes *but not pregnant women

Adapted from WHO Scaling Up Antiretroviral Therapy in Resource-Limited Settings: Treatment Guidelines for a Public Health Approach, 2003 Revision

Tool 1: How CBVs Can Assist Clients with First-line Regimens

Divide participants into pairs and read the following case study aloud:

Replace X with commonly used local name

Your client, X, has received ZDV-3TC-NVP as his first-line ART regimen. Based on information provided in this session and Handouts 2-1 and 2-4, what would you advise X?

Facilitator's Note: Ensure that participants make use of the ZDV-3TC-NVP Information Sheet provided in Handout 2-4 to educate clients on important side effects and when to take medications. Review Client Education Cards for Other Regimens and answer any questions participants have about providing clients with this information.

3. Second-line ARV regimens (40 minutes)

a) Defining Treatment Failure (5 minutes)

Treatment failure can be defined as a condition in which ARV drugs stop being effective. The criteria used for assessing treatment failure can include the return or increase of opportunistic infections, increase in symptoms of HIV infection, or decrease in CD4 counts.

b) What is a Second-line regimen? (30 minutes with Tool 2)

A **Second-line regimen** of ARVs is prescribed for individuals on First-line regimens when treatment failure occurs, or if the side effects of first-line drugs are too severe. A Second-line regimen is therefore a new or changed prescription of ARV medications.

The ARV drugs used in Second-line regimens will be **determined by a doctor** based on the First-line regimen of PLWHA and the reasons for treatment failure.

Tool 2: Explaining ART to Clients

PART A: Role Play

Divide participants into pairs and have them role play the following case study using both **Section 4 of the Flipchart for Client Education** and the **Client Education Cards Handout**:

Replace X with a commonly used local name

Your client, X, is about to begin ART. She has some questions about the treatment and comes to you for guidance. X asks you the following questions:

- How do ARVs work?
- My clinical team told me the drugs I am taking are part of a “first line regimen”, what does that mean?
- Is there anything special I should know about the drugs I am taking?

Facilitator's Note: In assessing this core skill, facilitator's should ensure that CBVs:

1. Use the **Flipchart for Client Education** tool properly when explaining Basic Facts About ART to clients.

Ask X the names of the drugs that are part of her first-line regimen. Then, based upon information on the **Client Education Cards** from Handout 2-1, give X specific information about her regimen.

4. Side Effects of ARVs (45 minutes)

- When clients start ART they may have some discomfort called side effects.
- For a few people ART can cause more serious side effects.
- CBVs should be able to recognise mild side effects and support the client to manage these.
- CBVs should also be able to recognise major side effects requiring referral to the local health facility.

a) Mild Side Effects (10 minutes)

Minor side effects may be a normal part of the body adjusting to ART, but if the side effect worsens or begins to affect the ability of clients to function, they must consult the local health facility immediately.

The following are some mild side effects that individuals starting a first-line regimen should be prepared to cope with:

- Sleeplessness
- Upset stomach (nausea)
- Diarrhoea
- Drowsiness
- Headache
- Fatigue
- Mild Rash
- Confusion
- Nightmares
- Dizziness.

If clients are experiencing mild side effects over a long period of time, if side effects are making clients very uncomfortable, or if a CBV is unsure of whether a side effect experienced by a client is mild or major, clients should be referred to the local health facility.

b) Major Side Effects

(35 minutes with Tool 3)

The following are some major side effects (also called toxic effects) that can be acquired when taking a First-line regimen:

- Severe headaches
- Tingling in extremities: hands, feet, arms and legs (neuropathy)
- Fat changes: arms, legs, buttocks and cheeks become thin; breasts, belly, back of neck gain fat
- Severe abdominal pain (pancreatitis)
- Yellowing of the skin and pain of internal organs (liver toxicity or jaundice)
- Severe rash
- Severe fatigue or shortness of breath (lactic acidosis)
- Fever
- Severe mental disturbance (confusion, psychosis, depression)
- Severe muscle pain or cramping.
- Anaemia

- If an individual is suffering from major side effects the CBV should refer him or her to the local health facility. PLWHA should NOT try and ease the side effects by changing the way they are taking their ARVs by themselves (reduce daily doses, stop taking ARVs and wait for the symptoms go away and start again when they disappear). A doctor or nurse will be able to advise when and if to stop taking medications, and what can be done to ease major side effects.

