

Greater Involvement of People Living with HIV in
PMTCT and HIV Care and Treatment Programs

Comprehensive Peer Educator Training Curriculum Participant Manual



ICAP

International Center for AIDS
Care and Treatment Programs

MAILMAN SCHOOL OF PUBLIC HEALTH
Columbia University

Foreword

Knowledge is like a garden: if it is not cultivated, it cannot be harvested. African proverb

More than 33 million people worldwide are now living with HIV infection and since 1981 an estimated 25 million men, women and children have died as a consequence of the disease. Over the last several decades families have been ripped apart, communities have been ravaged and national economies have been jeopardized – the losses have been devastating. However, the tide is slowly turning and changes have begun to take hold. HIV care and antiretroviral treatment are becoming available to more people each day, efforts to prevent new infections in adults and children are having an impact and People Living with HIV (PLHIV) are speaking up, combating widespread stigma and discrimination and taking an active role in shaping programs and in their own health care. In fact, one of the most remarkable achievements amid this ocean of devastation is the recognition of the vital importance of the active involvement of PLHIV in the health care system, engaging those most affected by the disease in self care and the care of others.

In Central Harlem, New York City, where we began our work more than twenty-five years ago, we witnessed the transformative power of actively engaging PLHIV within teams of multidisciplinary health care providers. We learned of their ability to communicate their experiences and to listen and understand the experiences of their peers. We learned that PLHIV are best poised to articulate their own health needs and that empowered with knowledge and authority they can play a substantial role supporting the health needs of others. And we learned that each time an individual with HIV infection makes the difficult decision to openly and publically acknowledge their status, their courage is reflected throughout their community by reducing stigma and discrimination and enhancing the quality of the services for themselves and others.

In our work in Africa supporting HIV prevention, care and treatment, our understanding and appreciation of the vital importance of PLHIV working within the health care system has continued to grow. In settings where human resources are severely constrained, Peer Educators have taken on more formal roles as counselors and health educators working with families to provide accurate information on HIV and enhance adherence to care and treatment and, through task shifting, freeing up the time of nurses and physicians. In addition to their valuable work with their peers, PLHIV have also provided meaningful feedback to health care programs, offering insights into the best ways to engage difficult to reach populations and to optimize the delivery of health care services. Most importantly, they have highlighted and demonstrated the critical importance of addressing the psychosocial as well as the biomedical needs of PLHIV to ensure optimal health outcomes for children, adults, families and communities.

We have had the privilege of working with countless individuals committed to the greater involvement of people living with HIV/AIDS and with many talented and inspiring PLHIV who openly and bravely acknowledged their HIV-status and devoted themselves to working with their peers. The *Comprehensive Peer Educator Training Curriculum* and *Implementation Manual* bring together the collective experience of hundreds of people who collaborated on the development of Peer Educator programs. We've drawn upon other curricula and program materials, adapted as needed, then pre-tested and implemented in collaboration with other partners and the Ministries of Health in our work in PMTCT and HIV prevention, care and treatment programs in Ethiopia, Rwanda and Swaziland. We have enhanced these materials based on field experiences as well as

invaluable feedback from facilitators, participants and health care providers. The Curriculum and Manual are presented as generic tools which can be easily adapted by Ministries of Health, health care facilities, PLHIV associations and other organizations seeking to initiate or expand health facility based Peer Educator programs. We are hopeful that the availability of these tools reflecting our collective learning and experiences will further support the active involvement of PLHIV in HIV prevention, care and treatment programs and contribute to the good health of families infected with and affected by HIV throughout the world.

We would like to express our appreciation of the individuals who contributed a significant amount of their time and effort to the development of the Curriculum and Manual. Special thanks go to Tayla Colton, independent consultant, for her technical support and expertise, Leah Westra, Project Officer, for coordination and editing of the materials and Peter Twyman and Cristiane Costa for conceiving of this project, gently and persuasively moving it forward and ensuring an excellent product. We admire their talent and vision and are inspired by their commitment to the greater involvement of people living with HIV as active providers and recipients of HIV prevention, care and treatment services.

Elaine Abrams and Wafaa El-Sadr

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We give our special thanks to the numerous peer educators, peer educator coordinators and multidisciplinary HIV care team members in the many countries where ICAP works. We admire your commitment to serving others with quality HIV care and to upholding the rights of all people living with HIV and their families. You are a source of hope and inspiration to many around the globe and in your countries, health facilities and communities.

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Acronyms

3TC	Lamivudine
ABC	Abacavir
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal care
ART	Antiretroviral therapy/treatment
ARV	Antiretroviral
AZT	Zidovudine
CD4	Cluster of differentiation 4 cell
CTX	Cotrimoxazole
d4T	Stavudine
DBS	Dried blood spot
ddI	Didanosine
DNA PCR	Deoxyribonucleic acid - polymerase chain reaction
DOTS	Directly observed therapy short-course
ECP	Emergency contraceptive pills
EFV	Efavirenz
HAART	Highly active antiretroviral therapy
HBC	Home-based care
HIV	Human Immunodeficiency Virus
HTC	HIV testing and counseling
ICAP	International Center for AIDS Care and Treatment Programs
IUD	Intra-uterine device
LAM	Lactational amenorrhea method
LPV/r	Kaletra
MCH	Maternal and child health
MTCT	Mother-to-child transmission (of HIV)
NGO	Non-governmental organization
NVP	Nevirapine
OI	Opportunistic infection
ORS	Oral rehydration solution
PCP	Pneumococcal pneumonia
PE	Peer Educator
PEP	Post-exposure prophylaxis
PID	Pelvic inflammatory disease
PLHIV	Person (or people) living with HIV
PMTCT	Prevention of mother-to-child transmission (of HIV)
TB	Tuberculosis
TDF	Tenofovir
SDM	Standard Days Method
SMS	Short message service (text message)
STI	Sexually transmitted infection
VCT	Voluntary counseling and testing
WHO	World Health Organization
ZDV	Zidovudine

MODULE 1:

Course Overview and Introduction to the Training



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Know more about the trainers and other training participants
- Understand the training agenda, objectives, and "ground rules"
- Assess your own baseline knowledge about content and skills to be covered during the training



CONTENT:

Session 1.1: Welcome, Introductions, Agenda and Ground Rules

Session 1.2: Review of Training Objectives

Session 1.3: Learning Needs Assessment

SESSION 1.1: Welcome, Introductions, Agenda and Ground Rules

Welcome to the training!



Suggested Training Agenda:

Week 1:

Time	Day 1	Day 2	Day 3	Day 4	Day 5
8:30-10:00	Official Opening Module 1: Course Overview and Introduction	Module 4: Communication and Counseling Skills	Module 6: ART	Module 7: HIV Prevention, Care and Treatment for Pregnant Women and their Children	Module 8, continued
10:00-10:15	TEA BREAK	TEA BREAK	TEA BREAK	TEA BREAK	TEA BREAK
10:15-12:00	Module 2: Roles and Responsibilities of Peer Educator	Module 4, continued	Module 6, continued	Module 7, continued	Module 8, continued
12:00-1:00	LUNCH	LUNCH	LUNCH	LUNCH	LUNCH
1:00-3:00	Module 3: HIV and Reproductive Health Basics	Module 5: Comprehensive HIV Care	Module 6, continued	Module 7, continued	Module 8, continued
3:00-3:15	TEA BREAK	TEA BREAK	TEA BREAK	TEA BREAK	TEA BREAK
3:15-4:30	Module 3, continued	Module 5, continued	Review or catch-up time	Module 8: Adherence and Psychosocial Support	Module 8, continued
4:30-4:45	DAILY RECAP, EVALUATION AND CLOSING	DAILY RECAP, EVALUATION AND CLOSING	DAILY RECAP, EVALUATION AND CLOSING	DAILY RECAP, EVALUATION AND CLOSING	DAILY RECAP, EVALUATION AND CLOSING

Week 2:

Time	Day 6	Day 7	Day 8	Day 9	Day 10
8:30-10:00	Module 9: Identifying and Tracing People Who Do Not Return to the Clinic	Module 10, continued	Module 12: Community Outreach, Education and Linkages	SUPERVISED PRACTICUM – DAY 1	SUPERVISED PRACTICUM – DAY 2
10:00-10:15	TEA BREAK	TEA BREAK	TEA BREAK		
10:15-12:00	Module 9, continued	Module 11: Stigma, Discrimination and Disclosure	Module 12, continued		
12:00-1:00	LUNCH	LUNCH	LUNCH		
1:00-3:00	Module 10: Positive Living	Module 11, continued	Module 13: Record-Keeping and Reporting		
3:00-3:15	TEA BREAK	TEA BREAK	TEA BREAK		
3:15-4:30	Module 10, continued	Module 11, continued Review or catch-up time	Module 14: Supervised Practicum (preparation)		
4:30-4:45	DAILY RECAP, EVALUATION AND CLOSING	DAILY RECAP, EVALUATION AND CLOSING	DAILY RECAP, EVALUATION AND CLOSING		

Week 3:

Time	Day 11	Day 12	Day 13	Day 14
8:30-10:00	SUPERVISED PRACTICUM - DAY 3	SUPERVISED PRACTICUM - DAY 4	SUPERVISED PRACTICUM - DAY 5	Practicum Debriefing
10:00-10:15				
10:15-12:00				
12:00-1:00				
1:00-3:00				
3:00-3:15				
3:15-4:30				
4:30-4:45				Module 15: Action Planning, Evaluation and Graduation

SESSION 1.2: Review of Training Objectives

Peer Educator Training Objectives

By the end of this basic training course (Modules 1-15), you will be able to:

1. Work as an integral part of facility multidisciplinary care teams, specifically at prevention of mother-to-child (PMTCT) and HIV care and treatment clinics
2. Provide one-on-one counseling and group education to clients and their families so they better understand, use and adhere to HIV prevention, care and treatment services
3. Assist clients and their families to access different services within the health facility
4. Help prioritize pregnant women for HIV care and treatment services
5. Follow up HIV-exposed babies and provide basic information to clients on caring for their HIV-exposed and HIV-infected babies and children
6. Implement family-focused care by encouraging clients to disclose to family members and bring them to the clinic for counseling, testing, care and treatment
7. Serve as a role model for positive living and adherence to care and treatment
8. Help clients, family members and community members live positively with HIV and prevent new HIV infections
9. Identify and trace clients who have missed appointments or have discontinued treatment in order to bring them back into care
10. Assist clients and their families to access community-based services, such as support groups, associations of people living with HIV (PLHIV) and food support
11. Conduct community mobilization and sensitization around HIV and prevention, care and treatment services
12. Keep records of daily, weekly and monthly activities

Depending on the length and schedule for this training, we may also complete some advanced training Modules. Or, you may complete these later on as part of your continuing Peer Educator training.

After completing the 4 advanced training Modules (Advanced Modules 16-19), you will be able to:

1. Provide basic counseling on conception, childbearing and family planning and make appropriate referrals
2. Understand the relationship between nutrition and HIV and provide practical nutrition advice to clients and their families
3. Provide more in-depth information to clients on caring for their HIV-exposed and HIV-infected babies and children
4. Organize and lead PLHIV support group meetings

SESSION 1.3: Learning Needs Assessment

The trainers will conduct a learning needs assessment to find out more about what you already know and what to focus on in the training to best prepare you to become a Peer Educator.



MODULE 2:

Roles and Responsibilities of Peer Educators as Part of the Multidisciplinary HIV Care Team



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Understand the goals and objectives of the Peer Education program, and the roles of key partners in the program
- Have a common understanding of the many roles Peer Educators can play in improving access and adherence to HIV prevention, care and treatment services
- Understand the day-to-day activities and expectations of Peer Educators
- Explain who is normally part of a multidisciplinary HIV care team and how the team works together



CONTENT:

- Session 2.1: Introduction: Overview of the Peer Education Program
- Session 2.2: Understanding Peer Education
- Session 2.3: Roles and Responsibilities of Peer Educators
- Session 2.4: Peer Educators as Part of a Multidisciplinary Care Team
- Session 2.5: Module Summary

SESSION 2.1: Introduction: Overview of the Peer Educator Program

Please take your own notes for this session.

SESSION 2.2: Understanding Peer Education

Key terms:

- A **peer** is a person who belongs to the same social group as another person or group. The social group may be based on age, sex, sexual orientation, occupation, social group or status, health status or other factors.
- **Education** refers to the development of a person's knowledge, attitudes, beliefs or behavior, as a result of the learning process.
- **Peer education** is the transfer of knowledge and skills to members of a social group by others within the same group.
- **HIV Peer Educators** are people who are themselves enrolled in HIV prevention, care and/or treatment services; have a good understanding of HIV, care, treatment, PMTCT and adherence; and have the skills to help other clients with their care and treatment. Usually, Peer Educators are volunteers.

Some of the good things about Peer Education programs:

- **People trust others in a similar situation:** Clients have the opportunity to discuss their personal circumstances in a safe environment with someone who relates to their situation.
- **Improved adherence:** Peer Educators can support clients' adherence to care and treatment because they may have a deeper understanding of what the client is going through.
- **Community participation:** Peer Educators can play a role in community mobilization, decreasing stigma and increasing support for PLHIV.
- **Empowerment of individuals:** Peer Educators can increase people's confidence that they can make good decisions and take action.
- **Job opportunities:** Training and work experience may improve Peer Educators' job opportunities in the formal economic sector.
- **Improved service quality:** Peer Educators can help to improve the overall quality and effectiveness of health care programs by giving feedback to the clinic about the needs of patients and communities.
- **Task shifting and saved time:** Peer Educators can help free up the time of doctors, nurses and social workers by providing basic education and counseling at the clinic.
- **Increased access:** Peer Educators can gain access to groups that are otherwise difficult to reach and encourage them to seek prevention, care and treatment services. Peer Educators can follow up with clients who have missed appointments since they are often from the same communities.



SESSION 2.3: Roles and Responsibilities of Peer Educators in Family-focused HIV Programs

Common tasks of Peer Educators:

- Spend time working in the health facility and also in the community
- Participate as an active member of the multidisciplinary care team, including attending multidisciplinary team meetings
- Openly disclose his or her HIV-status to clients and community members
- Conduct group education sessions, in coordination with other members of the multidisciplinary care team, including pre-ART and PMTCT sessions
- Conduct one-on-one counseling sessions with clients, caregivers and treatment supporters on a range of topics
- Help prioritize pregnant women for care and treatment services and follow up mothers and babies after delivery
- Help clients with referrals
- Act as a link between clients and the multidisciplinary care team
- Implement family-focused care by asking all clients about family members
- Help identify and follow-up with clients who do not return to the clinic for appointments
- Link clients and caretakers with community-based care and support services
- Conduct community outreach and education activities
- Lead support group meetings, and where none exist, form a support group
- Keep basic records and compile monthly reports.



SESSION 2.4: Peer Educators as Part of the Multidisciplinary Care Team

Peer Educators are part of a multidisciplinary HIV care team

No one person, no matter how skilled, can provide all the care and support that a client needs. This is why it is important for HIV prevention, care and treatment programs to have a multidisciplinary team that looks after every client.

Multidisciplinary means a mix of different professionals and volunteers – doctors, nurses, counselors, peer educators and others – working as members of a team.

Depending on your specific site, members of the HIV care team can include:

- Doctors
- Nurses
- Pharmacists
- Lab technicians
- Phlebotomists
- Counselors or social workers
- Peer Educators and lay counselors
- Data clerks/information officers
- Other clinic staff such as receptionists, cleaners and security guards
- Site coordinators or advisors
- Community-based workers and organizations
- Faith-based organizations and spiritual leaders
- Family members and friends
- The clients themselves



Remember:

- Multidisciplinary care teams need to work together, communicate with one another and respect each individual's contribution to improving the health and well-being of the client.
- If one "link in the chain" is missing, the client will not get the quality care they need in the hospital, in the community or in the home.
- It is important that multidisciplinary care teams plan ways to work together, such as by meeting regularly.

SESSION 2.5: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- You are an important provider and recipient of HIV prevention, care and treatment services.
- You will have many day-to-day roles and responsibilities to support clients and their families to access and adhere to prevention, care and treatment services.
- You make up an important part of the multidisciplinary care team and complement the work of other team members.

MODULE 3:

HIV and Reproductive Health Basics



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Discuss common myths and rumors about HIV and AIDS
- Discuss the difference between HIV and AIDS
- Discuss how HIV affects the immune system
- Identify sexual and reproductive body parts in men and women
- Describe the basic function of sexual and reproductive body parts in men and women
- Describe the ways HIV is transmitted
- Talk about ways HIV can be prevented
- Understand the major pieces of comprehensive HIV care and support and why each is important to PLHIV and their families
- Understand and incorporate the idea of "family-focused care" into your work



CONTENT:

- Session 3.1: Introduction
- Session 3.2: The Difference between HIV and AIDS
- Session 3.3: From HIV to AIDS - What Does HIV Do in the Body?
- Session 3.4: Sexual and Reproductive Body Parts and their Functions
- Session 3.5: HIV Transmission and Prevention
- Session 3.6: Introduction to Comprehensive, Family-Focused Care
- Session 3.7: Module Summary

SESSION 3.1: Introduction

Please take your own notes for this session.



SESSION 3.2: The Difference between HIV and AIDS

HIV stands for **Human Immunodeficiency Virus**:

- H** Human (refers to us)
- I** Immunodeficiency (lack of protection from getting sick)
- V** Virus (a type of germ in the body)

AIDS stands for **Acquired Immune Deficiency Syndrome**:

- A** Acquire (to get something)
- I** Immune (the way the body fights disease)
- D** Deficiency (not enough of something – in this case a lack of protection from getting sick)
- S** Syndrome (a group of symptoms or illnesses)

Basic Definitions

- **HIV** is a virus that gets into the body.
- **HIV-infected** is when HIV has entered a person's body. People who are HIV-infected might be very healthy and may not have any signs of illness for a long time, but they can pass the virus to others. The only way to tell if a person has HIV is with a blood test, not by looking at them.
- **AIDS** is a group of serious illnesses and opportunistic infections that develop after more and more HIV grows in the body and the body is too weak to fight back.
- **Opportunistic infections (OIs)** include pneumonia, tuberculosis, diarrhea and other infections. OIs can make people living with HIV – especially people not taking ART – sick because their body's immune system is weakened. OIs can occur before and after HIV has developed into AIDS.

SESSION 3.3: From HIV to AIDS - What Does HIV Do in the Body?

How do people know if they have HIV or AIDS?

- HIV infection can be diagnosed with a simple blood test (or, where available, an oral swab). Remember, you cannot tell if a person has HIV by looking at her or him!
- AIDS is diagnosed by clinical and lab tests done at the hospital or clinic (usually using blood samples). Where these tests are not available, a doctor can diagnose AIDS after examining a person's health and taking a history.

What does HIV do to the immune system?

- The immune system is the body's natural defense against diseases.
- The human body is made up of many tiny cells. Cells are the basic building blocks in our body – they give us energy and keep us healthy and alive.
- In a healthy person, the immune system fights off diseases that enter the body to keep the person healthy. A type of cell called the CD4 cell helps the body fight infections.
- HIV enters the blood stream and starts to attack CD4 cells.
- HIV reproduces itself in the CD4 cells. These are the same cells that the body uses to fight infection.
- For a while, the CD4 “guardian angel” cells keep HIV weak in the body.
- After some time, HIV becomes stronger than the CD4 cells and keeps making more of the virus and attacking more of the CD4 cells. HIV keeps reproducing and there is more and more of it in the body.
- This makes people more likely to get infections and it is harder for the body to fight these infections because it does not have as many CD4 cells, or “guardian angel cells.”
- Eventually, the HIV attacks so many of the CD4 cells that there are not enough to fight back. The body is attacked by infections and germs that the person cannot fight off.
- These infections (called opportunistic infections, or OIs) are what eventually make people develop AIDS and, without treatment, die.

CD4 cells are our “guardian angels” that protect our bodies from infections that can make us sick.

The higher a person's CD4 cell count, the better.

Making sense of CD4 test results:

- PLHIV should get a blood test to see the levels of CD4 cells when they first know they are HIV-positive and then regularly after that time (usually every 6 months).
- Healthy people with good immune systems have CD4 cell counts between 500-1500. People do not need to start taking ART when the CD4 count is this high but they should take cotrimoxazole (CTX) when they are advised to do so by health care workers.
- When people's CD4 cell count goes below about 500, they may start getting opportunistic infections that the body has trouble fighting.
- When people's CD4 cell count goes below a certain number, they will sometimes become quite sick and now need ART to stay healthy. The WHO recommends that all PLHIV with a CD4 count of 350 or less should begin ART (check your national guidelines).
- It is important to get CD4 tests on a regular basis because usually the CD4 cell count will fall first and then the person will get sick a bit later. If people know their CD4 cell count is dropping, they can take steps to avoid getting sick, like taking ART.

Stages of HIV and AIDS:

1. **HIV enters:** Virus enters the body.
2. **HIV-positive, high CD4 cell count, no major symptoms:** People carry HIV and can spread it to others, but feel healthy and have a lot of CD4 cells. People will not know they are HIV-positive unless they get tested. This stage can last up to 10 years in adults but lasts a much shorter time in children, who usually become sick quickly.
3. **HIV-positive, fewer CD4 cells, some symptoms:** People are healthy most of the time, but may start losing weight and getting sick more often as they have less and less CD4 cells. Also takes longer to feel healthy after being sick.
4. **AIDS, very few CD4 cells, lots of symptoms and infections:** People have many opportunistic infections and a hard time getting rid of them, CD4 cell count drops below 200 and amount of HIV increases in the body.



HIV Infection in Babies and Children

- The way HIV affects the immune system in babies and children is similar to adults.
- But babies and children with HIV usually progress from HIV to AIDS very quickly if they are not on ART.
- The CD4 cell count cut-offs for babies and children are different from those for adults. Also, for children under 5 years old, CD4% is used instead of CD4 cell count.

There is more on HIV in infants and children in *Module 7* and *Advanced Module 18*.

SESSION 3.4: Sexual and Reproductive Health Body Parts and Their Functions

Sex is a normal part of life, and we need to be comfortable talking about sex and reproduction openly with clients and in the community.

We may have different religious and cultural beliefs than some of our clients, but it is important never to judge other people because of their sexual behavior – even if we do not agree with the behavior.

Remember: People define sex differently, but it is important NEVER to judge people because of their sexual views or behaviors!

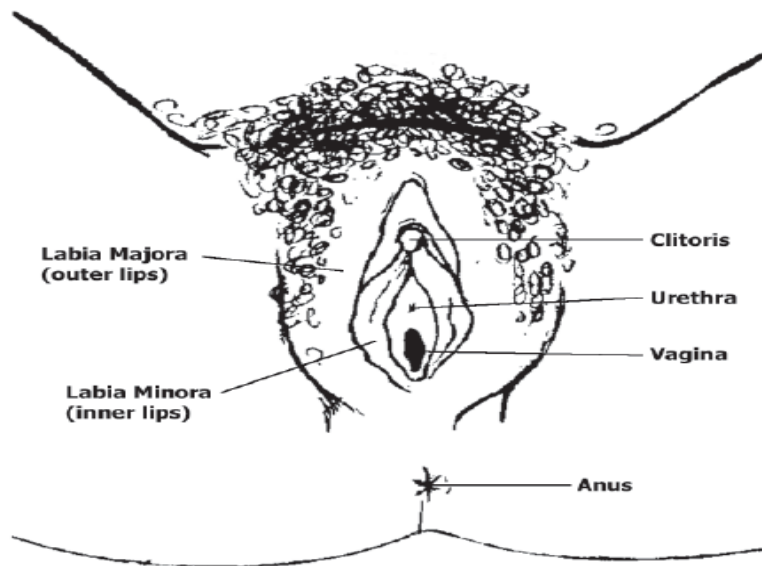
- There are many different ways people have sex.
- Also, some people have sex with men, some people with women, and some people with both men and women.