Tool 3: Correctly matching Minor and Major Side Effects

Write each of the minor and major side effects that can be associated with First-line regimens on separate cards. Create two flipcharts, one entitled “Minor Side Effects” and another entitled “Major Side Effects”.

Divide participants into two teams and have each team take alternate turns. Ask participants to draw one of the cards, read their side effect aloud and stick their paper under the appropriate heading. Participants should also say what they should advise a client having this side effect to do. The team with the most correct matches wins.

Facilitator's Note: The following information about side effects is very important for facilitators to highlight during participant presenatations.

- Minor side effects may be a normal part of the body adjusting to ART, but if the side effect worsens or begins to affect the ability of clients to function, they should be encouraged to consult their doctors.
- All clients showing any of the major side effects should be referred to a medical facility immediately and should NOT try and change the way they experience side effects by themselves by stopping or adjusting the way they are taking their ARVs.
- Whenever possible, CBVs should find out what drugs are included in their client’s ARV regimen and provide clients with specific information on side effects that can be found on the **Client Treatment Cards** provided in Handout 2-4.
- CBVs should also encourage clients to use the ‘client Self-Management Booklet’ for early detection of minor signs and symptoms.

5. Managing Side Effects (1 hour)

The best way CBVs can help clients manage the side effects of taking ARVs is to inform them of possible side effects and help them to record any side effects experienced so that they can discuss them with their clinical team.

CBVs should never attempt to change the way in which their clients take their ARVs or take it upon themselves to determine which side effects are 'unimportant' and which side effects deserve medical attention. Instead, CBVs should support PLWHA to pay attention to ways in which they think ARVs may be affecting their body and health and to record these symptoms to help the clinical team understand problems that ART may be causing.

CBVs can assist by helping clients and their families to manage minor side effects. Managing symptoms with food is discussed in greater detail in Module 6: Nutrition, and methods for symptom management in the home are discussed in Module 7: Palliative Care and the client Self-management Booklet.’

Facilitator's Note: Hand out copies of the Handout 2-5 Symptom Management to participants. Review these as group and answer any questions CBVs might have about the use of the handout in client homes.

a) Reporting Side Effects (30 minutes with Tool 4)

CBVs should encourage their clients to record the following information about side effects:

Recording Information on Side Effects	
	QUESTIONS TO BE ANSWERED
Frequency **The "When?" of Side Effects**	• How often do you experience these symptoms? • Where are the symptoms felt in your body? • When do symptoms occur? Do the symptoms occur all day, all night, only in the morning?
Duration **The "How Long?" of Side Effects**	• How long do the symptoms last? For example, do they last for 30 minutes, or for several hours? • Is there a pattern to when you experience the symptoms? For example, immediately after you take your medication or a few hours after a certain dose?
Severity **The "How Bad?" of Side Effects**	• How bad are the symptoms? • Is there anything that helps alleviate the symptoms?
Quality of Life **The "How are side effects impacting your life?"**	• How are the symptoms affecting you? For example, is the diarrhoea or headache stopping you from working or going outdoors? • Has your sleep been disturbed because of symptoms? • Are you able to eat as you normally would? • Has your sex drive been affected? • Are you worried about your weight?
Adherence **The "Are Side Effects changing the way you take ARVs?"**	• Are the side effects stopping you from taking your pills? • Do you forget to take pills or change the times they are taken due to side effects?

In addition to answering questions about frequency, duration, severity, quality of life and adherence, CBVs can help their clients to record the side effects they experience by keeping a side effects diary.

CBVs should encourage their clients to record side effects in their diary and bring this information to each medical appointment to discuss with their clinical team. Again, if PLWHA experience any of the major side effects or toxicities to ARVs listed in Section 4 b), they should not wait until their next scheduled appointment to discuss the symptoms with their clinical team. CBVs should ensure their clients seek medical attention immediately if any major side effects are experienced.

Tool 4: Helping Clients Record Side Effects

Helping clients to record side effects and keep a side effects diary is an important way that CBVs can help clients and their families to take control over any side effects to ART that are experienced.