Female sexual and reproductive body parts

External female body parts (parts you can see):

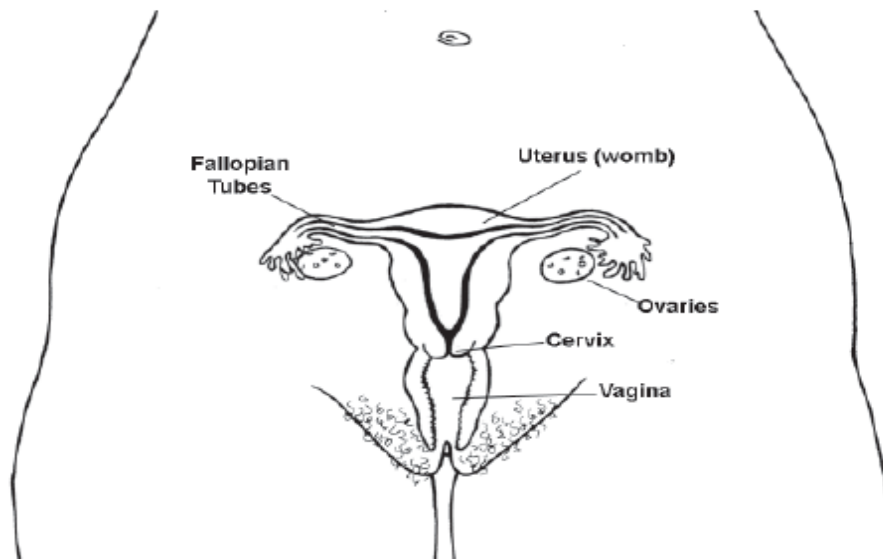
- **Urethra:** where urine (pee) comes out of the body
- **Vagina:** where the penis or fingers enter during sex and also where a baby comes out. The vagina is the opening to the cervix and the uterus, which is where babies grow.
- **Anus:** where stool (poop) comes out of the body and where the penis or fingers enter the body during anal sex
- **Labia minora** and **labia majora:** sometimes called the “lips” around the vagina and urethra
- **Clitoris:** where women can have strong pleasure and orgasm

Some women may have experienced genital cutting, where the clitoris and labia may have been removed in part or completely. Some women may also have had parts of their vaginas sewn up. It is important not to judge women who have or have not undergone these procedures.



Internal female body parts (parts you cannot see):

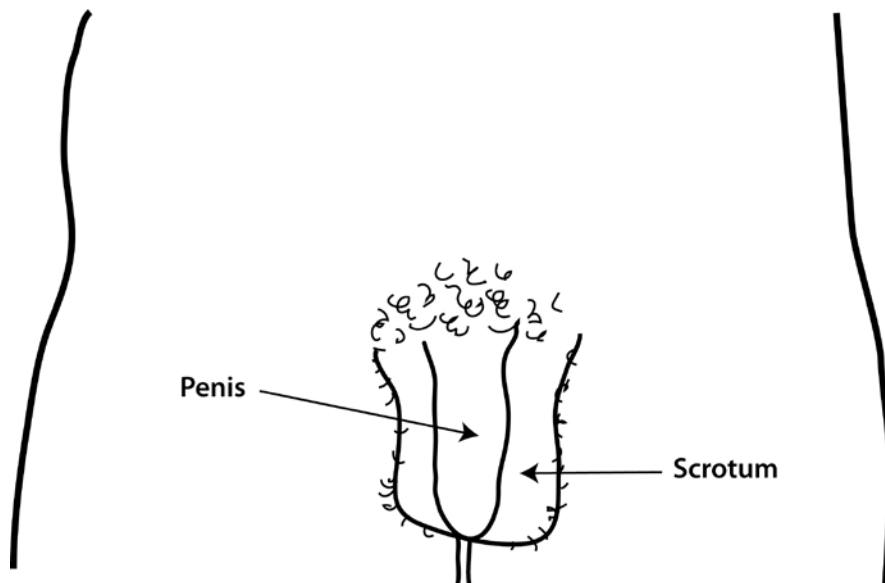
- **Uterus or womb:** where a baby grows and where monthly bleeding comes from
- **Ovaries:** where a woman's eggs are stored
- **Fallopian tubes:** attached to the uterus. The eggs travel through the fallopian tubes to get from the ovaries to the uterus.
- **Cervix:** "mouth" of the uterus. Sperm enters the uterus through the cervix and the baby comes out of the uterus through the cervix.
- **Vagina:** where the penis or fingers enter during sex and also where a baby comes out. The vagina is the opening to the cervix and the uterus (where babies grow).



Male sexual and reproductive body parts

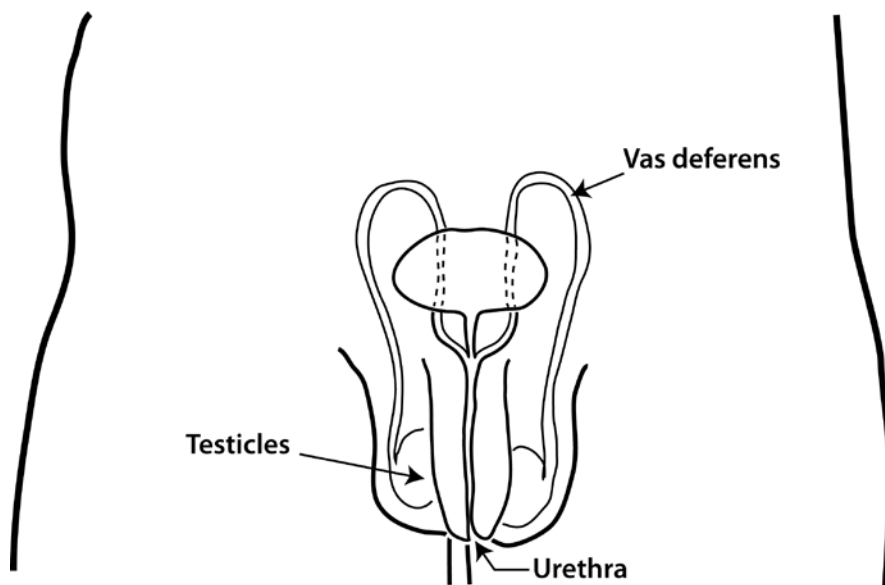
External male body parts (parts you can see):

- **Penis:** the main body part for sex and pleasure. The penis delivers the sperm that can make a woman pregnant during sex. The tip of the penis may have foreskin or, if the man has been circumcised, there will be no foreskin.
- **Scrotum:** sack that holds the testicles (balls)
- **Anus:** where stool (poop) comes out of the body and where the penis or fingers enter the body during anal sex. Note that the anus is not shown in the diagram below, but is located in the same place as in a female.



Internal male body parts (parts you cannot see):

- **Testicles or balls:** where sperm are made and stored. Sperm live in a fluid called semen (cum), which is what comes out when a man ejaculates. Semen can contain STIs and HIV.
- **Vas deferens:** attached to the testicles. Sperm travel through these tubes to get to the urethra.
- **Urethra:** the opening on the end of the penis where urine (pee) and semen (cum) containing sperm come out. Note that urine and semen do NOT come out at the same time.



SESSION 3.5: HIV Transmission and Prevention

Fluids that do and do not transmit HIV

HIV is most easily transmitted in these body fluids:

- Semen (cum)
- Vaginal fluids
- Blood
- Birthing fluids
- Breast milk

HIV is usually NOT transmitted in these body fluids – unless there is also blood:

- Urine (pee)
- Feces (poop)
- Saliva (spit)
- Sweat
- Mucous (snot)
- Pus

Ways HIV is passed from person to person

Sexual transmission:

- Unprotected sexual intercourse (no condom) with a person living with HIV – this includes male-female sex, male-male sex, and female-female sex
- Direct contact with body fluid of infected person (blood, semen, vaginal secretions)
- Note that sexual transmission accounts for 87% of HIV transmission worldwide.
- HIV transmission is more likely if:
 - One or both people have advanced HIV infection or AIDS
 - One or both people have just recently been infected with HIV

Mother-to-child transmission (MTCT):

- During pregnancy
- During labor and delivery (most MTCT happens at this stage)
- During breastfeeding
- Note that mother-to-child transmission is more likely if the mother has advanced HIV infection or AIDS, or if she is not taking ARVs. MTCT is also more likely if the mother is infected with HIV close to or during pregnancy and breastfeeding.

Blood-to-blood transmission:

- Transfusion with infected blood
- Direct contact with infected blood or body fluids

Use of unsafe sharp objects:

- Injecting drugs and sharing needles with an infected person
- Piercing, tattooing or cutting with unclean knives or other objects

Ways HIV is NOT transmitted:

- Sharing food or a drinking cup
- Hugging
- Kissing
- Shaking hands
- Coughing or sneezing
- Being near a PLHIV
- Sharing a latrine/toilet
- Using condoms
- Mosquitoes or insect bites – even if they carry human blood, HIV cannot live outside of humans

HIV prevention

Peer Educators have an important role to play in teaching people how to prevent HIV. Their efforts will benefit themselves, their families and their communities.

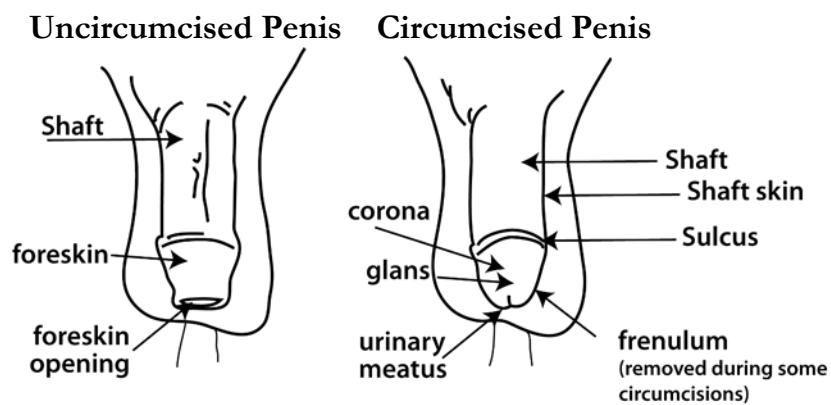
The ABCs of preventing sexual transmission:

- A:** Abstinence – this approach works best for young people
- B:** Be faithful to your partner (whether or not your partner is living with HIV or is HIV-negative)
- C#1:** Consistent and correct condom use (male or female) – every time – for “dual protection” against pregnancy and HIV
- C#2:** Circumcision – male circumcision can reduce the risk of sexual HIV transmission from women living with HIV to HIV-negative men (see the box below)
- D:** Delay sexual debut
- E:** Early and complete treatment of STIs
- F:** Free and open communication between partners about sex
- G:** Get to know your HIV-status



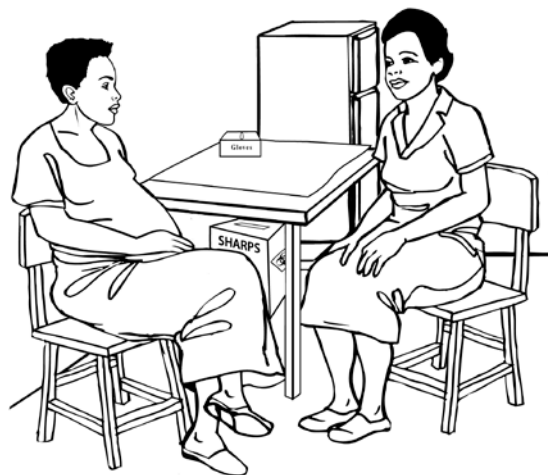
Male circumcision can reduce the risk of female-to-male sexual transmission of HIV, but should not be used as the only risk-reduction method.

- People still need to use condoms and get tested for HIV even if the man is circumcised.
- Circumcision involves removal of the foreskin on the penis, as shown in the drawing below. Circumcisions can be performed on babies or on adults but should only be done by trained doctors at a health facility.
- Circumcision has NOT been shown to reduce the risk of male-to-female sexual transmission of HIV.



Prevention of mother-to-child transmission (PMTCT):

- Help prevent unwanted pregnancies in the first place (this means talking with clients about family planning services and helping couples communicate about family planning).
- Help women and men get tested for HIV before deciding to become pregnant.
- Make sure all women get good, early antenatal care.
- Make sure women receive HIV counseling and testing as a routine part of antenatal care.
- Help mothers and family members learn about PMTCT through education and counseling.
- Work with clients to practice safer sex during and after pregnancy by using condoms.
- Work with families and communities to reduce stigma against pregnant women with HIV.
- Make sure that all mothers living with HIV take ARVs during pregnancy and that all babies get ARVs after they are born.
- Help enroll pregnant women on ART if they are eligible (during pregnancy and ongoing).
- Help mothers and families plan to deliver at a health facility.
- Counsel mothers on safe infant feeding – exclusive breastfeeding (no other fluids, foods or herbs at all, including water) OR exclusive formula feeding (only where it is safe and feasible) for as long as possible – 6 months is best. Then when the baby is 6 months old, counsel mothers on giving others foods along with breast milk OR formula.
- Help mothers prevent and treat breast infections.
- Make sure mothers and their babies get regular follow-up care at the clinic and at home.



Prevention of blood-to-blood transmission:

- Make sure all blood and blood products have been tested for HIV.
- Always follow infection-prevention procedures at clinics and during home care.
- Use protective equipment (like aprons, gloves, eye shields).
- Throw out needles and other sharp instruments directly into sharps containers.
- Clean and disinfect all surfaces with a mix of bleach and water.



Prevention of unsafe sharp object use:

- Do not share blades or knives in traditional ceremonies involving blood or cuts on the skin.
- Do not inject drugs or share needles. If you have to, be sure to clean them every time with bleach mixed with water.
- Do not share piercing or tattooing tools. If you have to, be sure to clean them with bleach solution every time.

SESSION 3.6: Introduction to Comprehensive, Family-focused Care

The goals of comprehensive HIV care are to:

- Improve the quality of life of PLHIV
- Improve the lives of families and communities affected by HIV
- Prevent further spread of HIV

Comprehensive care includes:

- HIV testing and counseling
- Early infant diagnosis for babies
- Prevention, diagnosis and treatment of OIs and other illnesses, such as TB
- ARVs and ART
- PMTCT, antenatal and reproductive health services
- Support for exclusive breastfeeding
- Regular immunizations for babies
- Ongoing monitoring of health status
- Follow-up of HIV-exposed babies
- Hospitalization for those who are very sick
- Counseling on adherence and positive living
- Couples counseling and disclosure counseling
- Referral and follow-up
- Home-based care (HBC)
- Malaria prevention and treatment
- Nutritional support
- Access to clean water
- Psychological support
- Social and spiritual support
- Material or economic support (money, clothes, food, etc.)
- Legal support
- End-of-life care, including pain management
- Care and support for family members, including children

Family-focused care:

- Family-focused care means that we think about the needs of all family members, and not just those of the client.
- It also means thinking about the linkages between the individual client, that client's family and the community as a whole.
- Peer Educators should make it a normal practice to ask clients about their family members and partners and encourage them to bring these people to the clinic for services.

Remember: People's day-to-day lives include their families, partners, friends and other community members, so it is important to ask about them at every visit!



Note: Some of the preceding information in this Module was adapted from the following sources:

Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). *Community Home-based Care for People and Communities Affected by HIV/AIDS: A Comprehensive Training Course for Community Health Workers*. Watertown, MA: Pathfinder International.

SESSION 3.7: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- You should know the facts about HIV and AIDS and help dispel myths and rumors among clients and in the community.
- People can be healthy and HIV-infected for many years before getting sick and developing AIDS. But they can still spread HIV to other people so it is important for people to know their HIV-status by getting tested.
- HIV attacks a person's immune system and makes it hard for the body to stay healthy and fight off diseases and infections.
- HIV attacks the CD4 cells in the body. The CD4 cells are like guardian angels that protect the body from illnesses. Eventually, HIV attacks so many of the CD4 cells that the body cannot fight infections anymore and the person develops AIDS.
- Babies and children with HIV develop AIDS much faster than adults.
- Health care workers can tell if someone needs to start ART by looking at the number of CD4 cells they have (through a blood test). The WHO recommends that all PLHIV with a CD4 count of 350 or less start ART. The test can also be used to see if the treatment is working.
- The higher a person's CD4 cell count, the better.
- You need to talk openly about sexuality with people and help them practice safer sex.
- It is very important that you know all the ways HIV can and cannot be passed from person to person and that you help people prevent new infections.
- HIV lives in semen, vaginal and birthing fluids, blood and breast milk.
- HIV can be passed through unsafe sex with a person living with HIV, from a mother living with HIV to her child, from blood-to-blood contact, and from sharing needles, knives and other sharp objects.
- You should know all the pieces of comprehensive care and help clients and their families understand and access these services over time.

MODULE 4:

Communication and Counseling Skills



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Reflect on your own attitudes, values and beliefs and discuss how these may affect communication with others
- Describe the importance of effective communication and counseling skills in PMTCT and HIV care and treatment settings
- Discuss the basic principles of counseling and challenges to implementing these principles
- Discuss what is meant by shared confidentiality and why it is important
- Demonstrate the 7 key counseling and communication skills
- Know how to communicate effectively in front of a group



CONTENT:

- Session 4.1: Introduction: Our Own Values and Attitudes
- Session 4.2: What Is Counseling?
- Session 4.3: Key Counseling Skills for Peer Educators
- Session 4.4: Communicating to Groups
- Session 4.5: Classroom Counseling Practicum
- Session 4.6: Module Summary

SESSION 4.1: Introduction: Our Own Attitudes and Values

Key terms:

- **Attitudes and values** are feelings, beliefs and emotions about a fact, thing, behavior or person.
- **Prejudices** are negative opinions or judgments made about a person or group of people before knowing the facts.
- **Being self-aware** means knowing yourself, how other people view you and how you affect other people.

As a Peer Educator, you should always try to:

- Think about the issues related to your own attitudes, values and prejudices, and how they may affect your ability to help provide effective counseling and support services to clients and community members.
- Be sensitive to the culture, values and attitudes of your clients, even if they are different from your own.
- Learn some of the main culture, values and attitudes of the people with whom you are working at the facility and in the community.
- Examine your own values and beliefs in order to avoid prejudice and bias. Try to make all people feel comfortable and that it is “safe” to talk with you openly and honestly.



Remember: Prejudice, stigma and negative attitudes drive the HIV epidemic, so you should avoid them!

SESSION 4.2: What Is Counseling?

What is counseling?

- Counseling is a two-way communication process that helps people look at their personal issues, make decisions and plan how to take action.
- The aim of counseling is not to solve every problem but to improve clients' coping skills.
- Counseling helps people talk about, explore and understand their thoughts and feelings.
- Counseling helps people work out what they want to do and how they will do it.

Counseling includes:

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)
- Listening attentively
- Helping people tell their stories without fear of stigma or judgment
- Giving correct and appropriate information
- Helping people to make informed decisions
- Exploring options and alternatives
- Helping people to recognize and build on their strengths
- Helping people to develop a positive attitude to life
- Respecting everyone's needs, values, culture, religion and lifestyle

Counseling does NOT include:

- Solving someone's problems
- Telling someone what to do
- Making decisions for another person
- Blaming the person
- Interrogating or questioning the person
- Judging the person
- Preaching or lecturing to a person
- Making promises that cannot be kept
- Imposing one's own beliefs on another person

Remember: Some clients may need professional counseling services. You should always talk with other members of the multidisciplinary team if they have a difficult case or are unsure what to do.

You should refer clients to a trained counselor right away if:

- They are very depressed
- They are very anxious
- They are thinking about suicide
- Things are not getting better after counseling sessions
- You are unsure what to do

Shared confidentiality:

In order for clients to trust you with their feelings and problems, it is important for them to know that this information will be kept confidential.

- This means that you and other members of the multidisciplinary care team will not tell other people what the client says, that the client is living with HIV or any other information about the client.
- Confidentiality is especially important in HIV programs because of the stigma surrounding HIV and discrimination against PLHIV in the home, at work, at school and in the community.

Shared Confidentiality

Shared confidentiality means that information about a client is disclosed to another person involved in the client's care – a member of the multidisciplinary team, a community health worker, a treatment supporter, etc. – ***with the client's consent.***

PRIVACY is a very important part of quality counseling. Even though space is a challenge in most HIV prevention, care and treatment programs, it is important that the multidisciplinary team works together to create private areas where counseling can take place. It is important that other people cannot see or hear a private counseling session and that there are no interruptions while you are counseling a client.

You need to assure clients that you will not discuss their concerns, health or problems with people in the community.

SESSION 4.3: Key Counseling Skills for Peer Educators

These are 7 essential skills that you should practice and use:

Skill 1: Use helpful non-verbal communication.

Skill 2: Ask open-ended questions.

Skill 3: Actively listen and show interest in your client.

Skill 4: Reflect back what your client is saying.

Skill 5: Show empathy, not sympathy.

Skill 6: Avoid judging words.

Skill 7: Help your client set goals and summarize each counseling session.

Skill 1: Use helpful non-verbal communication

- Make eye contact.
- Face the person.
- Be relaxed and open with your posture.
- Sit next to the person you are counseling. Do not sit behind a desk!
- Dress neatly and respectfully.
- Use good body language – nod your head and lean forward.
- Smile.
- Do not look at your watch, the clock or anything other than the person you are talking with.
- Try not to write during a counseling session, unless you are recording key information for the client to take home or for your records. Turn your mobile phone off and never take calls during a counseling session.

Skill 2: Ask open-ended questions

Closed-ended questions:

Closed-ended questions can be answered with a one-word or short answer. Examples of closed-ended questions are: “How old are you?” “What is your CD4 count?” and “Do you have children?”

Closed-ended questions are good for gathering basic information at the start of a counseling or group education session. They should not be used too much because they can make it seem that you are being too direct. They are not helpful in getting at how the client is really feeling.

Open-ended questions:

Open-ended questions cannot be answered in one word. People answer open-ended questions with more explanation. Examples of open-ended questions are: “Can you tell me more about your relationship with your partner?” or “How does that make you feel?”

Open-ended questions are the best kind to ask during counseling and group education sessions. They help clients explain their feelings and concerns and can help you get the information you need to help clients make decisions.

Skill 3: Actively listen and show interest in your client

- Listen in a way that shows respect, interest and empathy.
- Show the person you are listening by saying “okay” or “mmm hmm.”
- Use a calm tone of voice – not directive.
- Listen to the content of what the person is saying – are there themes?
- Listen to how they are saying it – do they seem worried, angry, etc.?
- Allow the person to express her or his emotions. For example, if she is crying, allow her time for this.
- Never judge a person or impose your own values.
- Keep distractions to a minimum and try to find a private place to talk.
- Do not do other tasks while talking to a person.
- Do not interrupt the person.
- Ask questions or gently probe if you need more information.
- Use open-ended questions that cannot be answered with “yes” or “no.” For example, “Can you tell me a bit more about that?”



Skill 4: Reflect back what your client is saying

Reflecting is when you repeat back the main themes and feelings of what your client communicated to you.

Reflecting also:

- Provides feedback to the person and enables the person to confirm that she or he has been listened to, understood and accepted
- Helps promote discussion
- Shows understanding of the person's story
- Helps you check if you have understood
- Provides a good alternative to always responding with questions
- Can reflect the content of what is being said, as well as the feelings the person has about the situation
- For example, after the person talks for awhile about her or his feelings and situation, you can say, "So I sense that you feel _____ because _____." Or, "I'm hearing that when _____ happened, you didn't know what to do."

Skill 5: Show empathy, not sympathy

Empathy or empathizing is a skill used in response to an emotional statement.

- Empathy shows an understanding of how the client feels, and encourages the client to discuss the issue further.
- Empathy is different than sympathy. When you sympathize, you feel sorry for a person and look at her or him from your own point of view.
- For example, if the client says, "My baby wants to feed very often and it makes me feel so tired," you could respond by saying, "You are feeling very tired all the time then?" If you respond by saying, "I know how you feel. My baby also wanted to feed often and I was exhausted!" this is sympathizing because attention is on the Peer Educator and her experiences rather than on the client.

Skill 6: Avoid judging words

- Judging words are words such as "right," "wrong," "well," "badly" and "properly." Using the words "these people" or "those people" to describe people living with HIV is also judgmental.
- If you use these words when asking questions, the client may feel that she or he is wrong or that there is something wrong with her or his actions or feelings.
- However, sometimes you need to use the "good" judging words to build a client's confidence.