Distribute Copies of the Recording Side Effects Chart in Handout 2-6 and Side Effects Diary located in Handout 2-7. Divide participants into pairs and ask them to conduct two separate role plays:

1. Helping clients to accurately record the following side effects:
   - Feeling sick to their stomach
   - Feeling unable to sleep
   - Fever
   - Severe rash

2. Explaining how to use the recording side effects chart and side effects diary to a client and the person in the home who provides daily care.

How to use the recording side effects chart

Use this page to record any changes in your health that could be related to side effects
You may not get any side effects but if you do then this diary will be useful.
Side-effects are listed below but include others even if they are not listed here.

1 Tingling or pain in hands/feet
2 Pain in hands/feet
3 Nausea/vomiting
4 Headache
5 Feeling tired
6 Dry Skin
7 Rash
8 Diarrhoea
9 Stomach pains
10 Hair loss
11 Body shape changes
12 Weight gain
13 Weight loss
14 Changes in taste or appetite
15 Sexual problems
16 Sleep disturbance
17 Vivid dreaming
18 Feeling anxious/nervous
19 Changes to your eyesight
20 Mood swings
21 Feeling depressed
22 Other(s) specify

Side effect symptom	Day	Time(s)	Scale 1= very mild 5 = very bad				
			1	2	3	4	5
			1	2	3	4	5
			1	2	3	4	5
			1	2	3	4	5
			1	2	3	4	5
			1	2	3	4	5
			1	2	3	4	5
			1	2	3	4	5
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			1	2	3	4	5
			1	2	3	4	5

3 Session Three: Special Considerations for ART

Purpose: The purpose of Session Three is to overview special considerations for ART in reference to OIs, TB, women and children.

Objectives:
By the end of this session, CBVs should be able to:

1. Describe to clients what OIs are and how CTX and OIs are linked.
2. Effectively inform clients about TB, identify clients with TB and refer clients with TB to HIV Testing and Counselling Services using the 5 As.
3. Help female clients to overcome identified challenges to taking ARVs in your community.
4. Impart key information about how ART for children is different than for adults to clients in a way that is easily understood.
5. Help drug users to overcome identified challenges to taking ARVs in your community.

Duration: 4 hours

Required Materials: Flipchart, cards, markers.

Recommended Preparation:
Make copies Handouts 2-8, 2-9 and 2-10 for distribution during the session.

Objective	Content	Time	Methodology
Describe to clients what OIs are and how CTX and OIs are linked.	1. ART and Opportunistic Infections (OIs)	45 minutes	Mini Lecture Tool One (ST): Group Exercise
Effectively inform clients about TB, identify clients with TB and refer clients with TB to HIV Testing and Counselling Services using the 5 As	2. ART and TB	50 minutes	Mini Lecture Tool Two (ST): Role Play
Help female clients to overcome identified challenges to taking ARVs in your community.	3. ART and Women	1 hour	Mini Lecture Tool Three: Part A (PS): Group Discussion PART B (ST): Role Play
Impart key information about how ART for children is different than for adults to clients in a way that is easily understood	4. ART and Children	50 minutes	Mini Lecture Tool Four (ST): Case Study and Role Play
Help drug users to overcome identified challenges to taking ARVs in your community	5. ART and Injecting Drug Users	20 minutes	Mini Lecture Tool 5 (PS): Group Discussion

1. ART and Opportunistic Infections (OIs) (45 minutes)

a) What are Opportunistic Infections (OIs) (5 minutes)?

Opportunistic Infections or **OIs** are diseases that attack the body when it is weak. OIs may cause problems including pain when swallowing, trouble breathing, frequent or very bad headache, problems seeing, feeling more and more tired, itching, fever, sweating, shaking, chills, problems with balance, walking or speech, losing weight for no reason, more than 5 watery or soft bowel movements a day, vomiting, sore mouth or tongue, stiff neck.

The role of CBVs is to encourage clients to seek early treatment for any OIs by linking them to health facilities and to support clients to adhere to treatments such as ART and prophylaxis as prescribed by their doctor.

b) What does prophylaxis mean? (10 minutes)

1. Prophylaxis is a therapy or treatment that clients take to prevent infections.
2. Good prophylaxis is neither expensive nor complicated and can increase the duration and quality of life.

Cotrimoxazole or **CTX** is a commonly prescribed prophylaxis for PLWHA.

Explain the benefits of CTX, how it needs to be taken and the side effects it can cause:

1. CTX prophylaxis can reduce the incidence of certain brain abscesses, pneumonia, and chronic diarrhoea.
2. CTX prophylaxis needs to be taken on a daily basis (it can be given once or twice a day).
3. All HIV+ patients in WHO clinical stage 2, 3 and 4 should be on CTX prophylaxis
4. If no access to ART, CTX should be taken lifelong; if access to ART, it can be stopped when the immune system is strong enough (ONLY health workers will determine when to stop CTX. This is not the CBV's role).
5. CTX may cause side effects such as nausea, rash, pale skin, yellow eyes.

c) The CBV's role with a client to whom CTX has been prescribed (30 minutes with Tool 1)

Explain that an CBVs should:

1. Educate the clients about the benefits of the treatment
2. Prepare the client to adhere to a long-term treatment of CTX (this will be discussed in Module 4: Adherence)
3. Make sure that the client is ready to initiate the treatment and explain how it should be taken (once or twice daily depending on the strength of the tablet)
4. During each home visit, monitor how CTX is taken and how the client is feeling. (this will be discussed in detail in Module 4: Adherence)

Explain that getting the client used to adhering to their prophylaxis as well as attending the clinic on a regular basis (adherence to care) is a good way of preparing them for ART.

Tool 1: Explaining CTX and OIs to Clients

Distribute or ask the following questions as a review for the class.

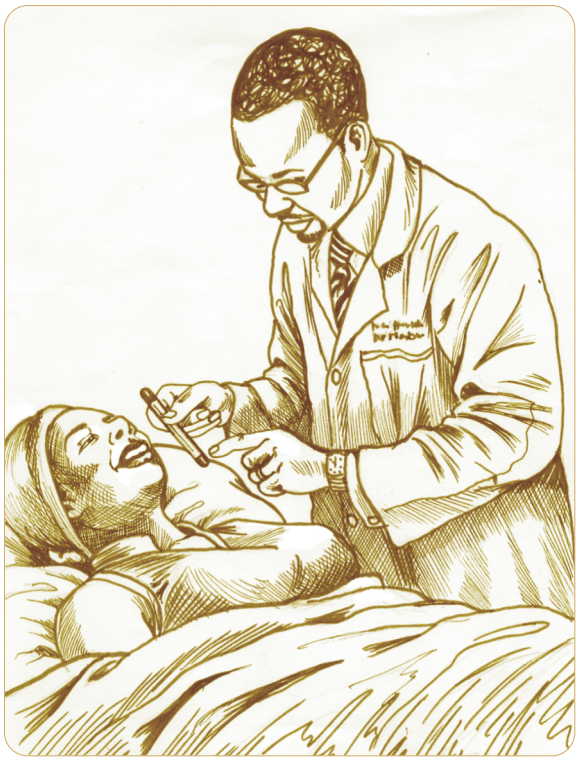
If participants are fast in reading and writing, you may consider having this exercise as a written exercise (it is printed in Handout 2-8). It will give you a better understanding of what they have learnt during the class.

1. What are OIs?
2. What does prophylaxis mean?
3. What are the benefits of CTX prophylaxis?
4. Who needs to take CTX prophylaxis?
5. How does CTX prophylaxis need to be taken?
6. For how long does CTX prophylaxis need to be taken?
7. What are CTX side effects?
8. What are the roles of CBVs?
9. What is not the responsibility of CBVs?
10. In addition to preventing infections, why is CTX prophylaxis good for the client?

Facilitators Note: To complete this exercise, ask participants to conduct a brief role play of how they would provide this information to a client using the Client Education Flipchart.