Skill 7: Help your client set goals and summarize each counseling session

Goal-setting skills:

Towards the end of a counseling session, you can work with your client to come up with “next steps” to solve their issues in the short- and long-term.

Next steps and goals:

- Should be developed jointly by you and your client
- Can empower clients to achieve what they want by agreeing to realistic short- and long-term goals and actions
- Provide direction and must be results-oriented
- Must be clear enough to help people measure their own progress (people feel good when they achieve something they’ve set out to do)
- To start, you could say, “Okay, now let’s think about the things you will do this week based on what we talked about.”

Summarizing skills:

You can summarize what has been communicated during a counseling session and clarify the major ideas and next steps.

Summarizing:

- Can be useful in an ongoing counseling session or in making sure you are clear on important issues raised during a counseling session
- Is best when both you and your client participate and agree with the summary
- Provides an opportunity for you to encourage your clients to examine their feelings about the session
- You could say, “I think we’ve talked about a lot of important things today. (List main points.) We agreed that the best next steps are to _____. Does that sound right? Let’s plan a time to talk again soon.”

SESSION 4.4: Communicating to Groups

As a Peer Educator, you will be asked to conduct one-on-one counseling as well as lead group education sessions in your work at clinics and in the community. While many of the good practices used in counseling can also be used in group education sessions, there are a few differences you should be aware of.

In general, these are the major differences between counseling and group education:

One-on-One Counseling	Group Education
Confidential (or shared confidentiality)	Not usually confidential within the group
Usually one-on-one or with couples	With small or large groups of people, who may not know each other
Based on needs of individual client(s)	Usually has a pre-set curriculum/content areas
Focused on specific actions and feelings of the client(s)	More general and less personalized

Important points to remember when speaking in front of a group:

- Be sure to plan the group session ahead of time and practice what you are going to say.
- Do not stand behind a desk or other furniture.
- Encourage participants to sit in a semi-circle to make it more comfortable to talk and less like a classroom. You should be part of the semi-circle. Make sure you can make eye contact with everyone and that no one is staring at your back.
- Speak loudly enough so everyone can hear you clearly, but so that you are not shouting.
- Start by explaining the goals and content areas of your topic and ask if there are any questions.
- Lead an introductory activity (have people introduce themselves or say something about their family) so participants feel more comfortable with one another.
- Interact with participants and engage them by moving around the room, asking questions and asking people to share personal stories/concerns.
- Acknowledge that the people attending will know something about the topic being discussed. Encourage them to share what they know.
- Make eye contact with all members of the group.
- Check in regularly to make sure participants are engaged and understand the messages.
- Pay attention to people who seem shy or quiet, and emphasize that everyone's personal experiences, questions and concerns are important.
- Use visual aids and avoid lecturing.
- Encourage participants to speak with you in private afterward if they have concerns they do not want to share with the group.
- Ask group participants to summarize what they have learned and actions they will take at the end.
- Always leave time for questions and re-explain anything that was not understood completely.



SESSION 4.5: Classroom Counseling Practicum

Case Study 1:

M___ is a client you see regularly at the ART clinic. He tells you that he has a male partner that he sees on the weekends. He is very worried that his family and co-workers will find out.

Case Study 2:

S___ meets with you after testing positive for HIV. He is very angry and tells you the test must be wrong because he has only had sex with 2 people in his whole life and they were very healthy.

Case Study 3:

N___ is pregnant with her first baby and has found out she has HIV. She says she is frightened that her husband might find out when he sees these medicines from the hospital.

Case Study 5:

B___ is living with HIV. She had her second child about 7 weeks ago. She comes to the clinic today and is very frightened that the baby is going to get sick and die.

Case Study 4:

L___ is enrolled in the care and treatment program and started taking ART about 4 months ago. She starts crying because she was not able to get enough money to pay for the bus to the hospital last month, so she has stopped taking her ARVs.

Note: Some of the preceding information in this Module was adapted from the following sources:

WHO & CDC. (2008). *Prevention of Mother-to-Child Transmission of HIV Generic Training Package: Trainer Manual*.

SESSION 4.6: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- Our own attitudes, values and prejudices should not be a part of communication and counseling with clients and other community members.
- Counseling is a way of working with people to understand how they feel and help them decide what they think is best to do in their situation.
- You are not responsible for solving all of the client's problems.
- Your role in counseling is to support and assist your client's decision-making process.
- There can be many challenges to providing quality counseling in PMTCT and ART clinics, including lack of time and lack of private counseling space.
- It is important for clients to know that what they say will be kept private. You should practice shared confidentiality.
- You should work with the multidisciplinary care team to ensure that there is private counseling space available and that counseling sessions are not interrupted for any reason.
- These are the 7 key listening and learning skills you should always use:
 - Use helpful non-verbal communication.
 - Ask open-ended questions.
 - Actively listen and show interest in your client.
 - Reflect back what your client is saying.
 - Show empathy, not sympathy.
 - Avoid judging words.
 - Help your client set goals and summarize each counseling session.
- You will also be expected to speak with groups and practice good group communication skills.

APPENDIX 4A: Counseling and Communication Checklist

Counseling and Communication Skills Checklist		
Skill	Specific Strategies, Statements, Behaviors	(√)
Skill 1: Use helpful non-verbal communication	• Make eye contact.	
	• Face the person (sit next to her or him) and be relaxed and open with posture.	
	• Use good body language (nod, lean forward, etc.).	
	• Smile.	
	• Do not look at your watch, the clock or anything other than the client.	
	• Do not write during the session.	
	• Other (specify)	
Skill 2: Ask open-ended questions	• Use open-ended questions to get more information.	
	• Ask questions that show interest, care and concern.	
	• Other (specify)	
Skill 3: Actively listen and show interest in your client	• Nod and smile. Use encouraging responses (such as “yes,” “okay” and “mmm hmm”).	
	• Use a calm tone of voice that is not directive.	
	• Allow the client to express emotions.	
	• Do not interrupt.	
	• Other (specify)	
Skill 4: Reflect back what your client is saying	• Reflect emotional responses back to the client.	
	• Other (specify)	
Skill 5: Show empathy, not sympathy	• Demonstrate empathy: show an understanding of how the client feels.	
	• Avoid sympathy.	
	• Other (specify)	
Skill 6: Avoid judging words	• Avoid judging words such as “good,” “bad,” “correct,” “proper,” “right,” “wrong,” etc.	
	• Use words that build confidence and give support (e.g., recognize and praise what a client is doing right).	
	• Other (specify)	
Skill 7: Help your client set goals and summarize each counseling session	• Work with the client to come up with realistic “next steps.”	
	• Summarize the main points of the counseling session.	
	• Other (specify)	

Note: This checklist was adapted from: WHO & CDC. (2008). *Prevention of Mother-to-Child Transmission of HIV Generic Training Package: Trainer Manual*

MODULE 5:

Comprehensive HIV Care



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Discuss the key clinical and non-clinical components of comprehensive HIV care for clients and their families
- Explain your role in HIV testing and counseling
- Explain the difference between comprehensive HIV care and ART treatment
- List the most common opportunistic infections (OI) and complications and explain their symptoms, prevention and treatment
- Describe your role in TB education, prevention, screening and treatment
- Identify and refer possible TB cases to the clinic using the TB screening tool
- Accompany clients to referred services and explain why these services are necessary



CONTENT:

Session 5.1: Introduction: Review of Family-focused Care

Session 5.2: HIV Counseling and Testing: The Entry Point to Care

Session 5.3: HIV Care and HIV Treatment: What is the Difference?

Session 5.4: Prevention and Treatment of Opportunistic Infections and Other Complications

Session 5.5: Tuberculosis Education, Screening and Referral

Session 5.6: Helping with Referrals to Ensure Comprehensive Care

Session 5.7: Module Summary

SESSION 5.1: Introduction: Review of Family-focused Care

The goals of comprehensive HIV care are to:

- Improve the quality of life of PLHIV
- Improve the lives of families and communities affected by HIV
- Prevent further spread of HIV

Comprehensive HIV care includes:

- Pre- and post-test HIV counseling, HIV testing and follow-up
- Early infant diagnosis for babies
- Prevention, diagnosis and treatment of OIs and other illnesses, such as TB
- Palliative care, including pain management
- ARVs and ART
- PMTCT, antenatal and reproductive health services
- Support for safer infant feeding (usually exclusive breastfeeding, but could also be exclusive formula feeding)
- Regular immunizations for babies
- Ongoing monitoring of health status (through lab tests and physical exams)
- Ongoing follow-up of babies who have been exposed to HIV
- Hospitalization for those who are very sick
- Counseling on positive living and prevention
- Couples counseling and disclosure counseling
- Referral and follow-up
- Home-based care
- Malaria prevention and treatment
- Nutrition education
- Access to clean water
- Psychological support
- Social and spiritual support
- Linkages to material or economic support (money, clothes, food, etc.)
- Legal support
- End-of-life care, including pain management
- Care and support for family members, including children



SESSION 5.2: HIV Counseling and Testing: The Entry Point to Care

HIV testing is an entry point to care and treatment:

We need to know for sure that people have HIV before we link them with care and treatment.

The HIV testing and counseling process includes 3 major steps:



Remember: HIV testing and counseling is the ENTRY POINT to care and treatment.

You can help people plan next steps after their post-test counseling by:

- Listening and providing support, using good communication skills
- Explaining CD4 testing, why it is done and when and where to pick up results
- Explaining the importance of enrolling in a care and treatment program, and helping people do this
- Helping clients find sources of support
- Supporting clients to disclose their HIV test result to someone they trust
- Encouraging clients to join a PLHIV association or a support group
- Asking about partners and children and encouraging them to come for testing and counseling
- For pregnant women, discussing PMTCT and the idea that if the woman enrolls in care and treatment she is “saving two lives.” Also, discussing antenatal care and safe delivery planning, as well as promoting safer infant feeding for all babies (this will be covered more in *Module 7*).
- Agreeing on a date for the next visit, recording this in your notebook and making sure it is recorded in the client’s appointment card. Make sure to talk with clients about how important it is for them to come back to the clinic.

You can mobilize clients' family members to get HIV testing and counseling:

- You can counsel clients on how important it is to test other members of the family, including partners and children.
- You can focus on the whole family of each client in order to improve the family's overall health and well-being and get them the services and support they need.
- If the client gives consent and this is part of your role, home visits are a good place to talk about family testing, as well as during support group meetings or individual counseling sessions at the health facility.

You can mobilize all community members to get HIV testing and counseling:

- Help educate and mobilize community members about the importance of knowing their HIV-status.
- Speak about HIV testing and counseling at community gatherings, religious events, in workplaces, and with community leaders and community organizations (such as youth groups and women's groups).



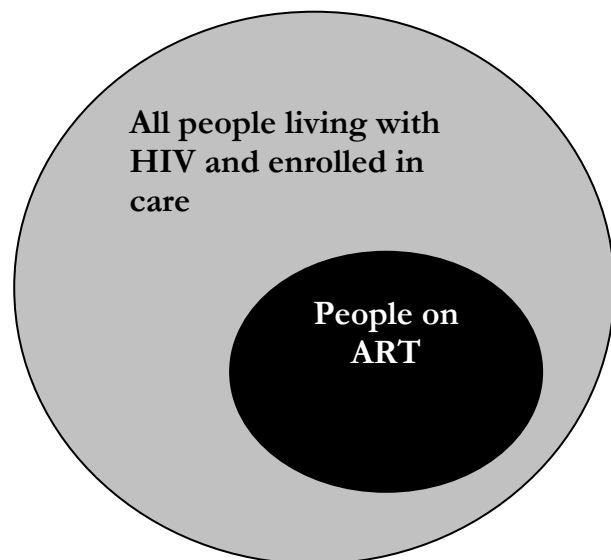
SESSION 5.3: HIV Care and HIV Treatment: What is the Difference?

There is a lot people with HIV can do to stay healthy even if they are not on ART:

- All PLHIV should come to the hospital for regular check-ups, tests, counseling and for medicines to help prevent opportunistic infections and to stay healthy.
- Also, when people come back to the clinic regularly for CD4 testing and check-ups, they can start ART right away when they are eligible.
- Starting ART as soon as possible once eligible reduces the chances that the person will become very sick and die.

Who needs HIV care services?

- Everyone who is living with HIV should be enrolled in care, even if they are not eligible for ART.
- People should return to the clinic at least once every 6 months for a check-up, counseling and a CD4 test to see if they are eligible for treatment.
- Babies that have been exposed to HIV should also all be enrolled in care from birth. Babies and pregnant mothers should come back to the clinic even more often.



Components of HIV care (other than ART):

- General health check-ups by the doctor and nurse
- Prevention and treatment of OIs, especially pneumonia, TB, malaria and hepatitis
- Infant diagnosis and care for babies exposed to HIV
- CD4 testing to see how much HIV is affecting the immune system and if ART is needed
- Other lab tests, such as one to test how well the liver is functioning (called "LFTs"), especially for people on ART
- Sexual and reproductive health services, including family planning and STI diagnosis and treatment
- Emotional counseling and support
- Positive living counseling and support
- Prevention, such as prevention of mother-to-child transmission and prevention of new infections

- Disclosure counseling and support
- Discussion and referral for testing and care of other family members (like children, partners, etc.)
- Nutrition counseling and support (direct support or through referrals)
- Education on hygiene, sanitation and clean water
- Linkages to support groups and community resources

SESSION 5.4: Prevention and Treatment of Opportunistic Infections and Other Complications

Opportunistic infections:

- Opportunistic infections, or OIs, are the infections that make PLHIV sick because the body's immune system is weakened and it cannot fight back.
- One of the best ways to live positively with HIV, whether you are on ART or not, is to prevent OIs from happening in the first place or treating them right away if they do happen.

You should be aware of common opportunistic infections and other infections in PLHIV, as well as signs and symptoms that your clients may experience.



Some common OIs, other complications and symptoms in PLHIV:

Tuberculosis (TB) – a common OI that usually affects the lungs

Signs and Symptoms: Cough, fever, weight loss

Prevention: Cover mouth when coughing or sneezing and do so into a tissue to prevent the spread of TB to other people, keep windows open, try to keep children away from people with active TB

Treatment: Usually 6-9 months of daily medication

Pneumonia (or PCP) – a serious lung infection

Signs and Symptoms: Coughing, weakness, shortness of breath

Prevention: Take cotrimoxazole (CTX) and wash hands with soap before eating and after using the toilet.

Treatment: A doctor will prescribe antibiotics.

Sores or Pain in and around the Mouth – may be caused by thrush, herpes, malnutrition, Kaposi's sarcoma (a form of cancer) or dental problems

Signs and Symptoms: Pain in or around the mouth, white patches (thrush), blisters, sores, cracks, dark spots, infected gums, loose teeth

Prevention: Brush teeth, tongue and inside of mouth at least 2 times per day, rinse the mouth with warm salt water

Treatment: ART will usually prevent thrush. Rinse the mouth with salt water, lemon juice or gentian violet solution (dark blue crystals). The doctor may give antifungal medicines or antibiotics.

Skin Problems – may be due to thrush, warts, bacterial infections, shingles, allergies, pressure sores, Kaposi's sarcoma (a form of cancer)

Signs and Symptoms: Rash, itchy skin, sores, very dry skin, boils or abscesses, pain. In the case of Kaposi's sarcoma, purple spots on the skin and swelling of the face, genitals and limbs

Prevention: Keep the skin clean and dry, wash with soap and water, try not to scratch, cool the skin with clean water, massage pressure areas and, for bedridden patients, change positions often.

Treatment: Use calamine lotion to help with itching, use gentian violet solution to help clean the skin, use hydrogen peroxide to clean wounds and sores, use local remedies that are safe. The doctor may prescribe antibiotics or other medication.

Clients who develop a rash while taking nevirapine should go to the clinic right away!

Malaria – spread by mosquitoes

Signs and Symptoms: High, spiking fever, weakness

Prevention: Sleep and rest under an insecticide treated bed net, drain standing water in and around the home, use insecticide room sprays.

Treatment: A doctor will prescribe anti-malarial medicine.

Sexually Transmitted Infections (STIs) and yeast infections (thrush, candidiasis)

Signs and Symptoms: Sores or rash in the genital or anal areas, unusual discharge from the penis or vagina, pain during urination (peeing) - sometimes there are no symptoms (especially in women)

Prevention: Practice safer sex, use condoms, avoid sex if you or your partner has an STI.

Treatment: The doctor may prescribe antibiotics, depending on which kind of STI. Do not have sex while treating an STI, take all medications and have all partners treated as well.

Major weight loss (wasting) – wasting is an AIDS-defining illness

Signs and Symptoms: Major weight loss, weakness – usually due to diarrhea, loss of appetite and reduced food intake

Prevention: Wash hands with soap (especially before eating and after using the toilet), use only safe, clean, boiled water for drinking and cooking, avoid eating undercooked meat, fish and eggs, only use pasteurized milk products. Also, increase food intake. Cotrimoxazole (CTX) can help prevent diarrhea in children.

Treatment: Oral rehydration solution, drink a lot of clear fluids, eat soft foods that are not spicy or greasy, increase food intake. The doctor may prescribe antibiotics.

Hepatitis B virus infection – Serious liver infection, which can lead to liver dysfunction, kidney problems, liver cancer and death. Spread through unsafe sex, sharing contaminated needles and from mothers to their babies

Signs and Symptoms: Some people have no symptoms, but others may feel tired, have belly pain, nausea, vomiting, fever, joint pain, jaundice (yellow skin and yellow eyes) or may vomit blood.

Prevention: Use of the Hepatitis B vaccine, practice safer sex, avoid use of contaminated needles, avoid body piercing and tattoos

Treatment: Doctors will prescribe medicines to treat Hepatitis B infection (some of the same medications used to treat HIV are also used to treat Hepatitis B).

SESSION 5.5: Tuberculosis Education, Screening and Referral

More about TB:

- TB is the most common OI among PLHIV. About 50% of PLHIV worldwide will also develop TB.
- TB usually infects the lungs, but it can also infect other areas.
- Usually people with TB have a bad cough that does not go away, they have fever and lose weight.
- TB is spread through the air, especially from coughing, sneezing and being in close quarters with a person with TB.
- It is VERY easy to spread TB from person-to-person, and PLHIV are especially likely to get it if they are in contact with a person with TB.
- Small children are at high risk for TB when they live with adults who have TB.

Your role in TB prevention and treatment

You can educate families about TB and prevention with these key messages:

- TB kills many people each year.
- People with HIV are much more likely to develop active TB.
- People living with HIV have a 50% risk of getting TB if they are exposed to it.
- With quick and correct treatment, TB is curable.
- Without treatment, TB spreads to others and can cause death.
- When people with TB cough, sneeze, spit, laugh or speak, the TB germs go into the air. When other people breathe the air, they can get infected with the TB germs.
- Spitting and coughing into a tissue can help prevent the spread of TB.
- Most people with TB do not need to be isolated from their family. It is important to ask the doctor when it is safe for a person with active TB to be in close contact with other family members.

At home, clients with TB should always:

- Cover their mouth when sneezing or coughing
- Avoid spitting, or spit into a covered container that is emptied into the latrine and cleaned regularly
- Keep the windows in the home open so that fresh air comes in
- Spend time outside
- If possible, sleep in a separate room – at least for the first few weeks of treatment



You can identify possible TB cases and refer people to the clinic:

- By asking clients, their families and community members these 5 simple questions, you can help identify new TB cases and prevent TB from spreading further.

TB Screening Questions

- Has the person had a cough for 2 or more weeks?
- Has the person had night sweats for 2 or more weeks?
- Has the person lost 3 kg or more in the past 4 months?
- Has the person had fever for 2 or more weeks?
- Has the person had recent contact with another person with active TB?

If the person answers **YES to any of these questions**, he or she should go to the clinic immediately for a TB test.

If the person answers **NO to all of the questions**, she or he probably does not have TB.

You can help people with TB take their medicine:

- TB treatment lasts at least 6 months and as long as 9 months. Like with ARVs, it is important to take the medicines the right way, every day, to make sure they are effective.
- The names of some of the most common drugs to treat TB are isoniazid, rifampicin, pyrazinamide and ethambutol.
- The most common strategy for TB treatment is Directly Observed Treatment Short-Course (DOTS). This is also called supervised treatment. This is when a trained community health worker observes the client taking medicine every day, provides support and keeps records about which medications were taken on which day.
- Explain that it is important to have a TB treatment supporter that can help remind the person to take the drugs every day.
- Even though people will feel better soon after starting TB treatment, they still have to take the medicines every day. If people stop the medicine, they can get sick again, possibly with a worse form of TB. This is called multi-drug resistant TB, which is very dangerous and very hard to treat. They will also pass TB to other people if the medicines are not taken the right way.
- Help people understand common side effects of TB medication and how to manage them. For example, clients may be alarmed that rifampicin turns their urine (pee) orange, but this is completely normal.
- If a person develops TB while taking ART, the doctor may or may not change the ART regimen and add TB drugs. If a person is not on ART yet, usually TB treatment is started first before beginning ART. Then, ART is started soon thereafter – usually in 2 weeks or 2 months after the person starts TB treatment.
- Adherence to both ART and TB medicines is important to get well and to prevent sickness and death.

You can help prevent the spread of TB in health facilities:

- Keep the windows open so there is always fresh air.
- Alert doctors and nurses about clients who are coughing so that they can be seen right away.
- Encourage coughing clients to cover their mouths and provide tissues, if possible.
- Ask people with TB to wait in a very well-ventilated area, if possible. But do not stigmatize or label people with TB (such as by making people with TB stand outside of the clinic).
- If possible, use protective masks when in contact with clients who have active TB.

SESSION 5.6: Helping with Referrals to Ensure Comprehensive Care

Helping clients with referrals

- Making a referral means that you formally send a person to another place in the health facility, to another health facility or to another organization for services.
- Many times people will need different services at health facility on the same visit. This can be very overwhelming for people who are not familiar with where things are or how to get from place to place – especially if they are not feeling well or have to wait a long time at each place.
- You can help people get from one place to another in the hospital or health center as easily as possible.

Key steps to successful referrals:

- Talk with members of the multidisciplinary team about the referral system so everyone is clear on how referrals are made and followed-up.
- Make sure you know where each service is at the hospital or clinic and how to get there the fastest way.
- Make sure you know which days and hours different services are offered.
- Make sure you know where the person is being referred and why.
- Use referral forms.
- Tell health care workers when you think a client needs to be referred.
- Help people understand why they are being referred.
- **If possible, WALK WITH THE PERSON to the referral point.**
- You should wait with the person at the referral point.
- You can tell staff that the client is waiting and try and get the person seen as soon as possible to reduce waiting, especially for pregnant women.
- If people need other services or get more referrals, stay with them until they leave the health facility.
- If needed, help clients plan follow-up actions and visits to the health facility and provide needed referrals to community-based organizations.



SESSION 5.7: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- HIV testing and counseling is the entry point to care and treatment.
- You can help with pre- and post-test counseling by providing emotional support, linkages to support groups and linkages to PMTCT, care and treatment services.
- You can also help motivate community members and clients' family members to get tested.
- You should counsel all PLHIV to enroll in care services at the clinic or hospital, even if they feel healthy and are not on ART.
- Important components of care that can help all PLHIV include: check-ups by health care workers, preventing and treating OIs (especially by taking CTX), regular CD4 tests, early infant testing for babies, counseling on positive living, nutrition, disclosure and linkages to support groups.
- One of the most important parts of HIV clinical care is to get a CD4 test done at least every 6 months, whether the person is on ART or not.
- Coming back often for care also means people can be identified and started on treatment as soon as they are eligible instead of waiting until they are very sick.
- Opportunistic infections, or OIs, attack the body when the immune system is weak.
- One of the best things PLHIV can do to stay healthy is to prevent OIs and other complications by living positively, taking certain medicines to prevent getting sick and by going to see the nurse or doctor right away when something is wrong.
- Tuberculosis (TB) is the most common OI among PLHIV.
- You can help educate families and community members to prevent TB and help find TB cases in the community by asking 5 key questions, referring people to the health center if they answer yes to any and helping clients adhere to TB treatment.
- You play a key role in referring clients for services, helping them understand why they are being referred and taking them to the referral point when possible.

MODULE 6:

Antiretroviral Therapy (ART)



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Dispel myths about ARVs and ART
- Define what is meant by "ARV" and "ART"
- Explain who needs ART and how we know when someone should start ART
- Understand key issues to be discussed and addressed before a person starts ART
- Discuss the goals and benefits of ART
- Help explain to clients that ART is "treatment for life"
- Know common first-line ARVs and ART regimens and explain to clients how to take them
- Help clients recognize, manage and know when to go to the doctor for ART-related side effects



CONTENT:

- Session 6.1: Introduction: Myths and Facts about ART
- Session 6.2: Who Needs ART?
- Session 6.3: Goals and Benefits of ART
- Session 6.4: Common ART Regimens
- Session 6.5: Common Side Effects of ARVs
- Session 6.6: Module Summary

SESSION 6.1: Introduction: Myths and Facts about ART

Some common myths and facts about HIV treatment:

Myth	Fact
ART is a last resort and is only good for people that are sick and dying.	Even people who look and feel healthy may need ART. The medicines work best if they are taken as soon as they are needed. People should not wait until they are very sick to start ART.
ART can cure AIDS.	ART is a lifelong, daily treatment. ART is not a cure for AIDS. There is NO CURE for AIDS.
It is hard to be on ART because you have to come to the clinic so often.	Most people taking ART only need to come back to the clinic once each month and sometimes even less often.
You have to take ARVs on a full stomach, so people who do not have enough food cannot take them.	It is true that some ARVs should be taken with food, but most of them can be taken with a small amount of food.
Only rich people can afford to take ART.	In most countries, people can get ART for free now.
Pregnant women cannot take ARVs because they will hurt the baby.	Pregnant women can safely take ARVs. ARVs help keep the mom healthy and can prevent HIV infection in the baby.
People can share ARVs with family members.	Each person in the family needs to get her or his own ARVs from the clinic. If you share them, it means you are not taking the correct dose for yourself.
Once you are feeling better, you can stop taking ART.	ART is for life! Even if you start to feel better after you start ART, stopping will eventually make you sick again. Stopping ART will also make it very difficult to have the medicines work if you start taking them again. When this happens, you might need to take different kinds of ARVs that are not always available.
If you take ART, you can have sex without condoms because the HIV will not spread anymore.	People can still pass HIV to others while on ART, even if they feel healthy. It is important to always use condoms when you have sex.
Traditional medicines are just as good as ART.	While some traditional medicines can help people feel better, research has shown that ART is the best way to treat HIV.

<p>If the ARVs make you feel sick, you should stop taking them.</p>	<p>Some ARVs can cause mild to serious side effects in some people, so it is important to know the signs and seek regular care by a doctor or nurse. Most side effects can be managed or will go away over time.</p>
<p>There are no ARVs for babies and children.</p>	<p>There are special kinds of ARVs for babies and children, and the dose is based on their weight. Children should not be given adult ARVs unless instructed by a doctor.</p>



SESSION 6.2: Who Needs ART?

ARVs and ART: Key Definitions

ARVs: Antiretroviral medications used to fight HIV. ARV refers to 1 single type of medicine, for example nevirapine (NVP) or zidovudine (AZT).

ART: Antiretroviral therapy, including a combination of at least 3 different antiretroviral medications, is used to fight HIV. Sometimes this is also called HAART. HAART stands for highly active antiretroviral therapy.

The cases in which a person should be given 1 or 2 ARVs for a short period of time, instead of ART, for:

- **Pregnant women** who are not eligible for ART but are given a combination of different ARVs (such as AZT during pregnancy, NVP at onset of labor and AZT+3TC during labor, delivery and postpartum) to prevent the transmission of HIV to their babies
- **HIV-exposed infants** who are given AZT or NVP at delivery and during breastfeeding to prevent mother-to-child transmission of HIV
- **Post-exposure prophylaxis (PEP)** – for example, if a person is raped or if a health-care worker is stuck by a used needle in the clinic

Who needs ART?

Not everyone who is living with HIV needs to start ART right away (except for infants and children who usually need to start ART right away). Only the health care team, with the client, can make the decision when to start ART.



Clinical staging (a check-up by the doctor or nurse looking for specific symptoms and signs of HIV and AIDS):

- If the person is very ill, losing weight very fast and has many OIs, such as bad diarrhea, fever or tuberculosis, she or he will usually need to begin ART immediately, no matter what the CD4 cell count.

CD4 test (depends on your national ART guidelines):

- CD4 cell count of 350 or less, even if the person does not show any symptoms
- For pregnant women, anyone who has a CD4 cell count below 350

Client readiness for ART (depends on your national ART guidelines):

It is important that a client be ready to start taking ART. There is more on adherence preparation and support in *Module 8*, but these are some key issues that should be addressed before a person starts ART.

- Wants ART and is committed to taking it correctly
- Received pre-ART education and counseling (see *Module 8*)
- Understands that ART is a lifelong commitment
- Understands and accepts possible side effects and how to manage them
- Understands the value of disclosing to at least one person
- Has a treatment supporter or “buddy”
- Has an adherence plan
- Has had any previous non-adherence issues to care or medicines addressed as part of the adherence plan
- Has support to address any psychosocial barriers to adherence
- Will accept a phone call or home visit from a Peer Educator, community health worker or health care provider if she or he misses an appointment at the clinic



Group Case Studies

Case Study 1:

T___ comes out of the clinic upset. He tells you he is angry because he traveled for two hours to get to the clinic, but the doctor would not give him ART today and said he needed to come back next week. What are some of the reasons why the doctor may not have given T___ ART today?

Case Study 2:

You are walking to the market and G___ stops you because she knows you are a Peer Educator. She tells you she tested positive for HIV and is going to the clinic to get ART because it will help her live longer. What questions would you ask G___? What things would you tell her about when people should start ART?

Case Study 3:

A client named W___ comes out of the doctor's office very confused. He does not feel well and his CD4 cell count is 150. The doctor would not give him ART because the Peer Educator and counselor mentioned they had some concerns – W___ has not told anyone about his HIV-status and he has often missed his CTX doses. The Peer Educator asked W___ to come back to speak with her again in 3 days. W___ is eligible for ART because his CD4 cell count is 150, but what are some of the non-medical issues that the Peer Educator needs to address with W___ before he can start ART?

SESSION 6.3: Goals and Benefits of ART

How does ART work?

HIV attacks the body's immune system and CD4 cells. HIV enters CD4 cells and reproduces itself to make more virus.

When on ART, we take a combination of 3 or more ARVs, from at least 2 different classes of drugs, because each medicine does something different in the body.

Different ARV medicines:

- Prevent HIV from entering the CD4 cells
- Prevent HIV from growing inside the cells
- Prevent HIV from leaving the cell to infect other cells

Why so many medicines?

People need to take many ARVs (usually 3, but sometimes more), not just 1 or 2, because HIV attacks the cells in many different ways and the different medicines work in different ways.

When a person takes ART the right way, every day, for life, it helps the CD4 cells fight against the HIV and the virus does not attack as many cells. This means the person has more healthy CD4 cells that can help the body protect itself from infection.

Goals and benefits of ART:

- Keep the person healthy by increasing the number of healthy CD4 cells
- Prevent HIV from reproducing (making more of itself) in the person's CD4 cells
- Prevent HIV from leaving one cell and infecting other cells
- Prevent transmission of HIV from a mother to her baby
- Keep the immune system strong so the body can prevent and fight infections
- Make the person feel healthier and be able to work, take care of self and family, and be an active member in the community



ART does NOT...

- ART does not cure HIV. Once people have HIV, they will have it for their entire lives, even if they feel healthy or their CD4 cell count is very high.
- ART does not prevent the spread of HIV to another person. ART helps keep the HIV under control in a person's body, but they can still pass it to other people.
- **This is why it is important to always practice safer sex!**

SESSION 6.4: Common ART Regimens

Important points to remember about ART regimens:

- You do not need to memorize every ARV medicine or ART regimen that exists, but you should be familiar with the names and instructions for the most common regimens in your setting.
- You can talk with clients about the medicines they are taking, why they are taking the medicine, how often, and how they take each one.

Changing brands, shapes, sizes and packaging

- Sometimes, clients may have to switch brands of the same medicines, depending on what is available in the country.
- This can be difficult for clients as the shape, size, packaging and dosing of their medications may change, even though they are still on the same regimen.
- You can work with the pharmacist to be up to date on drug changes, help people prepare for this change and make sure that adherence is kept up.

Key definitions: First-line and second-line ART regimens

- A first-line regimen is the group of ARVs prescribed when a person starts ART.
- A second-line regimen is the group of ARVs prescribed only after the first-line regimen does not work.
- Only a doctor or nurse can tell if a person needs to switch from a first-line to a second-line regimen.
- With good adherence, most people will respond well to the first-line ART regimen.
- First-line regimens are much cheaper, easier to take and more widely available than second-line regimens.



Common first-line ART regimens for adults (adapt to your national ART guidelines):

Common regimens	Drug name and dose		Timing	Possible side effects
AZT+3TC+NVP	AZT (or ZDV)	zidovudine 300 mg	Twice daily or every 12 hours	Nausea, headache, vomiting, fatigue, anemia, muscle pain, weakness
	TDF	tenofovir 300 mg	Once daily	Nausea, vomiting, diarrhea, flatulence (gas), kidney problems
AZT+3TC+EFV	3TC	lamivudine 150 mg	Twice daily or every 12 hours	Stomach pain, nausea, numbness or tingling in hands and feet, vomiting
TDF+3TC+NVP	FTC	emtricitabine 200 mg	Once daily	Diarrhea, headache, nausea, rash
TDF+3TC+EFV	NVP	nevirapine 200 mg	Once daily for 14 days, then twice daily or every 12 hours	Nausea, headache, vomiting, fever, rash. Rashes can be deadly – see a doctor right away.
TDF+FTC+NVP	EFV	efavirenz 600 mg (400 mg if <40 kg)	Once daily, at night. Do not take with a high fat meal. Should not be taken when pregnant.	Rash, nausea, dizziness, diarrhea, headache, sleeplessness, bad dreams
d4T+3TC+NVP*	d4T (note: d4T is being phased out in many places)	stavudine 30 mg if <60 kg 40 mg if >60 kg	Twice daily or every 12 hours	Changes in body shape, weight loss, fatigue, stomach pain, numbness in hands and feet. Numbness in hands and feet – see a doctor right away.
d4T+3TC+EFV*				
*No longer recommended as first-line therapy, but still in use in many settings				

Second-line ART regimens

If the first-line regimen does not work well, the doctor may switch a client to a second-line regimen. This regimen will probably include at least 2 new ARVs.

Some common second-line ART regimens may include the following ARV medicines (it depends on your national guidelines):

- ABC (abacavir)
- ddI (didanosine)
- TDF (tenofovir)
- LPV/r (Kaletra)
- ATZ/r (Atazanavir)
- Others

A note on pediatric ART:

Many of the same ARV medicines used for adults are also used in children, but there are some major differences:

- Pediatric ARVs are sometimes in syrups and need to be given with syringes.
- If syrups are not available, tablets may need to be crushed or dissolved in liquid.
- The dose of pediatric ARVs depends on the child's weight. The dose will change as the child grows.
- Giving ART to children requires a lot of dedication and hard work by caregivers!

SESSION 6.5: Common Side Effects of ARVs

For some people, one of the hardest parts of starting ART can be managing the side effects of the different medicines.

- You play an important role in helping clients to learn about, prepare for and manage their side effects as part of the multidisciplinary care team.
- It is important for clients to know that starting ART is not an immediate cure for feeling bad. The medicines will help them feel much better over time, but probably not right away.
- The body needs some time to adjust to any new medicine. Many side effects will go away after a few weeks of starting ART. It is important to be patient.
- Some side effects will last a long time, such as changes in a person's body shape.
- There is a difference between minor side effects that will go away and more serious side effects that require the person to see a doctor or a nurse right away.
- It is sometimes difficult to know which side effects children are having since they may not be able to describe what they are feeling.
- A client should never make the decision alone to stop taking some or all of the medicines. This should only be done in consultation with health care workers at the ART clinic.
- If a client has to stop taking ARVs for any reason, there is a safe way to do it.
- If a client is having problems with taking ARVs, the person should come to the clinic right away.

A side effect is a reaction to the medicine in the body – it can be good or bad, expected or unexpected.

Some important ARV side effects for you to know about:

Rash and skin problems:

- May go away, but may be a bad reaction if taking NVP
- You can advise clients to:
 - Keep skin clean and dry
 - Only use mild soaps
 - Drink a lot of clean, boiled water to keep skin healthy
 - **See the doctor or nurse if the itching is severe; the skin is peeling, looks infected, is blistering or has open sores; if the client has a fever, or if the rash is in the eyes and mouth**
 - **If taking NVP, see the doctor or nurse right away if there is any kind of rash**

Numbness or tingling feelings:

- Can be caused by taking d4T or ddI, but also other ARVs and TB medicines or if there are other infections. Diabetes and drinking too much alcohol can also be the cause.
- You can advise clients to:
 - Wear loose socks and shoes to protect the feet
 - Check the feet to make sure there are no infections or open sores
 - Keep feet uncovered when in bed
 - Soak feet in warm water and massage them if this feels good
 - Keep feet up
 - Do not walk too much at one time and take breaks
 - Eat healthy foods and take multivitamins every day
 - **See the doctor or nurse when numbness/tingling starts. There are some medications that may be able to help the symptoms.**

Nausea and vomiting:

- Usually go away in 2-4 weeks
- You can advise clients to:
 - Take medicines with food
 - Eat small meals more often
 - Eat crackers or dry bread
 - Chew on ginger or drink ginger tea
 - Stay away from fried or greasy and fatty foods
 - Stay away from very spicy foods
 - Drink a lot of clean, boiled water, weak tea and lemon water
 - Not drink too much coffee or strong tea
 - Stop using traditional medicines which may be making things worse
 - **See the doctor or nurse if there is fever, vomiting more than 3 times each day, inability to drink, stomach pains, dehydration or confusion**

Headaches:

- Usually go away in 2-4 weeks
- You can advise clients to:
 - Rest in a quiet, dark room
 - Put a cold cloth over the face and eyes
 - Stay away from strong tea and coffee
 - Take paracetamol or aspirin
 - **See the doctor or nurse if it does not go away with paracetamol or if there is fever, vomiting, blurry vision or convulsions**

Diarrhea:

- Usually goes away in 2-4 weeks
- You can advise clients to:
 - Not stop eating or drinking
 - Eat small meals during the day
 - Eat soft foods like rice and bananas
 - Stay away from spicy, greasy or fatty foods
 - Drink sips of clean, boiled water, weak tea, oral rehydration salts or lemon water
 - **See the doctor or nurse if there is blood or mucous in the diarrhea, if there is a fever, if diarrhea occurs more than 4-5 times in a day, if diarrhea occurs for more than 5 days in a row or if the person loses more than 2 kg**

Cannot sleep or has nightmares:

- Usually goes away in 2-4 weeks (most common with clients taking EFV)
- You can advise clients to:
 - Take ARVs at bedtime
 - Avoid heavy meals before going to sleep
 - Avoid drugs or alcohol
 - Avoid foods or drinks with sugar or caffeine before going to sleep
 - Talk about feelings and worries with friends or family members
 - **See the doctor or nurse if they are really depressed or suicidal**

Tiredness:

- This is very common and can be caused by many things.
- You can advise clients to:
 - Avoid alcohol and drugs
 - Do light physical activity, like taking a walk
 - Eat lots of fruits and vegetables and make sure to get enough iron
 - Take multivitamins
 - Try to get enough sleep at night and rest during the day if needed
 - **See the doctor or nurse if they have a drug or alcohol problem or feel really depressed**

Long-term side effects: Many of the side effects people have when starting ART will go away over time. However, there are some long-term side effects that you should be aware of. These may include:

- Changes in body shape – This is a long-term side effect that can be caused by ART, especially regimens with d4T. Some PLHIV may develop more fat on their stomach, breasts or other areas and lose fat in their face, arms and legs.
- A build up of lactic acid in the body, which can cause weakness, nausea and other symptoms
- Increased fat and sugar levels in the blood
- Changes to different organs in the body (rare)

You can advise clients to:

- Eat well and exercise
- Discuss any changes in their bodies with the doctor or nurse (there may be medications that can be given to limit these changes)
- Attend all of their clinic visits and get lab tests recommended by the doctor or nurse on schedule
- Continue taking the ARVs and never stop taking the medicines without consulting with the doctor or nurse

Remember: Clients should not stop taking their medications if they have side effects! The decision to stop or change ARVs should be made by the client and a health care worker together.

Serious Side Effects that Require Immediate Care at a Health Facility

Advise the client to come to the clinic right away if she or he has:

- Red rash that is getting worse
- Rash in the eyes or mouth
- Severe headache with stiff neck
- Numbness/tingling/burning in the hands and feet
- High fever that will not come down
- Vomiting for more than 3 days
- Diarrhea 5 times or more in a day, diarrhea for more than 5 days or if there is blood in the diarrhea
- Problems breathing
- Abdominal pain
- Dehydration or cannot drink
- Blurry vision
- Depression or thoughts of suicide
- A lot of confusion
- Seizures or convulsions



Note: Some of the preceding information in this Module was adapted from the following sources:

WHO. (2010). Antiretroviral therapy for HIV infection in adults and adolescents. Recommendations for a public health approach: 2010 revision.

AIDSinfo Drug Database. Available at: <http://www.aidsinfo.nih.gov/DrugsNew/Default.aspx?MenuItem=Drugs>.

Horizons/Population Council, International Centre for Reproductive Health, and Coast Province General Hospital, Mombasa, Kenya. (2004). *Adherence to antiretroviral therapy in adults: A guide for trainers*. Nairobi, Kenya: Population Council.

SESSION 6.5: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- There are a lot of myths about ARVs and ART. You need to know the facts and share correct information with others.
- ARVs are antiretroviral medications used to fight HIV.
- ART means antiretroviral treatment, including a combination of at least 3 different antiretroviral medications (ARVs), used to fight HIV.
- ART is a lifelong commitment, meaning people have to take the medicines every day, at the same time of day for their entire lives, even if they feel good.
- ART is not a cure for AIDS, and HIV can still be spread when taking ART.
- Traditional medicines may be able to help with some symptoms, but they are NOT a replacement for ART.
- Not everyone who is living with HIV needs to start ART right away (except for children who usually need to start ART sooner than adults).
- There are a number of criteria a person must meet to start ART. These include both medical criteria (stage of disease and CD4 cell count) and non-medical criteria (like their ability to understand and adhere to treatment). Clients should be part of the decision to start ART with the health care team.
- Since HIV affects the body in different ways, different kinds of ARVs need to be taken to fight HIV. At least 3 types of ARVs (from 2 classes of drugs) should be taken at a time to fight HIV. The only exception is for pregnant women who are not eligible for ART and HIV-exposed babies, who usually take 2 kinds of ARVs.
- If the first-line treatment does not work, the doctor may switch the client to a second-line regimen.
- The ARVs for babies and children are similar to the ones for adults. The difference is that some come in syrups while others are in capsules and tablets that can be broken or crushed. The doses are also different and change based on the child's weight.
- Some people on ART have side effects that make them feel very bad. Many side effects go away within a few weeks of starting ART or a new drug. It is important to be patient because it takes time to get used to all new medicines. Some side effects, like changes in body shape, are long-term and probably will not go away.
- Other side effects, including rash, severe headaches, severe diarrhea and numbness are severe. If a client has these side effects, it is important that she or he go to the clinic right away.
- Clients should never stop taking their ART without consulting with a clinician.

MODULE 7:

HIV Prevention, Care and Treatment for Pregnant Women and Their Children



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Define MTCT, PMTCT and MTCT-Plus
- Explain key PMTCT concepts and interventions before and during pregnancy, during the time of labor and delivery, and after the baby is born - and your role in each
- Explain the importance of ART for pregnant and breastfeeding women
- List different ways HIV-exposed and infected babies and children can be found and brought into care and treatment
- Help counsel families and caregivers on needed follow-up of babies exposed to HIV during pregnancy and breastfeeding
- Explain the importance of ART for HIV-exposed babies
- Understand when and how HIV can be diagnosed in infants and children
- Understand the major differences between adults and pediatric HIV care and treatment



CONTENT:

- Session 7.1: Introduction: Prevention of Mother-to-Child Transmission (PMTCT) Overview
- Session 7.2: Strategies to Prevent Mother-to-Child HIV Transmission
- Session 7.3: Supporting Pregnant Women and Mothers with Ongoing ART Services
- Session 7.4: Identifying and Caring for Babies Exposed to HIV
- Session 7.5: Introduction to Pediatric HIV Care and Treatment
- Session 7.6: Classroom Practicum on PMTCT
- Session 7.7: Module Summary

SESSION 7.1: Introduction: Prevention of Mother-to-Child Transmission (PMTCT)

Overview

Mother-to-Child Transmission (MTCT):

This is the transmission of HIV from a woman living with HIV to her baby during pregnancy, labor and delivery or during breastfeeding. PMTCT stands for Prevention of Mother-to-Child Transmission (of HIV).

- Without quality maternal and child health, PMTCT and HIV care and treatment services, about 32% of babies born to mothers living with HIV will become HIV-infected during pregnancy, delivery and breastfeeding.
- Without care and treatment, about 30% of HIV-infected babies will die before they are 1 year old, and 50% before they are 2 years old.

MTCT-Plus – Key concepts:

Key Concept 1 – Keep Moms Healthy

- The healthier the mom (the less HIV she has in her blood and the higher her CD4 cell count), the less likely it is that the baby will become HIV-infected. The sicker the mother (a lot of virus in the blood and low CD4 cell count), the more likely it is that the baby will become HIV-infected.
- A healthy mom is able to take care of herself and love and take care of her baby and her whole family. Without healthy moms, we will not have healthy families or communities!

Key Concept 2 – Reduce Risk at Every Stage

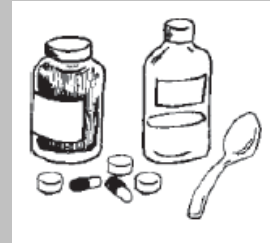
The risks of passing HIV from a mother living with HIV to her baby are different at various times during and after the pregnancy.

It is important to reduce the risk of transmission at each of these stages.



Key Concept 3 – All Moms Need ARVs

- One of the best ways to lower the amount of HIV in the mother's body, increase her CD4 cell count and make her healthy and less likely to pass HIV to the baby is for her to get the care and treatment she needs to be as healthy as possible, including ART. All pregnant women with HIV need to take ARVs.
- If a mom has a CD4 cell count **below 350**, the baby is at high risk of getting HIV. According to the WHO, women with a CD4 cell count of 350 or lower should start ART and stay on ART for their entire lives (check your own national guidelines).
- If a mom has a CD4 cell count **above 350**, the baby has a lower risk of getting HIV than if the mom's CD4 cell count is low. According to new WHO recommendations from 2009, women with a CD4 cell count above 350 should also get ARVs during pregnancy to prevent the baby from acquiring HIV. The WHO gives 2 options for ARVs for mothers with CD4 counts above 350. These options are explained in the next Session.



Key Concept 4 – All Babies of HIV-Infected Moms Need ARVs and CTX

- All babies need to take ARVs at the time of birth and for the first few weeks of life, to help prevent them from becoming HIV-infected.
- Either the mom or the baby needs to be taking ARVs for the **entire time the baby is breastfeeding**. This helps protect the baby from getting HIV during breastfeeding.
- The type of ARVs a baby takes, and for how long, depends on: if the mother is on lifelong ART, what ARVs the mother took during pregnancy and in the postpartum period and for how long (if not on lifelong ART) and whether or not the baby is breastfeeding. The different options are explained in the next Session and in Session 7.4.
- HIV-exposed babies need to take CTX starting at 6 weeks to prevent other infections that may make them very sick or lead to a rapid death. Babies should take CTX until it is certain that they are not HIV-infected.
- If the baby gets tested and is HIV-infected, the baby will also need lifelong ART (WHO recommends that all HIV-infected babies under age 2 years begin ART).