2. ART and TB (50 minutes)

a) TB and HIV (20 minutes)



Tuberculosis, or TB, is a disease that affects many PLWHA. TB can take two forms:

1. Pulmonary - TB affecting the lungs
2. Extrapulmonary - TB affecting organs of the body other than the lungs

The role of CBVs in TB and HIV Co-Management is to:

- Inform clients, family and treatment supporters about TB or TB-HIV and its treatment
- Identify clients with suspected TB and link these clients with health facilities
- Encourage clients with TB to make use of HIV Testing and Counselling Services
- Assist clients to take their TB and HIV (ART) medications as prescribed by health professionals

1. Informing Clients about TB

Ask the client questions such as:	Then give relevant messages:
1. What do you understand tuberculosis to be? What do you think may have caused your illness?	<u>What is TB?</u> Tuberculosis, or TB, is an illness caused by a germ that is breathed into the lungs. TB germs can settle anywhere in the body, but we most often hear about TB of the lungs. When the lungs are damaged by TB, a person coughs up sputum (mucus from the lungs) and cannot breathe easily. Without correct treatment, a person can die from TB.
2. Have you ever known anyone with TB? What happened to that person? Do you know that TB can be completely cured?	<u>TB can be cured</u> TB can be cured with the correct drug treatment. The client must take all of the recommended drugs for the entire treatment time in order to be cured. Drugs for treatment of TB are provided free of charge. Treatment can be done without interrupting normal life and work.
3. How do you think that TB spreads?	<u>How TB spreads</u> TB spreads when an infected person coughs or sneezes, spraying TB germs into the air. Others may breathe in these germs and become infected. It is easy to pass germs to family members when many people live closely together. Anyone can get TB. However, not everyone who is infected with TB will become sick.
4. How can you avoid spreading TB?	<u>How to prevent TB from spreading</u> Take regular treatment to become cured. Cover the mouth and nose when coughing or sneezing. Open windows and doors to allow fresh air through the home, using a fan Use UV lights There is no need to eat a special diet or to sterilize dishes or household items.

2. Identifying Clients with TB

TB can only be diagnosed at the health facility. However, CBVs should encourage clients presenting the following symptoms to visit their local health facility as soon as possible to have a TB test done:

- Cough for longer than 2 weeks
- Fever that does not go away
- Unexplained weight loss
- Severe under nutrition
- Swollen glands for a long period of time
- Night sweats

Other members of the family who should also be encouraged to go for testing where a person is suspected to have TB:

- **All children less than 2 years** should referred to the local health facility, where they can receive preventive therapy and/or an immunisation (called a BCG vaccine).
- **All children under 5 years** living in the household should be examined for TB symptoms at the local health facility. This is especially important because children under 5 years are at risk of severe forms of the disease. Young children may need preventive measures and should be referred to a health facility.
- **Other household members who have a cough.**

***Whenever possible CBVs should encourage clients showing symptoms of TB to collect a sputum sample to bring to the health facility.**

3. Referring Clients with TB to HIV Testing

CBVs who have clients with TB, or clients who are suspected to have TB, are responsible for encouraging these clients to have an HIV test. This information can be provided during home visits.

Distribute Handout 2-9 Encouraging Clients with TB to have an HIV Test and review as a group.

b) TB and ART (30 minutes with Tool 2)

Special consideration must be given to individuals co-infected with HIV and TB before beginning ART. For example, there are certain ARV medications PLWHA with TB should not take. The decision to start ART for PLWHA with TB is based upon the severity of HIV.

Quick facts on TB and ART:

- TB therapy should be completed before beginning ART when possible. If a person is in advanced stages of HIV (CD4 count less than 200) he or she should begin ART as soon as possible, even if co-infected with TB.
- Some ARVs can interact with TB medicine. Thus when treating a person with ART and anti TB drugs, the ART combination must be carefully selected.

There is a very important issue that we need to discuss today. People with TB are also very likely to have HIV infection. If fact, HIV infection is the reason many people develop TB in the first place. This is because people with HIV are not able to fight off diseases as well as persons who are not infected.

If you have both TB and HIV, it can be serious and sometimes life-threatening without proper diagnosis and treatment. Treatment for HIV is becoming more available and can help you feel better and live longer.

Also, if the health facility knows that you have HIV infection, they can treat your TB disease better.

This is why it is recommended that people with TB also be tested for HIV.

Assisting Clients to Monitor and Adhere to HIV and TB Medications

CBVs should be aware of the treatment plan of all clients with TB, particularly if they also have HIV infection. Side effects, special considerations for taking medication and identifying a treatment supporter are important for CBVs to review with clients who have TB-HIV Co-infection.

Refer to Module 4: Adherence for more information on how CBVs should assist their clients to choose a treatment supporter and adhere to their ART and TB medications.

Tool 2: Using the 5 As to Explain TB and ART

Divide participants into pairs. Ask each pair to use the 5 A's and handouts provided in this session to educate clients on:

1. Informing Clients About TB
2. Identifying Clients with TB
3. Referring Clients with TB for HIV Testing

Facilitator's Note: When conducting role-plays, ensure participants correctly use the 5 As to (Assess, Advise, Agree, Assist and Arrange) for referrals and treatment for TB and HIV.

3. ART and Women (55 minutes)

a) ART and Non-Pregnant Women of Child-bearing Age (10 minutes)

Special factors relating to women and ART:

- Women who do not wish to become pregnant and are taking ARVs should engage in safer sex, and possibly have effective methods of contraception available to them
- The commonly used first-regimen drug EFZ can affect a developing foetus, so should not be used in women who are in the first trimester of pregnancy or attempting to conceive
- If a woman taking ART chooses to begin or continue using hormonal contraceptives ('the pill'), the use of condoms should be recommended to prevent transmission of HIV and to compensate for any possible reduction in effectiveness of the pill while on ART.

b) ART and Pregnant Women (10 minutes)

Special factors relating to women who are pregnant and medically eligible to begin ART:

- During the first trimester (the first three months) of pregnancy, women may consider delaying ART if their health will permit. Women who are severely ill should begin ART, taking the point below into consideration
- Women who become pregnant on ART should continue their treatment, with the exception of EFZ, which should be avoided during the first trimester (replaced with nevirapine)
- Women can reduce the chance of transmitting HIV to their babies while pregnant (**Mother to Child Transmission** or **MTCT**) through ART or ARV prophylaxis**.** The doctor will decide which one is needed based on the clinical stage and CD4 count of the woman.

c) ART and Nursing Women (10 minutes)

Facilitator's Note: Facilitators who are not intending to conduct training on Module 6: Nutrition should review Session Four; Sections 2 and 3 which deal with nutrition for HIV positive mother's and their children with participants.

Special factors relating to women who are breastfeeding and ART:

- Women with HIV infection should be educated on the risks and benefits of breastfeeding by a health professional
- If a woman chooses to breastfeed (or the use of alternative formulas cannot be afforded or are unavailable), she should be advised by a health professional.
- The CBVs role is to support the woman in the choice she has made after being counselled by a health professional.

d) How does Exclusive Breastfeeding Work? (30 minutes with Tool 3)

Exclusive breastfeeding, where a mother only feeds her baby breast milk from 0 to 6 months of life, has been shown to lower the risk of HIV transmission because breast milk does not break the mouth or gut of the infant.

With mixed feeding (where a mother gives breast milk in addition to water, formula or dairy milk), the baby's mouth and gut can become damaged or swollen, allowing HIV to pass into the baby's blood stream.

The increased risk of transmitting HIV to the baby through mixed feeding is the reason why HIV positive mothers are encouraged to give breast milk only from 0 - 6 months of life as discussed with a health professional.

Tool 3: ART and Women

***PART A:**
Divide participants into two groups. Ask participants to discuss why women might face more challenges in taking ART than men in their community. Provide each group with one of the questions below and ask them provide possible solutions to problems they identify:

Group One: What are some challenges women (both of childbearing age and pregnant) in your community may face to taking ART? (i.e., ability to negotiate for use of condoms during sex, challenges of managing side effects of ART and morning sickness while pregnant, fear of disclosing HIV status to others due to discrimination against HIV positive women having children)

Group Two: Are there any issues in your community regarding mother to child transmission? (i.e., cultural practices of breastfeeding that conflict with recommendations for HIV positive mothers, availability of alternatives to breastfeeding)

***PART B:**
After each group presents their answers, brainstorm on specific ways that CBVs can help female clients and other women in the community to over come each challenge identified. Split participants into pairs and assign each pair to role play one of the challenges identified with a client and how they would help to resolve this problem.