SESSION 7.2: Strategies to Prevent Mother-to-Child HIV Transmission

PMTCT strategies before pregnancy:

Prevent HIV transmission in the first place.

Prevent unwanted pregnancies through good family planning and reproductive health programs.

Promote HIV testing and counseling, especially before having sex with someone, getting married and getting pregnant.

Make sure people know about sexually transmitted infections (STIs) and get treatment for themselves and their partner(s) right away.

Remember: All women have the right to have or not have babies, no matter what their HIV-status.

PMTCT strategies during pregnancy:

Promote antenatal care for all women (at least 3 visits, but more is better).

Promote HIV testing and counseling for all pregnant women and their partners (unless they do not want to be tested).

Make sure all pregnant women receive ARVs

- **The WHO recommendation for women eligible for ART (CD4 cell count equal to or less than 350):**
 - **Mom:** The mom gets AZT + 3TC + NVP (or another ART regimen – check your national guidelines) each day while she’s pregnant, during labor and continues on treatment after the baby is born.
 - **Baby:** The baby gets either daily NVP or AZT from birth until 4 to 6 weeks of age.

- **The WHO gives 2 options for women not eligible for ART (CD4 cell count more than 350). Each country chooses one of these options as the standard of care.**

- **Option A:**

MOM: The mom will start taking AZT at 14 weeks into her pregnancy. She will continue to take AZT every day throughout her pregnancy. During labor and delivery, she will continue taking AZT and also get a single dose of NVP, as well as an ARV called 3TC (or lamivudine) She should take AZT and 3TC for 7 days after delivery and then stop all medications.

- **BABY:** If the baby is breastfeeding then the baby should get a single-dose of NVP at birth and daily NVP from birth until one week after the baby stops breastfeeding. If the baby is not breastfeeding, then the baby should get a single-dose of NVP at birth and daily AZT or NVP from birth until 4 to 6 weeks of age.

- **Option B:**

MOM: The mom will start taking 3 different ARVs at 14 weeks into her pregnancy. She will continue to take the 3 ARVs every day throughout pregnancy. During labor and delivery, she will continue to take the 3 ARVs. After the baby is born, she will continue taking the 3 ARVs every day until one week after she stops breastfeeding. One week after the baby stops breastfeeding, the mom stops taking the ARVs. The mom is likely to use one of the following ARV regimens during pregnancy, labor and delivery, and breastfeeding: AZT+3TC+LPV/r, or AZT+3TC+ABC, or AZT+3TC+EFV, or TDF+3TC (or FTC)+EFV.

BABY: Babies born to mothers taking the Option B regimen (3 ARVs) should get a single-dose of NVP or AZT at birth, and then daily NVP or AZT until 4 to 6 weeks of age – regardless of being breastfeed or not.

- The mom needs to get a CD4 test within 3-6 months after delivery to check how she is responding to her ART, or if she is eligible to start taking ART.

**Note that along with the CD4 cell count, the doctor or nurse may also use WHO clinical staging to decide which pregnant women need to start ART. All women with stage 3 or 4 disease should start ART.

Make sure all pregnant women receive CTX prophylaxis.

Make sure women plan for a safe delivery at a health facility.

Promote safer sex and condom use during pregnancy.

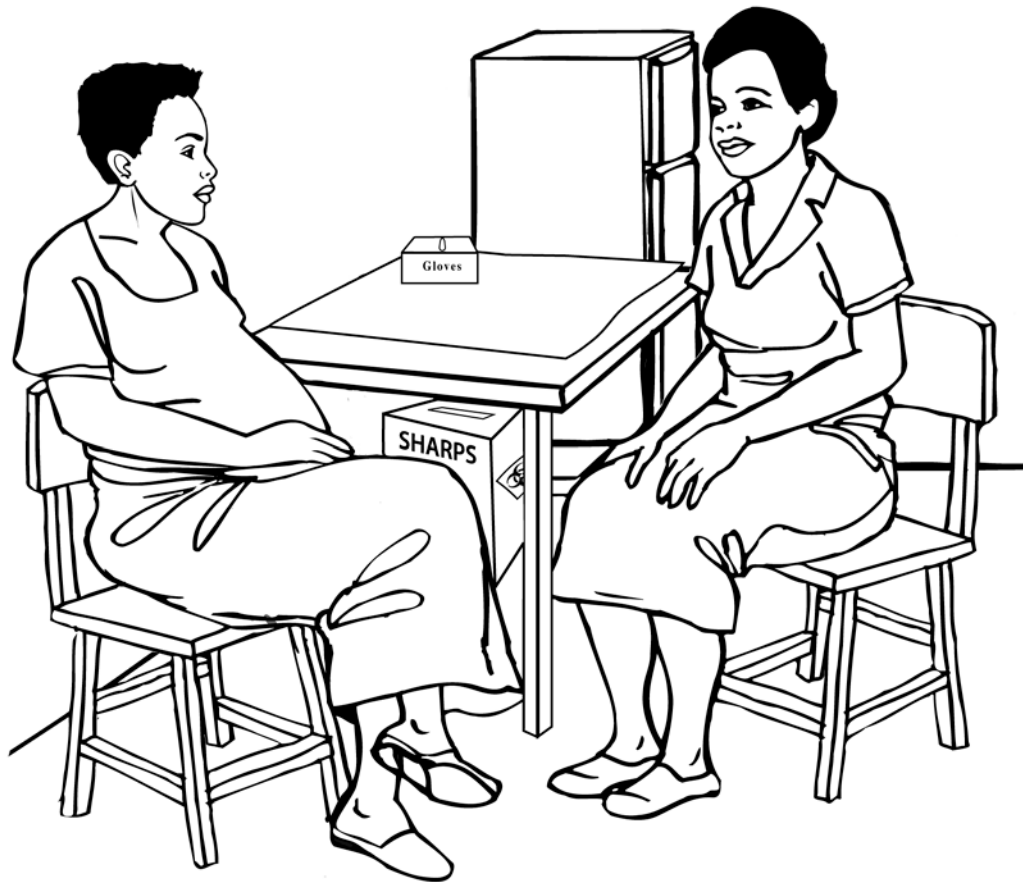
Make sure women receive nutrition advice and supplements (iron, multivitamins) and infant feeding education, support and counseling.

Promote prevention of malaria, TB and tetanus.

Promote treatment of STIs.

Create linkages to mothers support groups and other social support in the community.

Plan for postpartum follow-up of the mother and the baby.



Remember to promote the PMTCT motto of “saving 2 lives” (the mom’s and the baby’s) by enrolling in PMTCT services, taking ARVs and coming back to the clinic often.

Remember that most moms who need ART for their own health and to prevent HIV in their baby do not look or feel sick!

PMTCT strategies near to and during labor and delivery:

Help moms plan to deliver the baby in a health facility.
Encourage moms with unknown HIV-status to get tested right away.
If the mother took ARVs during the pregnancy, WHO recommends that: <ul style="list-style-type: none">• The mother should continue taking ARVs during labor and delivery.• The baby should receive the first dose of ARVs shortly after birth (within 72 hours, sooner is better) and for at least 4 to 6 weeks.• The nurse or doctor will decide what is the best ARV regimen for the baby to take based on national guidelines, the mother's ARV/ART regimen and infant feeding choice.
Encourage moms who did not start taking ARVs during pregnancy to take them during labor and delivery, according to national guidelines. The WHO recommends that: <ul style="list-style-type: none">• The mom gets AZT + 3TC and a single dose of NVP as soon as labor starts, followed by AZT+3TC for 7 days postpartum.• The breastfeeding baby should receive a single dose of NVP at birth plus daily NVP from birth until one week after all exposure to breast milk has stopped.• The non-breastfeeding baby gets a single dose of NVP at birth followed by daily AZT or NVP from birth until 4 to 6 weeks of life.
Promote good infection prevention practices for all births by keeping the delivery area clean, washing hands, cleaning instruments between deliveries, etc.
Review infant feeding education and counseling received during ANC and help the mom to implement her feeding choice before she leaves the hospital.

PMTCT strategies after the baby is born:

- All babies born to women with HIV are exposed to HIV because they shared blood and fluids with the mother. This does not mean that they will all become HIV-infected.
- Many babies will escape HIV infection, especially if the mother and baby get care and ARVs.
- It is important to explain follow-up care to mothers and families very well and make sure that they continue to come to the clinic after the baby is delivered.
- There is a lot that can be done to keep the baby healthy when it has been exposed to HIV and there are tests that can be done to tell if the baby itself is HIV-infected.

Follow-up for the mom and family:

Link new moms with community health workers.
Make sure that moms are enrolled in care and treatment programs , have adherence support and are on/continue taking ART either for their own treatment or for PMTCT during breastfeeding.
Counsel the mom and family on follow-up of the baby , including CTX prophylaxis, importance of routine child care visits and immunizations and HIV testing options for the baby.
Help create demand for needed HIV services by encouraging the mom to tell health care workers that she has HIV and that the baby has been exposed.
Provide ongoing emotional support and counseling to help the mom deal with any issues or concerns she may be having.
Discuss family planning desires and options (does she want to have another baby? If yes, how soon?) and refer her for family planning services.
Link the new mom to support groups, nutrition services, income-generating activities or other sources of needed support.

Follow-up for the baby:

The baby should be getting ARVs from birth and daily for at least the first 4 to 6 weeks of life. Breastfeeding babies whose moms are not taking ARVs will get ARVs for up to one year – until one week after breastfeeding stops. Remember, the ARVs the baby gets depends on if the mom took ARVs or ART during pregnancy and for how long, on breastfeeding, and on your national guidelines.
Make sure the baby goes for check-ups and gets immunizations on schedule.
Make sure the mother tells all health care workers that the baby has been exposed to HIV.
Help moms recognize oral thrush (white spots in the mouth or throat) and other health problems in the baby and bring the baby to the clinic right away for treatment.
Make sure the baby is getting good nutrition and growing well.
Explain to the mother that the baby needs to start taking CTX starting at age 6 weeks.

Recommend and provide counseling (and follow-up) about testing her baby for HIV.

PMTCT strategies during infant feeding:

- There is HIV in breast milk.

Key Definitions

Mixed feeding means giving babies breast milk together with other liquids, like water, herbal mixtures or juice, or other foods like cow's milk, formula milk or soft porridge.

Exclusive breastfeeding means only giving the baby breast milk (and any medicines prescribed by a doctor).

- It is important to note that most of the HIV transmission during breastfeeding happens when mothers mix-feed their babies and/or when the mothers are very sick with AIDS, have a low CD4 cell count and when either they or the baby do not take ARVs during breastfeeding.

There is much lower transmission from breast milk if:

- The mother is healthy
- The mother is on ART during breastfeeding
- The baby gets ONLY breast milk for as long as possible up to 6 months (exclusive breastfeeding), and there is no mixed feeding
- Breast infections are prevented and treated right away
- Thrush (white spots, yeast) in the baby's mouth is treated right away

You can support women to make good decisions around infant feeding and help them implement their infant feeding plan (or change the plan if it is not working).

Breastfeeding vs. Formula Feeding

- Exclusive formula feeding (no breast milk) is the only way to guarantee that a baby will not get HIV from its mother after delivery.
- HOWEVER, in many places, replacement feeding causes many babies to become sick and die from diseases, malnutrition, infections and other problems.
- Breastfeeding is much safer for the baby if either the mom or the baby is taking ARVs every day for the entire time of breastfeeding and one week after breastfeeding stops. Breastfeeding up to 12 months – with ARVs – helps keep the baby health, prevents the baby from getting sick, and lowers the chances that the baby will become HIV-infected.
- If for any reason the mother will not be able to practice safe formula feeding, it is safer for her to breastfeed the baby. The WHO recommends exclusive breastfeeding with ARVs for up to 6 months, and then breastfeeding with complementary foods and ARVs for up to 12 months.
- Also, there is stigma against women who do not breastfeed and it is often very difficult for the mom to prepare replacement feeds.
- You can help mothers decide which feeding choice is best for them and safest for the baby, and continue to support mothers to feed their babies safely, including supporting adherence to ARVs during breastfeeding.
- **Remember: for the majority of women you will work with, exclusive breastfeeding for as long as possible – up to 6 months – and continued breastfeeding with complementary foods – up to 12 months – with either the mom or the baby taking ARVs every day, is safest for the baby.**



Key messages about infant feeding:

Breast milk is “the norm” in most places. Breastfeeding is healthy, free and helps prevent diseases in the baby like diarrhea and respiratory problems that could be deadly. Breast milk is the only food babies need until they are 6 months old.

ARVs make breastfeeding safer and protect the baby from HIV during the first year of life when they are breastfed.

- **Women should take ART if they are eligible** for treatment (CD4 equal to or less than 350), because ART decreases the amount of HIV in their blood and breast milk.
- **Women not eligible for treatment** (CD4 above 350) should take ARVs themselves, or give their baby ARVs every day during breastfeeding and for one week after stopping breastfeeding. When the mother or the baby takes ARVs, it protects the baby from become HIV-infected while breastfeeding.

In most developing-country contexts, **exclusive breastfeeding for as long as possible up to 6 months** is usually the best and healthiest choice for all babies. Mothers may also opt to exclusively formula feed their baby if it is safe to do so.

Women should not wean (stop breastfeeding) before 6 months. Early weaning will cause more harm than good to the baby.

At 6 months, the baby’s immune system is stronger and the baby needs to have other foods, in addition to breast milk or formula, to get the nutrients it needs. Women should not be advised to quickly wean the baby off of the breast at 6 months.

The baby can have breast milk and other foods through 12 months old – and the mom or the baby should be taking ARVs every day during breastfeeding and for one week after stopping breastfeeding. It is important that moms do not stop breastfeeding if there are not enough healthy foods for the baby to eat.

If the baby is tested and found to be HIV-infected, the mother should keep breastfeeding.

Women should watch out for breast infections (cracking, sore nipples, strange discharge from nipples, pain, etc.) and come to the clinic right away if this happens.

Link women with nutritional support during the weaning period.

Table 7.1: Summary of PMTCT Regimens for Moms and Babies

(to be filled in by participants, with guidance from facilitators and using national PMTCT guidelines)

Mother's CD4 count	Mother's ARV/ART Regimen	Infant's ARV Regimen
CD4 equal to or below 350	<p>During pregnancy:</p> <p>During labor and delivery:</p> <p>Postpartum:</p>	<p>At birth:</p> <p>If breastfeeding:</p> <p>If not breastfeeding:</p>
CD4 above 350	<p>During pregnancy:</p> <p>During labor and delivery:</p> <p>Postpartum:</p>	<p>At birth:</p> <p>If breastfeeding:</p> <p>If not breastfeeding:</p>

SESSION 7.3: Supporting Pregnant Women and Mothers with Ongoing ART Services

Some possible solutions to link PMTCT and ART services include:

- You can provide quality information and counseling to women in their homes and at the clinic on the benefits of ongoing care and treatment for women themselves and other family members.
- You can walk with clients from one part of the hospital or health center to another and help them understand why they are being referred and what to expect.
- You can work with other multidisciplinary team members to prioritize pregnant women for care and treatment.
- You can greet pregnant or newly delivered clients at the ART clinic to make them feel comfortable and welcome.
- You can keep your own records about which women you should follow up with.
- You can educate the community, including community leaders, about the importance of antenatal care for all moms, and care and treatment services for moms and babies living with HIV.
- You can start mothers support groups so women have the support and information they need to keep themselves and their babies healthy.



SESSION 7.4: Identifying and Caring for Babies Exposed to HIV

It is important to explain follow-up care to moms and families very well and to make sure that they continue to get the medical attention they need and are not lost after the baby is delivered. There is a lot that can be done to keep the baby healthy when he or she has been exposed to HIV and there are tests that can be done to tell if the baby itself is HIV-infected.

Finding babies and bringing them into care:

PMTCT programs are one of the best ways to find babies exposed to HIV who should be tested and enrolled in care and treatment. But there are other places where you can find babies exposed to HIV or infected with HIV, including:

- Under-5 clinics
- Pediatric inpatient wards
- Adult ART clinics
- Health centers and hospital outpatient departments
- Homes with adults living with HIV
- With community health workers and community-based organizations, especially those working with orphans
- With traditional healers and traditional birth attendants



It is important to remember that while most babies living with HIV are infected through MTCT, others may have been victims of sexual abuse. You should always turn to a professional counselor in these situations.

Caring for babies exposed to HIV:

The most important thing for babies exposed to HIV and HIV-infected babies is that they **come back to the clinic often** and that they take NVP (if breastfeeding and mom not on ART) and CTX every day.

- Babies with HIV may get sick very quickly and they need to be seen at the clinic more often than adults with HIV or children that do not have HIV.
- You can counsel moms and other caretakers about bringing babies back to the clinic every month for a check-up and whenever they are sick.

Right away after the baby is delivered to a mom with HIV:

- The baby should get single-dose NVP at birth. NVP can be given in the maternity ward. In some places, where women often deliver their babies at home, NVP is given to the mother to take home during her pregnancy so that the mother can give the dose to the baby right away after delivery. Babies delivered at home should be seen at the clinic as soon as possible for a check-up and for ARVs.
- The baby will continue to get either NVP or AZT daily from birth to 4 to 6 weeks.
- If the mom is not taking any ARVs or ART after delivery, and is breastfeeding the baby, the baby will need to take NVP every day until one week after stopping breastfeeding.

At 6 weeks of age:

- All exposed babies should start taking CTX.
- The dose of CTX will depend on the baby's weight.
- Where available, babies should be tested for HIV with DNA PCR as soon as possible after 6 weeks of age.

Ongoing:

- If the baby is HIV-infected, a CD4 test needs to be done. The results will be interpreted by a health care worker, but you should know that what is considered a high or a low CD4 cell count in adults is not the same for children.
- Babies should keep taking CTX until it is definite that they are not HIV-infected and they are no longer breastfeeding.
- Make sure the baby goes for check-ups and gets immunizations on schedule.
- Health care providers should look for and treat infections.
- Make sure the baby is getting good nutrition and growing well.

Focus on the family:

- Having a sick baby and knowing that the baby may have HIV can be a very hard thing for parents and caregivers.
- It is important to spend time talking with families about how they are feeling and making sure they understand what is happening with the baby (tests, medicines, side effects, etc.).
- HIV is a family disease and parents of sick babies will often themselves be sick and in need of care and treatment and support to adhere, disclose to others or seek community services.
- Parents and caregivers should be active in the baby's care and monitoring as they often know best when "something is not right" with the baby.
- You should always ask about all caregivers of the baby, as they often change.

6 key points about caring for babies exposed to or infected with HIV:

- Come back to the clinic often. If baby is sick, don't wait – come in right away.
- Go for early HIV testing.
- Give ARVs to the baby every day for the first 4-6 weeks (all babies) and every day until one week after breastfeeding has stopped (babies whose moms are not taking ARVs/ART)
- Give CTX to the baby every day (starting at 6 weeks).
- Weigh and measure the baby at every visit.
- Focus on the whole family.

HIV testing in Babies and Children

HIV testing in babies under 18 months of age:

- The only way to know for sure if a child under 18 months of age is HIV-infected is through DNA PCR testing with dried blood spots, or DBS. If this test is not available, the doctor can also examine the baby, check the CD4 cell count and look for signs of HIV and AIDS.
- Rapid HIV tests used in adults can be used to test babies, but they will only tell us if the baby is exposed to HIV, not if the baby is definitely HIV-infected.
- Once the baby is 6 weeks old, a small amount of blood can be taken from the baby's heel and a test can be done to see if the baby is HIV-infected (this is for the DNA PCR test).
- Help the mom think about her support system – who will help her if the baby is HIV-infected? Who will help her come to clinic appointments? These people can be treatment supporters if and when the baby starts taking medicines.
- Make sure mothers understand that the results will take time and schedule an appointment for the mother and baby to return to the clinic to pick up results. You can follow up if the mom or caregiver does not come back to pick up the results.
- If the test is positive, the baby is HIV-infected and most babies should start ART right away. Help the mom and the baby go to the ART clinic to get the child enrolled as soon as possible. If the mom is breastfeeding, she should continue to do so as this will help the baby.
- If the result of the test is negative and the mom is still breastfeeding, she should keep breastfeeding, make sure the baby is brought to the clinic for regular visits and then retest the baby 2-3 months after she has stopped breastfeeding completely. The baby is still at risk of becoming HIV-infected as long as it is breastfeeding.

HIV testing in children over 18 months of age:

- Once children are 18 months old, they can be tested for HIV with the rapid test used on adults.
- If the child is still breastfeeding, he or she should be retested after the mother has completely stopped breastfeeding.

SESSION 7.5: Introduction to Pediatric HIV Care and Treatment

Pediatric HIV:

- Children are not little adults. Adults can live many years with HIV before they get sick. But children, particularly babies, are not as strong and can get sick very quickly once infected with HIV.
- 50% of babies with HIV will die before their second birthday without care and ART.
- Caring for sick children and having a child die can be very hard emotional experiences for families.
- Children are our future and we need to keep them healthy to build strong communities and a strong nation.
- Babies and children with HIV who are in care and take ART can live long, healthy lives and grow up to be healthy adults.

Pediatric ART:

- As with adults, ART can help keep babies and children with HIV healthy, strong and able to live a whole lifetime when they adhere to their care and medication regimens.

You can help families understand and access pediatric ART and the care and treatment services they need to have healthy families and communities.

Common first-line ART regimens for infants and children (depends on your national pediatric HIV guidelines – these are just some examples):

AZT + 3TC + NVP or (EFV)
AZT (or ABC) + 3TC + LPV/r
ABC + 3TC + NVP (or EFV)

**Note that EFV should not be given to children under 3 years of age.

Common ARV names

AZT = zidovudine
3TC = lamivudine
NVP = nevirapine
EFV = efavirenz
ABC = abacavir
LPV/r = lopinavir/
ritonavir (Kaletra)

Key issues for pediatric ART:

- Most babies and young children with HIV will need ART since they get sick quickly and are at great risk for illness and death.
- All HIV-infected babies and children also need CTX.
- The WHO recommends that all children less than 2 years of age who are HIV-infected start ART, but it is important to follow national guidelines.
- You can help caregivers understand pediatric HIV and make an ART adherence plan with the multidisciplinary care team.
- Success with pediatric ART depends on a partnership among the caregiver(s), the child, the multidisciplinary care team at the clinic, and the community.
- All members of the family and all caregivers must be prepared to give the child ART at the same time, the right way, every day. Children must cooperate and be involved in their treatment.
- There are many barriers to adherence with pediatric ART.
- Pediatric ARVs are not always available in syrup form, so pills may need to be crushed or dissolved in water or juice.
- The dose of different ARVs will change often in children because it depends on their weight.
- If parents or caregivers have not disclosed their HIV-status it makes it hard to tell people about children's HIV-status.
- As children get older, they should know about their own HIV-status.



The most important thing to remember about pediatric ART is that clients and caregivers need to come back to the clinic often to see the doctor.

They also need support at home and in the community. Like with adults, it is very important for children to take ARVs at the right time, the right way, and at the same time every day.

SESSION 7.6: Classroom Practicum on PMTCT

Case Study 1:

A 22-year-old woman named W___ comes to the ART clinic for a regular appointment. She is doing well on her ART regimen and confides in you that she really wants to have a baby. She has discussed it with her husband, who is also living with HIV, but he told her that it is not responsible for them to have a baby because it will definitely be born with HIV. What would you tell her about PMTCT services, family planning, etc.?

Case Study 2:

You are talking with a pregnant woman named L___ who just received her CD4 test results. Her CD4 cell count is 150. You sense that she does not understand why the CD4 test was done or what the number means. She has not disclosed to her partner yet and is very afraid that her baby will have HIV. What things would you talk to her about?

Case Study 3:

C___ comes to the health center for her first antenatal care visit. She takes an HIV test, which is positive. She is very upset because she's certain that she's been cursed and her baby will have HIV for sure. You want to discuss ARVs with her to protect herself and the baby, but she says that ARVs will kill the baby – they are too strong to take while pregnant. What would you tell her about ARVs during pregnancy?

Case Study 4 (for countries using WHO Option “A” only):

F___ is 2 months old. His mother is HIV-positive, took ARVs during pregnancy and for 7 days after delivering, and now has brought F___ to the clinic. The mother says that she is breastfeeding the baby but complains that he does not feed well and cries a lot, and that she is thinking of adding some formula so that the baby can get full. When you talk to the mother, she says she sometimes forgets to give F___ the NVP syrup every day because she is busy and feels badly when she gives him medicines and he cries. Her husband also questioned her about why the baby needs medicines at such a young age. What would you talk with F___'s mother about?

Case Study 5: (for countries using WHO Option “B” only):

A 30-year old woman named P___ is a client in the PMTCT program. Her CD4 count was 700 and she began taking 3 ARVs during her pregnancy and delivery. She is returning to the clinic for the baby’s check up. P___ is exclusively breastfeeding her baby. The baby took NVP at birth and every day for 6 weeks. P___ complains that she is facing a challenge at home. Her boyfriend does not understand why she is still taking ARVs every day because she is feeling good and has a high CD4 count. He thinks it’s dangerous for the baby if she continues to take ARVs during breastfeeding and she is not sure what to tell him. How would you counsel P___ about why she needs to keep taking ARVs during breastfeeding, even though her CD4 count is high and she is feeling well?

Case Study 6:

S___ brings her niece to the clinic for immunizations. In talking with S___, you learn that the baby is HIV-infected and is taking CTX and ART. The baby’s mom (S___’s sister) is very busy at her market shop and does not bring the baby back to the clinic often, causing him to run out of medicines. S___ wants a 3-month supply of medicines so that she and the baby do not have to come back to the clinic so much. What would you say to S___ about how important it is to bring the baby back to the clinic often?

Case Study 7:

At a mother’s support group meeting, a woman named O___ asks a question. She has an 8-week-old baby and she wants to know if her baby has HIV like she does. She is worried that her husband and mother-in-law will be very angry with her if the baby is HIV-infected. She feels very lonely and afraid. Some of the other women in the group say they are going through the same thing. What would you discuss during the support group – for example, testing babies for HIV, caring for babies that are exposed to HIV, ongoing care for mothers, safe breastfeeding, etc.?

Note: Some of the preceding information in this Module was adapted from the following sources:

WHO. (2010). *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: towards universal access, Recommendations for a public health approach*. Geneva, Switzerland: World Health Organization.

WHO. (2007, revised in 2010). *Antiretroviral therapy for HIV infection in infants and children: towards universal access, Recommendations for a public health approach*. Geneva, Switzerland: UNAIDS.

WHO. (2010). *Antiretroviral therapy for HIV infection in adults and adolescents, Recommendations for a public health approach*. Geneva, Switzerland: World Health Organization.

SESSION 7.7: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- MTCT-Plus programs try to reduce the risk of HIV to the baby, but also try to give the mother, the baby and the whole family ongoing care, support and treatment.
- The PMTCT motto is “SAVING 2 LIVES” (the mom’s and the baby’s).
- Peer Educators should help women receiving PMTCT services enroll in the care and treatment program, receive follow-up services for themselves, their babies and other family members, join support groups and find nutritional and other support services in the community.
- Not all babies born to women living with HIV will have HIV. About 1 out of 3 will become HIV-infected if there are no PMTCT interventions (including ARVs for the mother and baby).
- There are many things that can be done to prevent MTCT before pregnancy, during pregnancy, during the time of labor and delivery, and after the baby is born and during breastfeeding. Peer Educators should be familiar with interventions at each stage and talk to people in the community about the importance of PMTCT services.
- All pregnant women need to take ARVs. Pregnant women should be prioritized for HIV care and treatment with ART if they are eligible (according to national guidelines). Pregnant women not eligible for ART should take ARVs starting at 14 weeks of pregnancy (according to national guidelines). Most ARVs will not hurt the baby and this is one of the best ways to prevent MTCT.
- All babies exposed to HIV also need to take ARVs. All babies need to take ARVs at birth and for the first 4-6 weeks of life. Breastfeeding babies whose moms are not taking ARVs need to take ARVs every day until one week after stopping breastfeeding.
- Pregnant women should also take cotrimoxazole (CTX) if they are eligible (according to national guidelines).
- There is HIV in breast milk. Exclusive formula feeding is the only way to prevent HIV transmission from the mother to the baby after it is born, but there are also many risks of formula feeding for the baby, including sickness and death.
- For most women, exclusive breastfeeding – with either the mom or the baby taking ARVs - for as long as possible up to 6 months is best for the baby. After 6 months, the baby needs other foods in addition to breast milk or formula. Giving other foods, along with breast milk or formula, does not increase the risk of MTCT after the baby is 6 months old.

(KEY POINTS, CONTINUED)

- When the mom or the baby takes ARVs during breastfeeding, it makes breastfeeding safer and lowers the chances that the baby will become HIV-infected. Moms can safely give breast milk plus complementary foods – with the mom or the baby taking ARVs every day until one week after stopping breastfeeding – through 12 months.
- Mothers should only stop breastfeeding when there is a good, safe supply of replacement foods for the.
- Women and their babies should keep coming back to the clinic for care and treatment, child health and other services.
- All HIV-exposed babies should get follow-up care and take CTX until their HIV-status is known for sure.
- HIV makes babies and children sick quickly, so we need to identify them early and get them enrolled in care and treatment as soon as possible.
- The only way to tell for sure if a baby under 18 months of age is HIV-infected is through “DNA PCR” testing with dried blood spots (DBS), which can be done when the baby is at least 6 weeks old.
- Adult HIV tests can be used to tell if a baby under 18 months has been exposed to HIV or if a child over 18 months old is HIV-infected.
- Without ART, most children with HIV will die before their second birthday.
- With ART, children with HIV can become healthy, productive adults.
- The 6 key points to remember with following HIV-exposed and infected children are:
 - Come back to the clinic often. If the baby is sick, come in right away.
 - Go for early HIV testing.
 - Give ARVs to the baby every day for the first 4-6 weeks (all babies and every day until one week after breastfeeding has stopped (babies whose moms are not taking ARVs/ART).
 - Give CTX to the baby every day (starting at 6 weeks).
 - Weigh and measure the baby at each visit.
 - Focus on the whole family.

MODULE 8:

Adherence and Psychosocial Support



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Define adherence and psychosocial support
- Understand the importance of adherence and psychosocial support in HIV prevention, care and treatment programs
- Describe common factors affecting adherence and psychosocial well-being among clients
- Work within the multidisciplinary team to provide preparatory and ongoing adherence and psychosocial education, counseling and support to clients and families, including group education sessions and individual counseling sessions
- Conduct a client-centered adherence and psychosocial support assessment
- Provide clients and families with follow-up adherence and psychosocial support counseling, support and referrals



CONTENT:

- Session 8.1: Introduction: The Importance of Adherence
- Session 8.2: Adherence Basics
- Session 8.3: Psychosocial Support Basics
- Session 8.4: Common Barriers to Adherence and Psychosocial Well-Being
- Session 8.5: Helping People Adhere to Care
- Session 8.6: Helping People Prepare for and Adhere to Treatment, Part 1 - Group Education
- Session 8.7: Helping People Prepare for and Adhere to Treatment, Part 2 - Individual Counseling, Assessment and Planning
- Session 8.8: Providing Ongoing Adherence and Psychosocial Support

Session 8.9: Classroom Practicum on Adherence
and Psychosocial Support Counseling
Session 8.10: Module Summary

SESSION 8.1: Introduction: The Importance of Adherence

Adherence describes how faithfully a person sticks to, and participates in, her or his HIV prevention, care and treatment plan.

Adherence:

- Includes active participation of the client in her or his care plan
- Includes adherence to both medications and care
- Depends on a shared decision-making process between the client and health care providers
- Determines the success of HIV care and treatment programs
- Is not static – it changes over time



SESSION 8.2: Adherence Basics

Adherence to care includes:

- Entering into and continuing on a care and treatment plan
- Taking medicines to prevent and treat opportunistic infections (OIs)
- Participating in ongoing education and counseling
- Attending appointments and tests, such as regular CD4 tests, as scheduled
- Picking up medications when scheduled and before running out
- Recognizing when there is a problem or a change in health and coming to the clinic for care and support
- Adopting a healthy lifestyle and trying to avoid risky behaviors

Adherence to treatment includes:

- Taking ARVs correctly, as prescribed, for the person's whole life, even if the person feels healthy ("every pill, every day")
- Taking other medicines, such as CTX, as prescribed
- Not taking any treatment "breaks"
- Giving medications to HIV-exposed and HIV-infected babies and children as prescribed

Non-adherence includes:

- Missing appointments at the hospital or health center, lab or pharmacy
- Not following the care plan
- Missing a dose or doses of medicine
- Sharing medications with other people
- Stopping medicine for a day or many days, or taking a treatment "break"
- Taking medicines at the wrong times
- Taking medicines without following instructions about food or diet
- Not reducing risk-taking behavior (for example, not practicing safe sex or not delivering a baby with a trained health care provider)

Remember: No one is perfect. It is important not to judge clients if they are non-adherent. Instead, we should try to uncover the root causes of non-adherence and help clients find ways to resume good adherence as soon as possible.

Why is adherence important?

- To ensure that ART and other medications do their job
- To increase the CD4 cells and decrease the amount of HIV in the body
- To avoid the HIV becoming resistant to certain medicines
- To make sure people get all the benefits that OI medicines and ARVs have to offer, such as feeling better, not getting OIs, etc.
- To prevent mother-to-child transmission of HIV
- To monitor the person's health and also help the person find community support resources
- To keep the person looking and feeling good so they can get back to normal life
- To prevent sickness and death
- To keep families, communities and our nation healthy and productive



What happens when a person does not adhere?

- The levels of drugs in the body drop and HIV keeps multiplying.
- A mother is more likely to pass HIV to her child during pregnancy, delivery or breastfeeding.
- The CD4 cell count will drop and people will start getting more OIs.
- Children will become ill very quickly.
- People's HIV can develop resistance to one or all of the drugs, meaning that the drugs will not work anymore even if they are taken correctly again.
- The ARV combination the person was originally taking will not work anymore and people may have to start taking a new regimen or second-line ARVs (but there might not be many kinds of these ARVs available).

Remember: Development of drug resistance must be avoided. There are not many other drug options if people develop resistance to the drugs they are started on!

SESSION 8.3: Psychosocial Support Basics

Psychosocial support addresses the ongoing emotional, social and spiritual concerns and needs of people living with HIV, their partners, their family and caretakers of children living with HIV.

Common psychosocial support needs of clients living with HIV:

- Support in understanding and coming to terms with their HIV-status and the effect it has on their own and their family's lives
- Discussion of views about taking medication, especially during pregnancy – including the fact that many pregnant women are not “sick,” which impacts their views on taking and adhering to medication and coming to the clinic for ongoing care
- Empathy and acceptance from caregivers and family members
- Peer support from other pregnant women and mothers
- Strategies to disclose their HIV-status to their partner and other family members
- Strategies to encourage their partner and other family members to test and, if appropriate, enroll in care and treatment programs
- Access to social welfare services
- Access to community-based organizations that support income-generating activities
- Spiritual support and referrals to spiritual counseling
- Knowledge about their legal issues and rights
- Support for mental health, including anxiety and depression
- Substance abuse management



SESSION 8.4: Common Barriers to Adherence and Psychosocial Well-Being

Common barriers to adherence and psychosocial well-being

Things about individual people that can affect adherence and psychosocial well-being:

- How well they think they can adhere
- Acceptance of HIV-status
- Ability to disclose
- Having a treatment supporter
- Understanding the benefits of care and treatment and PMTCT services
- Quality of life while on treatment
- How sick or well a person feels
- Travel and migration
- Health status
- Mental illness, like depression
- Drug or alcohol abuse
- Concern for the family's well-being

Things about our communities and our culture that can affect adherence and psychosocial well-being:

- Poverty
- Lack of food
- Stigma
- Social support
- Lack of child care to attend clinic
- Ability to take time off work to attend clinic
- Family structure and decision-making
- Gender inequality
- Violence
- Forced migration
- Distrust of the clinic/hospital
- Use of traditional medicine
- Political instability or war
- Physical environment (for example, mountains, seasonal flooding, etc.)



Things about health services that can affect adherence and psychosocial well-being:

- The cost of health services or medicines
- Drug stock-outs
- Distance to the clinic/transportation costs
- Convenience of clinic hours
- Patient record and tracking systems
- Number and type of health care workers
- Provider attitudes
- Provider language
- Youth-friendliness of services
- Waiting times
- Space for private counseling
- Linkages between different services
- Referral systems
- Linkages to social and material support in the community
- Linkages to home-based care services
- Support groups
- PLHIV involvement

Things about ARV medicines that can affect adherence and psychosocial well-being:

- Side effects
- Number of pills in regimen
- Dose timing
- Availability of reminder cues – pill boxes, calendars, alarms, etc.
- Taste
- Changing pediatric doses
- Changes in drug supplier – labeling, pill size, color, formulation

SESSION 8.5: Helping People Adhere to Care

Adherence to care includes:

- Entering into and continuing on a care and treatment plan
- Taking medicines to prevent and treat opportunistic infections
- Participating in ongoing education and counseling
- Attending appointments and tests, such as regular CD4 tests, as scheduled
- Picking up medications when scheduled and before running out
- Recognizing when there is a problem or a change in health and coming to the clinic for care and support
- Adopting a healthy lifestyle and avoiding risk behaviors
- Making a commitment to preventing new HIV infections

Standard appointment follow-up schedule for adults, pregnant women and children (depending on national guidelines)

Adults enrolled in care, but not on ART:

- At least every 6 months, or more often if needed
- For clients with advanced HIV, every month

Adults starting ART:

- Second week after starting ART
- Fourth week after starting ART
- Every month for the first year on ART
- Every 3-6 months for a check-up

Adults on ART

- Every month for the first year on ART
- Every 3 months for medicine refills after the first year on ART
- Every 6 months for a check-up

Pregnant women living with HIV

- Every month

Postpartum women living with HIV

- 6 days postpartum
- 6 weeks postpartum and during newborn's immunization visits
- Then every 3 months

HIV-exposed children

- Every month if under 1 year of age
- Every 3 months if over 1 year of age
- Visits should be timed with immunizations when possible

HIV-infected children not on ART

- Monthly during the first year
- Then every 3 months

HIV-infected children on ART

- 2 weeks after starting ART
- Every month for the first year on ART
- Then every 3 months for a check-up after the first year on ART
- Every 6 months for lab tests

Adherence for pre-ART clients

- Adherence is very important for all clients enrolled in HIV care, not just clients taking ART.
- In many places, clients not on ART are lost to follow-up and only return to the clinic after becoming ill.
- You can counsel clients not taking ART on the importance of adherence to their care plan, including returning for clinic appointments, getting routine laboratory tests and taking CTX, TB treatment and other medications as prescribed.
- It is very important that clients not on ART get regular lab tests (like CD4 cell counts) and check-ups so that when they become eligible for ART, they can start right away before becoming very ill.

Strategies to improve adherence to care

Client-friendly services:

- Welcoming and comfortable environment
- Pregnant women are given priority
- Clinic is easy to access and services are “co-located,” meaning that a person can get many health needs taken care of in one visit
- Child care facilities at clinic
- Convenient/flexible hours



Good communication:

- Use good communication and active listening skills.
- Ask open-ended questions about adherence to help the client share.
- Use reflection to make sure you understand what the person is saying.
- Show concern and respect.
- Never judge someone who you are counseling.

Confidentiality:

- Make sure all clients understand that what is said at the clinic is confidential.
- Assure that HIV-status will not be disclosed without consent.
- Remind clients that they might see other community members at the clinic and help them prepare for this.
- Remind clients that care and treatment information may be shared among the multidisciplinary care team, but not beyond it (shared

Remember, clients have a right to privacy and confidentiality. Their HIV-status should never be disclosed without prior consent.

Education and peer support:

- The Peer Educator program can help clients understand their illness and the need to return to the clinic even if they are not on ART.
- You can talk with clients about potential adherence challenges, and jointly come up with solutions. You can help clients create an individual adherence plan.
- Support groups and one-on-one counseling sessions are good for adherence support.
- PLHIV associations can also help their members with adherence.

Psychosocial assessment and support:

- You can conduct a one-on-one psychosocial assessment when clients first enroll in care.
- Another psychosocial assessment should be conducted when clients are preparing to take ART.

Strong outreach and follow-up, including an appointment and a tracking system:

- Use an appointment system to know which clients are supposed to come to the clinic each day and for which services.
- Give clients reminder cards so they know when to come back to the clinic.
- Develop tracing systems when clients miss appointments – plan ahead with the staff at the clinic.
- Keep contact information updated and organized for each client.
- Respect clients' wishes about how they prefer to be contacted.
- If the person gives consent, make a follow-up phone call or conduct home visits for those who have missed appointments (according to the specific follow-up plan at the facility).
- Conduct community education on the importance of adherence to care and treatment.
- Link clients with PLHIV associations and NGOs in the community that can help support adherence.

Remember: All members of the multidisciplinary team are responsible for supporting clients' adherence to care!

SESSION 8.6: Helping People Prepare for and Adhere to Treatment: Part 1 – Group Education

You play an important role in helping clients and their families prepare to start taking ART!

Adherence preparation and initiation

Make sure clients' information is recorded and regularly updated in the file, including:

- Name
- ART or ANC #
- Sex
- Age
- Physical address and description (if needed)
- Phone contact # (and whether it is their own or someone else's)
- Treatment buddy contact information
- Consent for phone call, SMS, and/or home visit noted

This information should be checked and updated at EVERY CLINIC VISIT!

What is a treatment buddy?

A **treatment buddy** or **treatment supporter** is someone who is chosen by a client about to start ART to provide ongoing support for adherence to care and treatment.

Conduct group education sessions:

In many countries, the national policy is that clients starting ART should participate in 2 or 3 group education sessions. For pregnant women initiating ART, this number can be reduced to 1-2, as we do not want to delay initiation.

Important points about group education sessions:

- Split up pre-ART initiation sessions into 2 or 3 distinct groups. Do not mix all clients into the same session because they will have different knowledge levels and questions depending on which sessions they have already been to.
- Divide clients based on which session they are coming for, and have separate times for group education sessions 1, 2 and 3.
- Invite treatment buddies to the group education sessions.
- Make sure the different group education sessions have structure – a list of key topics for each group education session is suggested in the table below.
- Try to hold group education sessions in a meeting room or large clinic room – it is better not to do the sessions in the waiting room.
- Make sure to note which people come to a session and note this in the clients' file.
- If possible, give clients take-away educational materials to remind them of what was covered in the sessions.
- Use the tips for conducting group sessions from *Module 4*.



Key Topics to Discuss in Group Education Sessions with Clients Starting ART

Pre-ART Session 1: HIV CARE AND TREATMENT BASICS

- Understanding the diagnosis
- How HIV is transmitted and prevented
- How HIV affects the immune system
- Meaning of CD4 cell count
- Who needs ART (for pregnant women, discuss that all mothers and babies will need ARVs, and some will need lifelong ART)
- Importance of ongoing care and regular clinic visits
- Positive living
- Safer sex, dual protection and prevention and treatment of STIs
- OI prophylaxis (especially CTX)
- TB prevention and treatment
- Importance of disclosure
- Family testing and enrollment
- Identify sources of social support (family, counselor, support groups, community groups)
- Summarize, answer questions and remind participants when the next session will be held
- Offer to provide follow-up on any of these topics in individual counseling

Key Topics to Discuss in Group Education Sessions with Clients Starting ART

Pre-ART Session 2: ADHERENCE TO HIV CARE AND TREATMENT

- Beliefs and attitudes about ART
- ART = lifetime commitment
- Importance of adherence to care plan and to treatment
- What can happen if you don't adhere to care and treatment
- Importance of social support and disclosure to adherence, including concept of a treatment buddy
- Previous adherence experiences (CTX, TB, etc.)
- Common adherence barriers/challenges
- Adherence strategies/tips
- Importance of support groups
- Linkages to home-based care
- Special adherence issues for pregnant women and children
- Summarize, answer questions and remind participants when the next session will be held
- Offer to provide follow-up on any of these topics in individual counseling

Key Topics to Discuss in Group Education Sessions with Clients Starting ART

Pre-ART Session 3: STARTING ART

- Understanding the treatment plan (explanation of each ARV, dosing schedule, missed/late doses)
- Preventing and managing side effects
- Problem solving around adherence barriers, including the use of tools such as medicine diaries, pill boxes, watches, cell phones, etc.
- How to make care and treatment plan part of every day life
- What to do if there is a problem or question
- Plan for 2-week and subsequent follow-up visits
- Reminders on positive living and safer sex
- Linkages and referral to support groups and community support services
- Summarize, answer questions and remind participants when the next session will be held
- Offer to provide follow-up on any of these topics in individual counseling

SESSION 8.7: Helping People Prepare for and Adhere to Treatment: Part 2 - Individual Counseling, Assessment and Planning

Conduct one-on-one psychosocial and adherence readiness assessments, help make an adherence plan and provide individual counseling

- At least one individual counseling session (more is better) should be provided to all clients before they begin taking ART.
- This is a good time to see what the client has taken from the group education sessions and in which areas they need extra support.
- The individual counseling session should include an adherence readiness and psychosocial support assessment (these may be conducted at the same time or at different times).



Key Topics to Address and Provide Additional Counseling on during the Adherence Readiness and Psychosocial Support Assessments

Adherence readiness assessment:

- Participation in group education sessions (how many, dates)
- Understanding of CD4 cell count
- Expectations about taking ART
- Understanding of how ARVs can prevent MTCT and make people healthier
- Confidence in ability to take medications every day, for entire life
- Confidence in ability to give infant medicines the right way
- Other caretakers of children and their knowledge of how to give medications
- Past experiences with adherence (for example, to CTX)
- Specific ARV regimen (names of drugs, color/shape, how and when to take)
- Common side effects
- How to manage side effects
- Importance of adherence and consequences of non-adherence
- Remembering to come to the clinic for regular appointments – how?
- Remembering to take pills on time, every day – how?
- Use of tools, such as medicine diary, pill box, calendar, watch, etc.
- Use of other medications, including traditional medicine
- Difficulties in coming to the clinic
- Plan for time spent away from home (during the day or for long periods of time)
- Plans for medication storage
- What to do if doses are missed
- What to do if people ask about ART
- What to do if there are any problems
- Concerns about taking ART
- Questions about care and treatment plan for self, baby or other family members



Key Topics to Address and Provide Additional Counseling on during the Adherence Readiness and Psychosocial Support Assessments

Psychosocial Assessment:

- Current living and relationship situation
- Disclosure to family members and partner
- Partner and other family member testing
- Partner or family members on ART
- # and ages of children
- Children tested, children on ART, children who are sick
- Disclosure to children
- Disclosure of children's status to other people
- Sources of support at home and in the community
- Actual or potential risk of stigma, discrimination, and/or violence at home and in the community
- Treatment supporter (record name and contact information)
- Member of support group or community organization or church
- Challenges with poverty, such as transport to the clinic, food security, etc.

SESSION 8.8: Providing Ongoing Adherence and Psychosocial Support

Provide on-going adherence monitoring and individualized support

- It is very important to assess adherence at each visit, but we must also take the next steps after assessment to offer clients ongoing, individualized adherence support.
- The purpose of ongoing adherence monitoring and support is to encourage clients (or caregivers) to express challenges and to be open about any problems they may be facing so that you can provide them with ongoing support.
- Make adherence a normal part of every clinic visit. Remember, adherence and psychosocial support needs change over time.
- Do not judge people. Make clients feel comfortable and not fearful that they will be punished or judged if they openly discuss adherence challenges.
- Talk about clients' adherence at multidisciplinary team meetings.
- Use tools to help assess and improve adherence, such as:
 - Pill counting
 - Reviewing medicine diaries or calendars with clients
 - Others



At each visit, ask:

- *Can you tell me more about how you took your medications this month?*
- *How many pills did you miss or take late in the last 7 days?*
- *How did the medicines make you feel?*
- *Can you tell me more about any problems you had with your medicines this month?*
- *What challenges did you have taking your medications this month?*
- *What support do you have to take your medications?*

Examples of questions about missed doses

- *Many people taking these medications find it difficult from time to time. What has your experience been?*
- *How many doses have you missed in the past day? Week? Month?*
- *Do you ever share your medicines with family members, like your husband/ wife or children?*

Examples of questions about adherence challenges

- *When is it most difficult to remember your medications?*
- *It is not easy to take medicine every day. What makes it hard for you?*
- *What things help you to take your pills?*
- *It's always hard to give children medicine. What problems have you had giving your child ARVs?*
- *What things make it hard to remember to take your medicines now that you're feeling better?*

If you feel that they are adhering well:

- Praise them for good adherence.
- Remind them to come back if there are any problems.
- Talk about how important it is to be open and solve challenges together.