Facilitator's Note: Facilitator's should record identified challenges for women and ART and the ways that CBVs can help to overcome challenges identified in Part B for use in assessing core skills at the end of the module.

4. ART and Children (50 minutes)

a) Diagnosing HIV in Children (10 minutes)

- Most babies are diagnosed with HIV based upon symptoms or an HIV positive test of the mother or the child
- Children born to mothers with HIV may test positive until they are 18 months old even if they are not infected, as the child will carry 'passive antibodies' given by the mother during pregnancy and breast feeding. For this reason, another HIV test after 18 months is recommended for children who test positive for HIV after birth.
- The symptoms for HIV can be different in adults and children. Children born to HIV positive mothers should be referred to the clinical team.

b) When to Start ART in Children (5 minutes)

- WHO has a different different clinical staging of HIV/AIDS for infants and children, called the 'Paediatric Stages of HIV'. Children in Stage III of this system are recommended for ART regardless of their CD4 count
- Unlike adults, using CD4 levels as a decision to start ART is based on a percentage rather than a CD4 count. Children with a CD4 cell percentage less than 20% are recommended to start ART.

C) ARV Regimens for Children

(5 minutes)

The ARVs used in the first-line regimen are different depending on the age and weight of the child and will be determined by the clinical team.

The dosage of ARVs given to children is determined by a doctor based upon a weight or body-surface area calculation.

Discuss any national guidelines pertaining to the use of ARVs in children.

d) The Role of CBVs in ART and Children (30 minutes with Tool 4)

The role of CBVs in assisting children with ART is to link the parents and caregivers of HIV infected children to appropriate health services.

- HIV positive parents should always be encouraged to have their children tested for HIV
- CBVs should link child-headed households to local health facilities, where issues regarding consent for HIV testing and ART will be addressed by health workers.
- In the case of disclosure of HIV status to children, CBVs should arrange for family consultation at the local health facility

Tool 4: Explaining ART for Children to Parents

Divide participants into pairs and ask them to role play the scenario provided. Read the following case study aloud, and/or hand out copies of the case study from **Handout 2-10.**

Mary is a client who has just begun taking ARVs. Mary has a two year old daughter who has recently been diagnosed as HIV positive, but has not yet begun ART. While her daughter has not been extremely ill for the past six months, Mary suggests that she has considered sharing small portions of her ARVs with her daughter to keep her immune system strong.What do you say to Mary?

Facilitator's Note: Use the following checklist of important information CBVs should share with Mary in a way that can be easily understood:

- ☐ The symptoms of HIV are different in babies and children. Because of this, if Mary's daughter becomes sick, she should take her to the doctor immediately.
- ☐ The decision of when to start ART, and the types of ARV medications given to children are different than in children than they are in adults. For this reason, Mary should never share her ARVs with her daughter, as this could make her daughter sick.
- ☐ The decision to put Mary's daughter on ART can only be made by a doctor, and the types of ARVs provided will be based on a number of different factors that only a doctor can determine.

5. ART and Injecting Drug Users (20 minutes with Tool 5)

The criteria for starting ART among injecting drug users is the same as the general recommendations for starting ART discussed in Session One. While the recommendations of when to start ART are the same, there are some special considerations for ART with IDUs:

- Challenges of injecting drug use on a client's ability to take their ARVs at the right time, in the right amount and in the way prescribed by a doctor (also called adherence) should be addressed.
- Potential drug interactions between ARVs and drugs taken as part of replacement therapy should be taken into consideration by the health facility. CBVs should encourage IDUs to inform their health care team about any other medication or drugs they are taking.
- Whenever possible, methadone or detoxification (detox) programmes should be started before ART.
- If this is not possible, health facilities should stabilise the client and CBVs should be prepared to provide these clients with enhanced treatment support.
- CBVs should educate clients on harm reduction including injection safety and the use of sterile needles and syringes.

Tool 5: Helping IDUs with ART

As a group, discuss challenges to ART that IDUs may face in your community. For each challenge identified, problem solve ways that CBVs can assist these clients.