If you feel that they have experienced some challenges with adherence:

- Give one-on-one counseling or refer to a counselor for difficult cases.
- Try to identify the specific challenges.
- Discuss specifics of how challenges affect adherence.
- Help solve challenges and reduce barriers.
- Discuss the importance of adherence.
- Give referrals to support groups or other organizations.
- Plan for next steps, including the clinic return date.
- Praise them for sharing their challenges.
- Record the session on the patient record.
- Follow up at next visit.

Giving advice about missed doses

For medicines taken twice per day:

- **Take** the missed dose if your next dose is scheduled for more than 6 hours away.
- **Do not take** the missed dose if the next dose is scheduled for less than 6 hours away.

For example, let's say that you usually take your medications at 7 am and again at 7 pm. If you miss your first dose at 7 am, **TAKE** the missed dose if you remember before 1 pm. **DON'T TAKE** the missed dose if you remember after 1 pm. Instead, just wait to take your next dose at 7 pm.

For medicines taken once per day:

- **Take** the missed dose if you remember within 12 hours of the scheduled dose time.
- **Do not take** the missed dose if the next dose is scheduled for less than 12 hours away.

For example, let's say that you usually take your medication at 7 am, once every day. If you miss this dose, **TAKE** the missed dose if you remember before 7 pm. **DON'T TAKE** the missed dose if you remember after 7 pm. Instead, just wait to take your next dose in the morning.

Never take a double dose (two doses at a time)!

SESSION 8.9: Classroom Practicum on Adherence Counseling

Case studies to discuss as a large group

Group Case Study 1:

N___ is married and has 4 children. She is 3 months pregnant and just found out during an ANC visit that she is HIV-positive. Her CD4 cell count is 175, so she is eligible for ART. What steps would you take to prepare N___ to start ART?

Group Case Study 2:

T___ is a 24 year-old man who just tested positive for HIV after he was referred for testing from the TB clinic. His CD4 cell count is 85 and the doctor asks you to start preparing him to start ART. T___ works as a truck driver. He is married and has 3 children. What steps would you take to prepare him to start ART?

Group Case Study 3:

A 27 year-old woman named C___ comes to you because she is in a lot of pain, is losing weight and has a high fever. She said she started taking ART about a year ago and felt really good within about 3 months. C___ admits that once she was feeling better she did not always take her ART every day because it was just a reminder that she had HIV. She wants to know why her ART is not working like it used to and why she is getting sicker and sicker even though she is taking the ART at the right time every day again.

Group Case Study 4:

A man named P___ comes to the clinic for a regular check-up and to get his ARV refill. You spend some time with him before he sees the doctor. How would you ask P___ about his adherence? What advice would you give him when you learn he usually misses his morning dose because he has no food to eat – he only has enough for one meal per day, which he eats at night?

Case studies to discuss in small groups

Case Study 1:

M___ is a 34-year-old married woman with two children aged 3 and 7. Her children live with their grandmother in another province. M___ is working as a domestic worker and has been on HAART for two months but has not disclosed to her employer or her family. She returns to the clinic to pick up her refill. The pharmacist notices she has many pills left over and she says she is having trouble remembering to take her medicines every day. How would you provide adherence and psychosocial support to M___?

Case Study 2:

N___ is 15 years old, pregnant, and tested positive for HIV during her first ANC visit. During adherence counseling, she disclosed to the health worker that if the treatment is for life, it will be difficult for her to take because she will not disclose to anybody. She expressed her fears of her parents throwing her out of the house and not supporting her, but she wants to protect her unborn baby. What kind of psychosocial support would you provide to N___?

Case Study 3:

A man named V___ has been on ART for 4 years. Usually his adherence is almost perfect and he is feeling fine when he comes for refills, but this time he says things are not going well. You talk to him about what is going on. He says he got fired from his job at an office and now is working as a bus driver. He is working different hours and far from home. Some days he starts work at 6 in the morning and sometimes at noon. Since starting this new job, V___ forgot to take his pills with him to work two different times and has had to wait until he gets back home to take them. He does not want anyone at his new job to know he is HIV-positive.

Case Study 4:

A 26 year-old woman named B___ tested positive for HIV 6 months ago. She is caring for a sick husband and has 5 children. She is so busy that she has missed a couple of appointments at the ART clinic. Her husband is the only one who knows she is HIV-positive, and he himself has not been tested. She comes to the clinic because she thinks she might be pregnant and you meet her in the waiting area. How would you counsel B___?

Case Study 5:

A woman named D___ comes to you because she has diarrhea and a rash all over her body and wants to stop taking ART. She tells you that she's missed 3 doses in the last month but thinks that taking the doses most of the time is good enough. She is worried about being a burden on her family so she doesn't talk to them about the medicines, but they do know she's HIV-positive. How would you counsel D___?

Case Study 6:

You meet with a mother named T___ and her 4-year-old child at the clinic. When you ask how the mother is doing, she cries and says she feels so badly because her son is spitting up his medicine and refuses to cooperate. She stopped giving him the medicines because she didn't want him to cry and it made her feel like a bad mother. How would you counsel T___?

SESSION 8.10: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- Adherence means how faithfully people stick to the care and treatment plan.
- Adherence support is most successful when it is provided by a number of people on the multidisciplinary care team in partnership with clients and their families.
- Adherence to care is important to make sure people stay healthy, understand how to live positively, know when to start ART and get psychosocial support at the clinic and in the community.
- Adherence to treatment is important to lower the amount of HIV in people's body and to make sure they get all the benefits that OI medicines and ARVs have to offer (feeling better, not getting OIs, etc).
- Non-adherence to treatment can lead to drug resistance, preventing the ART from working and making people very sick.
- There are many barriers and challenges to good adherence and psychosocial well-being, including things related to people's lives, to the medicines, and to the health care system and HIV program.
- ART preparation includes group education sessions, one-on-one counseling sessions, and adherence and psychosocial support assessments and planning.
- Adherence barriers and challenges will change over time. It is important to ask about adherence at all follow-up visits.
- It is important that health care workers build a trusting relationship with clients so that they feel comfortable being completely honest about their adherence and psychosocial support needs.
- The use of tools, such as pill counting or an adherence calendar or diary can help support adherence activities.
- It is important to remember to use good communication and counseling skills whenever conducting adherence and psychosocial support groups or one-on-one sessions.

APPENDIX 8A: Generic Adherence Readiness Assessment Form

Clinic Name: _____

Date: _____

Client Name: _____

Client #/ART #: _____

1. Have you attended group education sessions at the clinic?

Yes. How many? _____ No

2. Can you explain why you think you need to take ARVs?

3. What do you expect from taking ARVs?

4. Do you feel confident that you can take (or give children) medicines every day for the rest of your life?

Yes No *counsel on lifelong adherence*

5. For caregivers, who else takes care of the child other than you?

Have these caregivers been trained on giving medications?

Yes No *counsel on training all caregivers*

6. Have you had any challenges taking other medications (TB treatment, CTX, etc.) every day at the same time?

Yes No

7. Can you tell me the names of the ARVs you will be taking and what time you will take each medicine? List:

8. Can you tell me some of the side effects of your medicines?

9. What will you do if you have side effects? *counsel on side effect management*

10. Do you know what can happen if you do not take all of your ARVs every day, at the same time, for life? *counsel on lifelong adherence*

11. Do you have a treatment supporter?

Yes No

Name and contact number: _____

Has he/she been to the clinic with you? Yes No

12. Do you have any difficulties coming to this clinic for appointments?

Yes No *counsel on adherence to care*

13. How will you remember to come for your clinic appointments?

14. How will you remember to take your pills on time everyday?

15. Are you taking any other medicines other than the ones prescribed for you by the doctor? (Include traditional & herbal medicines)

Yes No *counsel to be cautious of other medicines*

16. How and where will you store your medication?

17. What will you do if you are about to run out of pills?

18. What will you do if you miss a dose of your medication?

19. Do you have any questions about your care and treatment plan?

Assessment of patient readiness to start ART:

Patient ready to start ART

Patient requires more preparation & counseling

Other issues and notes:

Name of person completing assessment: _____

APPENDIX 8B: Generic Psychosocial Assessment Form

Clinic Name: _____

Date: _____

Client Name: _____

Client #/ART #: _____

1. Who lives with you at home? List:

2. Have you disclosed your HIV-status to your family?

Yes No *counsel on disclosure*

3. Have you disclosed your HIV-status to your partner(s)?

Yes No *counsel on disclosure*

4. Has your partner(s) been tested for HIV?

Yes No *counsel on partner(s) testing*

5. Is your partner taking ART (if living with HIV)? *If yes, clinic name*

Yes No

6. Do you have any children?

Yes No *counsel on HIV testing for all children*

Age: _____ Tested for HIV? Yes No

Age: _____ Tested for HIV? Yes No

Age: _____ Tested for HIV? Yes No

Age: _____ Tested for HIV? Yes No

7. Are any of your children taking ART (if HIV-infected)?

Yes No *counsel on pediatric treatment*

8. Have you told the children their HIV-status (if HIV-infected)?

Yes No *counsel on disclosure to children*

9. Who else have you told about the children's HIV-status (if HIV-infected)?

counsel on involvement of all caregivers

10. Do you have a treatment supporter?

Yes No *counsel on treatment support*

Name and contact number: _____

Has he/she been to the clinic with you? Yes No

11. Who do you go to for support at home or in the community? List:

12. Do you belong to a community organization, support group, or religious group?

Yes No *counsel on support groups*

Name of organization or group: _____

13. Do you ever fear discrimination or violence at home or in the community?

Yes No *counsel and refer for support*

14. Who is your community health care worker?

Name: _____

Would it be okay if someone visited you at home if you miss an appointment at the clinic?

Yes No

15. Do you face financial challenges, like not having enough food to eat or not being able to pay for transport to the clinic?

Yes No *refer to community support*

List specific challenges:

Other issues and notes:

Name of person completing assessment: _____

APPENDIX 8C: Generic Adherence Follow-up Assessment Form

Clinic Name: _____

Date: _____

Client Name: _____

Client #/ART #: _____

A. Individual Counseling Session

1. Can you tell me more about how you took your medications this month?
2. How many pills did you miss or take late in the last 7 days?
3. How did the medicines make you feel?
4. Can you tell me more about any changes or problems you had with your medicines this month?
5. What challenges did you have taking your medications this month?
6. What support do you have to take your medications?

B. Results of Pill Count (if applicable)

C. Review of Medicine Diary or Calendar (if applicable)

D. Review of Chart (including CD4 cell count and viral load, if available; this should be completed by a pharmacist or clinician)

Specific adherence challenges identified:

Next steps for the client:

Next appointment date: _____

Other issues and notes:

Name of person completing assessment:

MODULE 9:

Identifying and Tracing People Who Do Not Return to the Clinic



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Help prevent missed appointments through good communication and counseling with clients, as well as using appointment reminders
- Describe local policies and procedures to identify and trace clients who have missed appointments
- Obtain and record consent for different types of follow-up
- Describe the ways you can identify clients who have missed appointments
- Conduct a follow-up phone call with a client who has missed an appointment
- Conduct a follow-up home visit with a client who has missed an appointment
- Record key information from a follow-up call or visit
- Provide supportive counseling for clients who are returning to the clinic after missing 1 or more appointments



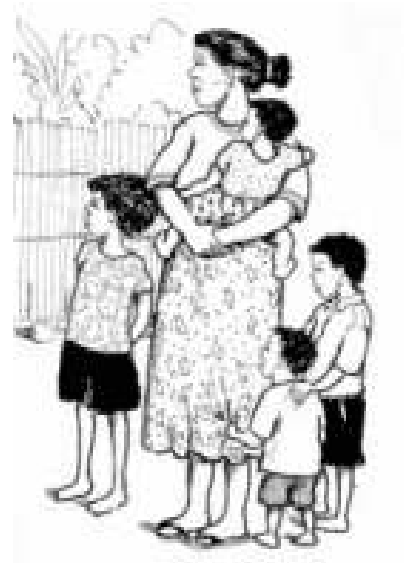
CONTENT:

- Session 9.1: Introduction: Why Do Clients Miss Clinic Visits?
- Session 9.2: Identifying People Who Do Not Return to the Clinic
- Session 9.3: Strategies to Follow Up with People Who Do Not Return to the Clinic
- Session 9.4: Classroom Practicum on Client Follow-up
- Session 9.5: Module Summary

SESSION 9.1: Introduction: Why Do Clients Miss Clinic Visits?

Common reasons clients miss clinic visits:

- Clinic hours are not convenient
- Work schedule is not flexible
- Long distances to travel
- Lack of funds for transportation to clinic
- Long wait time at the clinic
- Unfriendly environment at clinic
- Embarrassed or ashamed about adherence challenges
- Need to take care of a child or a family member
- Too sick to leave the house and reach the clinic
- Forgot when the next appointment is
- Feel well and do not want to go to the clinic
- Do not understand the importance of returning to the clinic at the right times
- Do not understand when or why the next visit was scheduled
- Moved to another home that is not near the clinic
- Prefer to use traditional medicines
- Went away for a long visit, seasonal work or holiday
- Worried that a family member, neighbor or other clients will see them going to the clinic or at the clinic
- Client died
- Others



You can help prevent clients from missing clinic visits by supporting them to understand how important it is to adhere to the care plan, even if they are not on ART!

SESSION 9.2: Identifying People Who Do Not Return to the Clinic

You can make sure clients' information is recorded and regularly updated in the file at each visit, including:

- Name
- ART or ANC number or health record number
- Sex
- Age
- Physical address and description (if needed)
- Phone contact number (and whether it is their own or someone else's)
- Treatment buddy contact information
- Consent for phone call, SMS (text message) and/or home visit

In some places, clients may not give correct phone and address information on purpose because they do not want to be contacted. The best way to prevent this is to encourage open and honest communication and to explain how important it is to have the correct contact information on file.

Getting consent to follow-up with clients:

It is very important to get each client's consent for follow-up by phone or by a home visit. You should talk with other members of the multidisciplinary team to figure out how a client's consent is noted on the ART or ANC card. You should always check the client's file before following up by phone call or home visit.

Here are some ways to do this:

On the ART or ANC card, near the place where the client's contact information is written, you can use the following notations (adapt to your clinic setting):

SMS

PC

HV

In this example, the client has consented to receive an SMS, a phone call (PC) and a home visit (HV) if he or she misses an appointment at the clinic.

OR

SMS

PC

~~HV~~

In this example, the client has consented to receive an SMS and a phone call (PC), but not a home visit.

OR

~~SMS~~

~~PC~~

~~HV~~

In this example, the client has refused an SMS, a phone call (PC) and a home visit (HV).

It is important to respect every client's right to refuse follow-up SMS, phone calls and home visits.

If clients do not give consent for follow-up, explore their reasons during an individual counseling session and follow up at the next clinic visit.

Identifying clients who have missed an appointment:

There are many tools that can be used to see who has missed an appointment, including:

- ANC and ART clinic appointment books
- Laboratory registers
- Pharmacy registers
- Others

Appointment books:

- Each health facility should have an appointment system in place, including an up-to-date appointment book.
- You should speak with other members of the multidisciplinary team to learn more about the appointment system and your role in this system.
- See *Appendix 9A* for a sample appointment book page.



Appointment reminder cards:

- When each client is done with the clinic visit, he or she should be given an appointment to come back to the clinic.
- It is important to write down the date and time for clients and to explain clearly why they need to come back to the clinic on that day.
- See *Appendix 9B* for a sample appointment card.

Weekly listing of clients who miss appointments:

- At least once each week, you and your team should work together to make a list of all of the people who were at least one week late for their appointment at the clinic, lab or pharmacy.
- Once there is a list of people who have missed appointments, it will be easy to know who needs follow-up.

SESSION 9.3: Strategies to Follow Up with People Who Do Not Return to the Clinic

Every health facility should have a system to identify clients who have missed appointments and follow them up to bring them back into care!

Phone call or SMS to the client or the client's treatment supporter:

Always follow the policies and procedures at your clinic. Always check that the client has given consent before calling.

Here are some general tips on following up with clients by phone:

- If sending an SMS, use the agreed upon messages. Never give lab results or specific information about the client's care in an SMS.
- If the client still does not call back or return to the clinic after sending an SMS, you can follow up with a phone call.
- If making a phone call, make sure you are in a quiet room.
- Make sure you have all of the client's information and file in front of you before you call.
- Always try and speak with the client her- or himself.
- Use scripts to know what to say when you talk with a client.
 - Tell the client your name.
 - Tell the client your reason for calling (that she or he has missed an appointment for _____ service).
 - Discuss reasons why the client should come back to the clinic.
 - If the client refuses, provide adherence counseling and try to determine why the client will not come back. You could also ask if the client would be willing to accept a home visit so you could talk more in person.
 - If the client accepts, make an appointment at a time and day that is convenient for the client (as soon as possible).
 - Thank the client for taking the time to speak with you.
- Phone calls should be focused on giving basic adherence counseling and getting the client to return to the clinic. Never give test results over the phone!
- Keep information confidential! If you talk to someone other than the client, do not say you are from the ART clinic.
- Record every call and SMS in a call logbook. See *Appendix 9C* for a sample.



Home visit by a community health worker or other Peer Educator linked to the health facility:

If the client has given consent for a home visit, you or other members of the multidisciplinary team can meet with community outreach to plan for follow-up home visits.

Home visit by Peer Educators:

Remember, a home visit should only be conducted if a client has given consent. You should learn more about the home visit policies and procedures at your clinic, but here are some general tips:

- Talk with the rest of the multidisciplinary team before doing any home visiting.
- During the home visit, first introduce yourself and say that you are from the clinic.
- Always try and talk to the client in person and in a private spot. Ask if it is a good time to talk, or if you should come back another time.
- Always keep information confidential when you are speaking with other members of the family or community.
- Once you talk with clients, discuss why they missed the appointment, what makes it hard to come to appointments and how they can come back to the clinic as soon as possible. Help clients make a concrete plan for coming back (such as they will ask a family member to babysit next Tuesday and will get there by taxi).
- Provide adherence counseling and remind clients how important it is that they return to the clinic for specific services.
- Ask clients if you can check in every now and again to see how things are going.
- Always be supportive and never judge clients for missing an appointment.
- Write down the outcomes of all home visits, even if you were not able to find the client.
- Discuss the outcomes of home visits with the rest of the multidisciplinary team. Contact the clinic right away if you find that a client is very ill and try to arrange for her or him to be transferred to the clinic or a hospital.
- If clients still cannot be located during a home visit, do not give up. They might be traveling and eventually come back to the clinic. Keep following up through calls and home visits, even if the first try is not a success.



When clients do return to the clinic for their appointment, it is very important to discuss how important it is to keep appointments and adherence to care and treatment. Some clients may require individual adherence counseling and problem solving.

Communicating with the rest of the multidisciplinary team:

The rest of the multidisciplinary team should be updated on the results of follow-up through SMS, phone calls, and home visits and also be informed of any issues faced. The monthly multidisciplinary meeting is a good time to discuss the outcomes, issues and challenges with patient follow-up.



SESSION 9.4: Classroom Practicum on Client Follow-up

Case Study 1:

The social worker asks you to call B__ because she missed her ART refill appointment 7 days ago. What would you say to B__ on the phone?

B__ tells you that she missed her appointment because she cannot leave her new job to come to the clinic. What would you say to B__?

Case Study 2:

You are asked to call C__, a woman who missed her appointment to pick up her child's HIV test results (which are positive). You check the file and C__ has given consent to call her. You call and a man answers the phone. What would you say?

The man says that he is C__'s husband and you can tell him what is going on. What would you say?

Case Study 3:

You have been trying to reach M__ by phone because he missed his appointment at the clinic. You know the number is working because one time a woman answered but said that M__ was not there. What would you do?

The nurse asks you to get in touch with the PLHIV association to do a home visit. You check M__'s file and notice that he gave consent for a phone call but not for a home visit. What would you do?

Case Study 4:

You go to the home of P__, a woman in care who has missed her 6-month check-up at the clinic. P__ says she is feeling fine now and is using holy water and herbs, which have made her well. She sees no need to come to the clinic since she feels well. What do you say to P__?

Case Study 5:

You ask the community health worker to visit A__, a PMTCT client who has missed an appointment at the clinic. What would you ask the community health worker to say during the home visit?

The community health worker reports back to you that A__ does not feel well enough to come to the clinic and that she is very busy taking care of her children and husband. What would you do next?

Case Study 6:

You are out in the community with a list of 5 clients to visit at home. You cannot locate the first client's home based on the information you have. What would you do?

You go to the home of another client, named T__, who missed his ART refill date almost 2 weeks ago. A woman answers the door when you knock. What would you say?

You learn that T__ is working in another province for the next 2 months. What would you say?

SESSION 9.5: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- Your priority should be to help clients understand the need to come to the clinic for all of their appointments. Good communication and counseling – starting when a client enrolls in care – can prevent missed visits.
- All health facilities should have policies and procedures in place to identify and follow up with clients who miss appointments.
- It is important for you to get a client’s consent to send an SMS, call or do a home visit if she or he misses an appointment. You should record this on the client’s file.
- Having an appointment system is the only way to know which clients did not come back to the clinic on time.
- Each week, you can work with the rest of the multidisciplinary team to identify which clients did not return to the clinic on time. This list of clients is the first step in client tracing.
- There are many ways for you to follow up with clients who miss appointments. You should follow the policies and procedures at the clinic. Follow-up can be by SMS, phone call or home visit by you or a community health worker.
- Always keep client information confidential during follow-up SMS, phone calls or home visits. Never disclose that the person is living with HIV or is receiving HIV care to anyone but the client or the treatment supporter.
- It is important that you record the outcomes of ALL follow-up SMS, phone calls and home visits.
- Part of follow-up is to provide individual adherence counseling to identify barriers and come up with solutions. You should provide adherence counseling during follow-up and also when the client returns to the clinic.