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My Notes

My Notes

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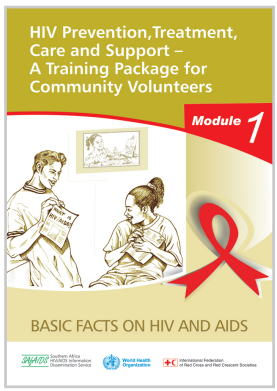

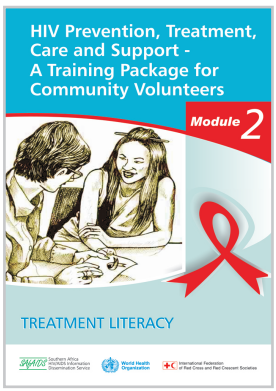

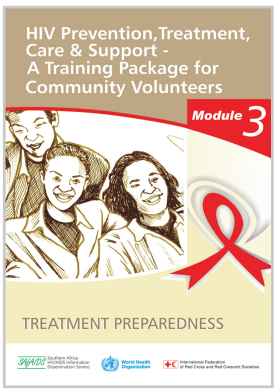

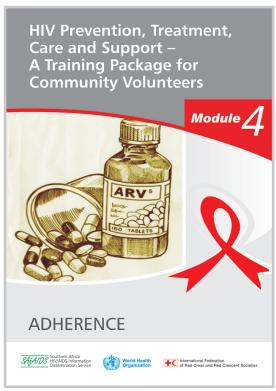

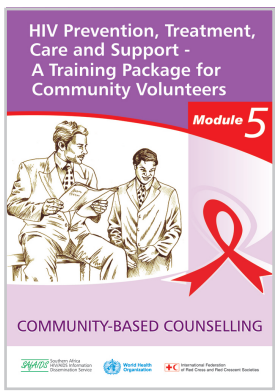

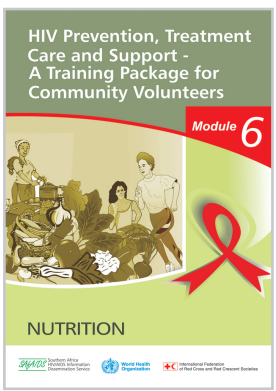

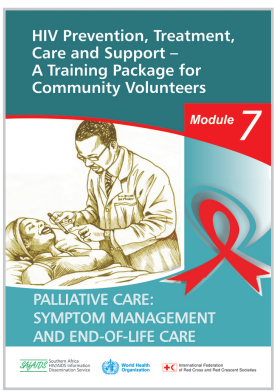

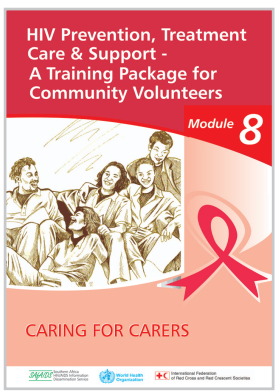

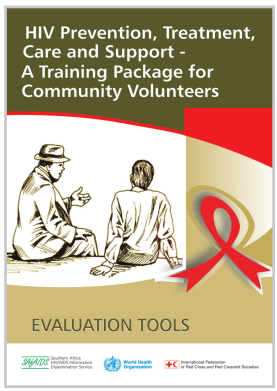

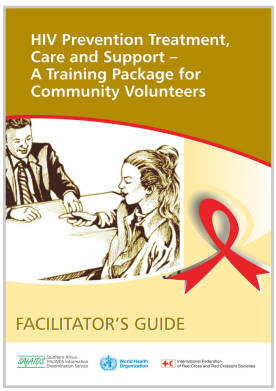

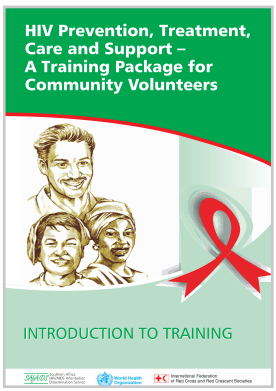

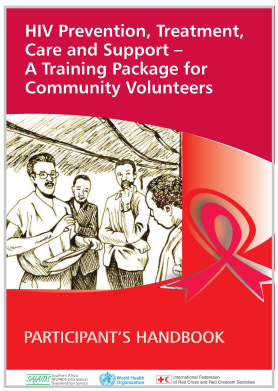

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