APPENDIX 9A: Sample Page from a Clinic Appointment Book (adapt to your local setting)

Date: Thursday – 4 June 2009

	Patient Name	Clinic number (if none, use ANC #)	Phone number	Reason for visit FU=Follow up Rx=Refill C=Counseling LT=Lab test LR=Lab results O=Other (list)	Attend?		If no, action taken			Outcome		Comments (patient died, moved, transferred, wrong phone number on file, etc.)
					Yes	No	SMS	Call	Home visit	Come back	Did not come back	
1												
2												
3												
4												
5												
6												
7												
8												
9												
10												
11												
12												
13												
14												
15												
16												
17												
18												
19												
20												
Total												

APPENDIX 9B: Sample Patient Appointment Card (adapt to your local setting)

Appointment Card	
Name: _____	
Health Facility: _____	
Date	Reason
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	
PLEASE COME TO ALL OF YOUR APPOINTMENTS!	
If you cannot attend, call: _____	

APPENDIX 9C: Sample Phone Follow-up Logbook (adapt to your local setting)

Date	Patient name	ART or ANC number	Initials of caller	Phone number	Outcome	Next step	Call duration
					<input type="checkbox"/> Sent SMS <input type="checkbox"/> Phone not working <input type="checkbox"/> No answer <input type="checkbox"/> Spoke with patient <input type="checkbox"/> Spoke with someone else _____ <input type="checkbox"/> Other _____	<input type="checkbox"/> None – patient will return on ____ <input type="checkbox"/> Try again on _____ <input type="checkbox"/> Call treatment buddy <input type="checkbox"/> Home visit <input type="checkbox"/> Other _____	
					<input type="checkbox"/> Sent SMS <input type="checkbox"/> Phone not working <input type="checkbox"/> No answer <input type="checkbox"/> Spoke with patient <input type="checkbox"/> Spoke with someone else _____ <input type="checkbox"/> Other _____	<input type="checkbox"/> None – patient will return on ____ <input type="checkbox"/> Try again on _____ <input type="checkbox"/> Call treatment buddy <input type="checkbox"/> Home visit <input type="checkbox"/> Other _____	
					<input type="checkbox"/> Sent SMS <input type="checkbox"/> Phone not working <input type="checkbox"/> No answer <input type="checkbox"/> Spoke with patient <input type="checkbox"/> Spoke with someone else _____ <input type="checkbox"/> Other _____	<input type="checkbox"/> None – patient will return on ____ <input type="checkbox"/> Try again on _____ <input type="checkbox"/> Call treatment buddy <input type="checkbox"/> Home visit <input type="checkbox"/> Other _____	
					<input type="checkbox"/> Sent SMS <input type="checkbox"/> Phone not working <input type="checkbox"/> No answer <input type="checkbox"/> Spoke with patient <input type="checkbox"/> Spoke with someone else _____ <input type="checkbox"/> Other _____	<input type="checkbox"/> None – patient will return on ____ <input type="checkbox"/> Try again on _____ <input type="checkbox"/> Call treatment buddy <input type="checkbox"/> Home visit <input type="checkbox"/> Other _____	
					<input type="checkbox"/> Sent SMS <input type="checkbox"/> Phone not working <input type="checkbox"/> No answer <input type="checkbox"/> Spoke with patient <input type="checkbox"/> Spoke with someone else _____ <input type="checkbox"/> Other _____	<input type="checkbox"/> None – patient will return on ____ <input type="checkbox"/> Try again on _____ <input type="checkbox"/> Call treatment buddy <input type="checkbox"/> Home visit <input type="checkbox"/> Other _____	
					<input type="checkbox"/> Sent SMS <input type="checkbox"/> Phone not working <input type="checkbox"/> No answer <input type="checkbox"/> Spoke with patient <input type="checkbox"/> Spoke with someone else _____ <input type="checkbox"/> Other _____	<input type="checkbox"/> None – patient will return on ____ <input type="checkbox"/> Try again on _____ <input type="checkbox"/> Call treatment buddy <input type="checkbox"/> Home visit <input type="checkbox"/> Other _____	

MODULE 10:

Positive Living



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Understand the “recipe” for positive living for individuals and families
- Support clients to have a healthy mind
- Recognize common signs of anxiety and depression and provide basic counseling and referrals
- Support clients to have a healthy body
- Help clients and their partners practice safer sex and prevent new HIV infections
- Help clients prevent and seek care for sexually transmitted infections
- Work with clients to actively participate in their own care and advocate for themselves (and their children) as a part of positive living



CONTENT:

- Session 10.1: Introduction: The Recipe for Positive Living
- Session 10.2: Healthy Mind
- Session 10.3: Healthy Body
- Session 10.4: Safer Sex
- Session 10.5: Preventing and Treating Sexually Transmitted Infections (STIs)
- Session 10.6: Helping Clients Be Active Participants in Their Own Care
- Session 10.7: Classroom Practicum on Positive Living
- Session 10.8: Module Summary

SESSION 10.1: Introduction: The Recipe for Positive Living

Positive living means having a positive outlook on living and life. It also means living responsibly with HIV and preventing new infections.

PLHIV can live full and healthy lives if they take care of themselves, access care and treatment, and feel supported to make healthy choices. Families can also live positively with HIV by supporting and taking care of each other.

Positive living includes:

- Keeping the mind healthy
- Keeping the body healthy
- Keeping the soul healthy
- Preventing new HIV infections
- Keeping the whole family healthy

You play a key role in helping other PLHIV live positively and following the “recipe for positive living:”

KNOWLEDGE + DETERMINATION TO LIVE

with actions for a

**HEALTHY MIND + HEALTHY BODY +
HEALTHY SOUL**

= A LONG, HEALTHY LIFE

SESSION 10.2: Healthy Mind

Helping clients have healthy minds:

You can help people deal with their feelings about HIV. Clients will often need extra support in dealing with their feelings:

- After learning they or a family member is HIV positive
- When preparing to disclose to friends or family members
- When preparing to disclose to a child
- When starting ART
- When they become pregnant
- When they are about to lose a loved one or are grieving the loss of a loved one
- When they face stigma, discrimination or violence
- And many other times

Helping clients with anxiety and depression

Key Definitions

Anxiety is when you feel nervous, have a lot of fear or do not want to do things that you normally enjoy. Sometimes people also use the word “stress” to describe their feelings of anxiety.

Depression is when you feel very sad and hopeless.

Signs of anxiety:

- Cannot eat
- Cannot breathe
- Shaking and sweating
- Heart pounding fast
- Tingling in the hands or feet
- Cannot sleep
- Cannot concentrate on anything
- Feel “jumpy” or “stressed”
- Feel worried about many things

Signs of depression:

- Feel like you just do not know what to do (helpless or hopeless)
- Really tired with no energy
- Cannot find good in anything
- Do not enjoy the things you used to
- Sleep too much or not enough
- Get angry for no reason
- Cannot eat or eat too much
- Do not feel like being social with friends or family
- Do not feel like having sex
- Talk about running away
- Think about suicide (killing yourself)

What to do when you think a client has anxiety or depression:

You should always consult with other members of the multidisciplinary team if they think a client might be anxious or depressed.

- Provide continuous supportive counseling to clients so they feel “heard.”
- Encourage clients to join a PLHIV association and a support group.
- Link clients with community support services, like groups that provide spiritual support, counseling, home care or nutritional support.
- Remind clients that they should not use alcohol or drugs because this will only make things worse.
- Make a plan with clients to stay hopeful and feel good again.
- Encourage clients to continue any religious or spiritual practices that make them feel peaceful.
- Talk with family members (if clients say it is okay to do so) – they may be discouraged and need support, too.
- Remind clients that their feelings are normal and that they will feel better.
- Talk with a professional counselor or social worker about the clients’ symptoms and next steps. Give clients a referral to meet with a counselor or social worker.
- Symptoms of anxiety and depression can also be due to a medical illness, so it is important for clients to have a check-up with the doctor or nurse.



Peer Educators should seek help from other members of the multidisciplinary team right away when:

- Clients might hurt themselves or another person
- The depression is so bad that clients are thinking about killing themselves
- The family cannot cope with the person any more and wants to throw her or him out
- Clients cannot eat or sleep (may be due to side effects of ARVs like efavirenz, but may also be anxiety or depression)
- There is any kind of emotional crisis

Peer Educators can help people find hope and joy, accept their situation and want to live for the future!

SESSION 10.3: Healthy Body

Healthy behaviors:

You can counsel clients on the many things PLHIV can do to keep their bodies healthy and live positively with HIV, including:

- Use condoms and practice safer sex every time.
- Get STIs treated right away and tell your partner to get them treated too.
- Get a TB test and treat TB right away.
- Use a family planning method if you want to limit or space children.
- Go to the hospital or clinic for check-ups, lab tests and to pick up medicines. Never miss an appointment.
- Take medicines the right way (at the right time, the right number, etc.).
- Tell the nurse and doctor if there are any changes, even small ones, in your health.
- Stay busy and active.
- Get enough rest.
- Get sunlight and breathe fresh air every day.
- Sleep and rest under a treated mosquito net if you live in a place with malaria.
- Join a PLHIV association and a support group and talk about things openly.
- Exercise or stretch every day to stay healthy. If bedridden, have a family member help with stretches to keep blood flowing and prevent bedsores.
- Stay clean – wash regularly and wash hands often, especially after going to the toilet and before making food.
- Eat enough good food and take multivitamins (there is more about nutrition in *Advanced Module 17*).
- Boil drinking water to make sure it is clean.
- Cook food well to get rid of germs.
- Wash raw fruits and vegetables well with clean water.
- Keep the house and compound clean, including getting rid of any still water and garbage.
- Use a germ-killing bleach solution (like Jik, Barakina or Gentian Violet) diluted with water to keep household surfaces clean.

Unhealthy behaviors:

You can also talk about avoiding practices or behaviors that are not healthy. These include:

- Drinking too much alcohol
- Using drugs
- Smoking
- Sharing medicines or stopping them without talking to the doctor
- Having unsafe sex
- Avoiding social contact and staying alone too much
- Missing appointments at the clinic
- Taking traditional medicines that you have not discussed with the doctor
- Eating too many sugary or fatty foods
- Not eating enough good foods



SESSION 10.4: Safer Sex

What is safer sex?

- Safer sex is any kind of sex that reduces the chances of passing STIs or HIV from one person to another.
- Safer sex includes preventing contact with your partner's body fluids.
 - These fluids include semen, fluid from the vagina and blood.
 - To be safe, these fluids should not enter the vagina, the anus or the opening of the penis.
 - They should not enter open sores, cuts or broken skin anywhere on the penis, in the mouth, on the vagina, in the anus or anywhere else on the body.

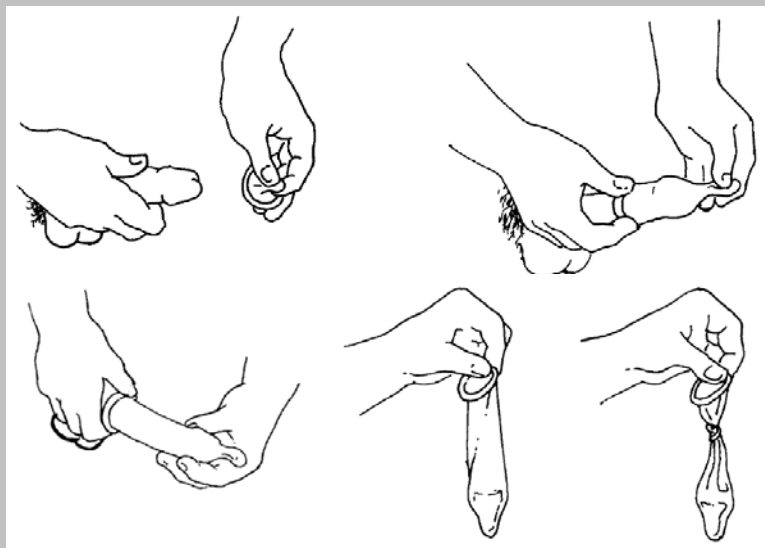
Ways to practice safer sex:

- Use a condom for all kinds of sex (vaginal, anal, oral).
- Reduce the number of partners and use condoms all the time.
- We know that HIV is often transmitted between regular partners. If both partners have not been tested, then it is safest to use condoms – in both regular and casual partnerships.
- Stay in a relationship where both partners have been tested for HIV and are faithful to one another.
- Masturbate (alone or together).
- Replace risky practices with safer practices, like touching, massage, kissing and hugging.
- Do not put products or herbs in the vagina before sex.
- Do not have sex if you or your partner have an STI or any kind of sore in the genital area.
- Take all medicines (such as for STI treatment or ART) as prescribed by the doctor or nurse.
- If possible, avoid sex while you or your partner has her period (is menstruating). If you do have sex during menstruation, try to use condoms.
- Do not have sex at all.
- Never force another person to have sex.



How to use a Male Condom

These are the basic steps you should know for using, and demonstrating how to use, a male condom. If penis models are not available, you can use a bottle, banana or corn. Only condoms made out of **latex** protect against HIV.



Steps to use a male condom:

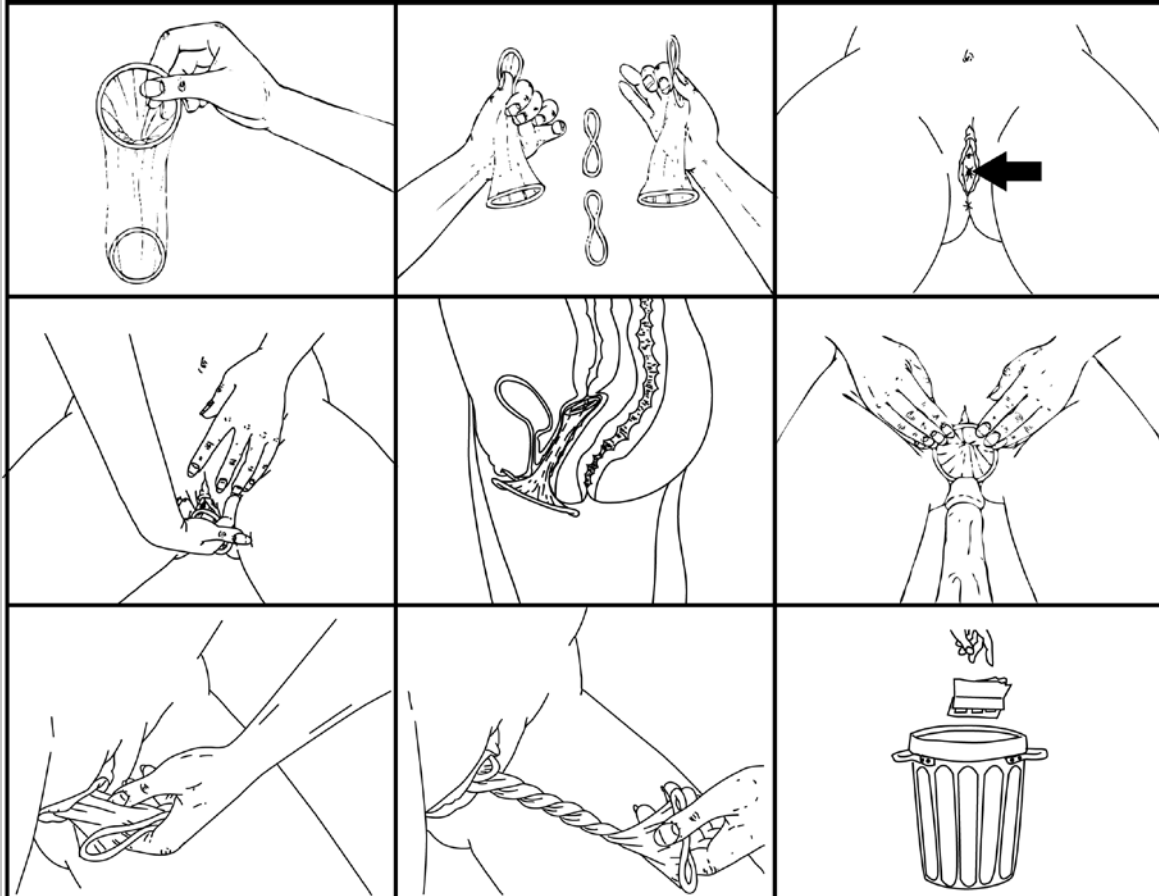
1. Look at the condom package and check the date to make sure it is still good and that the package does not have any damage.
2. Open the packet on one side and take the condom out. Do not use your teeth to open the package.
3. Pinch the tip of the condom to keep a little space at the tip. This will hold the semen and prevent the condom from breaking.
4. Hold the condom so that the tip is facing up and it can be rolled down the penis.
5. Put it on the tip of an erect (hard) penis (only use condoms on an erect penis) and unroll it down to the bottom of the penis.
6. After ejaculation (coming), hold the rim of the condom while the man removes his penis without spilling the semen. The penis must be removed while it is still hard to make sure the condom does not fall off.
7. Remove the condom and tie it in a knot to avoid spilling. Throw it away in a latrine or bury it.
8. Use a new single condom every time!

Also, it is important to:

- Use only lubricants made out of water (not oils).
- Store condoms in a cool, dry place, out of the sun. Do not keep them in a wallet.
- Do not use condoms that seem to be sticky, a strange color or damaged in any way. Throw them away.

How to Use a Female Condom

These are the main steps for using a female condom. If no vaginal model is available to demonstrate its use to people, you can use a box with a round hole cut in it or your hand.



Steps to use a female condom:

1. Open the packet. Do not use your teeth.
2. Find the inner ring at the bottom, closed end of the condom. The inner ring is not attached to the condom.
3. Squeeze the inner ring between the thumb and middle finger.
4. Guide the inner ring all the way into the vagina with your fingers. The outer ring stays outside the vagina and covers the lips of the vagina.
5. When you have sex, guide the penis through the outer ring. It has to be **INSIDE** the ring.
6. After the man ejaculates (comes), before the woman stands up, squeeze and twist the outer ring to keep the semen inside the pouch and pull the pouch out.
7. Put the used condom in a latrine or bury it. Do not put it in a flush toilet.

Part of your job is to teach clients how to use condoms to protect themselves and their partners, and how to talk to their partners about condoms.

- Promote condom use every time with all partners, and especially with any non-regular partners or partners who do not know their HIV-status.
- Give out condoms to clients and community members.
- Link with community organizations and community leaders to make sure everyone in the community knows about condoms and how to get them.
- Recruit respected men in the community to talk about condoms with other men.
- Help people make condoms fun and pleasurable. For example, suggest that a woman help a man put on a condom.
- Help people practice what they are going to say about condoms to their partners.



Some ways you can encourage your partner to use condoms:

If your partner says...	You could say...
It will not feel as good.	It may feel different. But it will still feel good. Here let me show you.
I do not have any diseases!	I do not think I have any either, but one or both of us could and not know it. Let's be safe.
You are already using family planning.	I would like to use a condom anyway. One of us might have an infection from before that we might not know about.
Just this once without a condom...please.	It only takes one time without a condom to get HIV or an STI. Also, I am not ready to be pregnant.
Condoms are for loose women. Why do you want to use one?	Condoms are for everyone who wants to protect themselves.
If you love me, we do not need condoms.	I do love you and I want us to be safe so we can be happy together.
NO CONDOM, NO SEX!!!	

SESSION 10.5: Preventing and Treating Sexually Transmitted Infections (STIs)

Sexually transmitted infections, or STIs, are infections passed from one person to another during sex. STIs can also be passed from a pregnant woman to her baby before it is born or during the delivery. **When a person has an STI, especially one with sores, it is much easier to spread HIV.**

Unless STIs are treated, they can cause:

- HIV to spread more easily
- Infertility (not able to have children)
- Premature or unhealthy babies
- Very bad pain in the abdomen
- Cancer of the cervix
- Cancer of the penis
- Cancer of the anus
- Death from a bad infection

The most common signs of STIs include (many times, there are no symptoms, so it is always best to practice safer sex with condoms):

- Strange discharge from the vagina
- Strange discharge from the urethra, the place where pee comes out (in a man this is at the end of the penis and in a woman it is just above the vaginal opening)
- Pain or bleeding when peeing or during sex
- A rash, bump or sore on or around the penis, vagina or anus
- Red and itchy genital area or anus
- Warts or bumps in the genital area or around the anus
- Swollen glands around the genital and thigh areas
- For men, swollen or painful testicles (balls)
- For women, pain in the lower belly
- High fever

Names of Common STIs:

- Trichomonas
- Gonorrhea (“clap,” VD)
- Chlamydia
- Genital warts
- Syphilis
- Chancroid
- Genital herpes
- HIV
- Hepatitis B
- Pelvic Inflammatory Disease (PID)

How to prevent STIs:

- Always practice safer sex.
- Use condoms every time you have sex.
- Keep the genital and anal areas clean.
- Do not douche or use herbs or powders in the vagina.
- If you or your partner(s) have an STI, do not have sex until it is treated and cured. This will prevent the STI from spreading to your partner(s).

What to tell clients if they may have an STI:

- Go to the clinic right away.
- Help your partner get checked by a doctor or nurse and get treated.
- Make sure to take ALL of the medication, even if you feel better.
- It is best to not have sex until your and your partner's STI signs have gone away AND you both have finished all of the medicines.
- Keep the genital and anal areas clean.
- Try to wear underclothes made of cotton, and wash and dry them in the sun every day.
- To relieve pain or discomfort, you can sit in a pan of clean, warm water for 15 minutes, 2 times each day.
- Go back to the clinic if you do not get better by the end of your medicines.
- Practice safer sex with condoms when you do have sex again.



SESSION 10.6: Helping Clients Be Active Participants in Their Own Care

Encourage clients to:

- **Be involved:** Be a part of every decision that is made about your health.
- **Think ahead:** When you talk to your health care providers about your health BEFORE problems happen, you will get the best possible care.
- **Ask questions:** If you do not understand something that the doctor, nurse, counselor or pharmacist tells you, always ask questions.
- **Learn more about your health and treatment:** Collect as much information as you can about your diagnosis, care and treatment.
- **Join a PLHIV association and a support group:** This will help you talk to others facing similar situations and how to deal with specific challenges.
- **Understand which medicines you and your children are taking:** Make a list of all the prescription medicine, traditional medicine and anything else you or your children are taking or doing for your treatment. Make sure you write down or tell your health care worker if you are allergic to any drugs. Before you take any medicines, make sure you ask a health care worker about:
 - *How to use the medicine.*
 - *How you might feel when you are on the medicine (side effects).*
 - *What other medicines you should NOT take when using the medicine.*
 - *How long you will need to take the medicine.*
- **Get the results of every test:** Ask for the results of the tests you or your children get. Ask what the results mean.
- **Ask for more information about referrals.**
- **Understand the treatment plan:** Before you leave the clinic, ask your health care workers to explain the treatment plan you will use at home. Know what you need to bring back to your health care worker. Also make sure you understand your follow-up care plan and what medicines you must continue to take.
- **Follow up with a community health worker or Peer Educator:** This can help you remember things you may have forgotten and help implement the care and treatment plan.

SESSION 10.7: Classroom Practicum on Positive Living

Case Study 1:

A 40-year-old married man living with HIV knows he should use condoms to prevent HIV from spreading, but is embarrassed to talk about them with his wife and fears she will think he's cheating on her. He told his wife that he is HIV-positive but has not discussed condoms with her, and does not know how to use condoms. He asks you for advice.

Case Study 2:

A pregnant woman tells you she is having trouble breathing sometimes and feels like her heart might jump out of her body because she is so scared her baby will die. She cannot sleep and is having trouble eating. How would you help her?

Case Study 3:

You stop by a client's house on your way home because he has missed an appointment at the clinic. He is there completely alone, in dirty clothes, lying on a dirty blanket on the floor. He says he is so angry about having AIDS that he does not care if he lives or dies anymore and is not going to come to the clinic ever again. He tells you to leave his home right away. What would you say and do?

Case Study 4:

A young mother of 3 children just started coming to the ART clinic. She is worried about her children and wants to stay as healthy as she can to take good care of them. What would you tell her about living positively with HIV?

Case Study 5:

A 25-year-old man on ART tells you he feels good and wants to have sex with his wife. She is also on ART and feeling really good. He wants to know if he needs to use condoms because they are both HIV-positive, on ART and doing well. He also says he cannot afford condoms and does not like how they feel. What would you say?

Case Study 6:

You learn that a client of yours can often be found at the local bar drinking and smoking into the morning hours. You worry that he may be hurting himself and missing doses because he is drunk when he gets home. What would you say to him about positive living and adherence?

Case Study 7:

A pregnant woman comes to you and says her husband refuses to wear a condom. He thinks they are only for sex workers and does not see the point because she is already pregnant. She is worried that she and the baby will get HIV from him because he is living with HIV, even though she is still negative. How would you help this woman?

Case Study 8:

A young man comes to the clinic and tells you that he recently had sex with another man at university. He wants to keep it a secret, but wants to be safe. He asks you how he can be safe and protect himself. What would you tell him about safer sex?

Case Study 9:

A client comes to you and says she does not care about her treatment anymore. It is so confusing and she is always just referred from one place to the next. She does not have time to wait anymore and feels angry that she does not know why she had to come to the clinic today in the first place, just to wait around for the nurse. How would you help her be an advocate for her own care and treatment?

Case Study 10:

A woman at the ART clinic tells you she has a strange, itchy bump on her vagina. She is worried because her husband has been staying out late at night and she thinks he may have a girlfriend. How would you advise her?

Note: Some of the preceding information in this Module was adapted from the following sources:

Burns, A., Lovich, R., Maxwell, J., & Shapiro, K. (1997). *Where women have no doctor: A health guide for women*. Berkeley, CA: The Hesperian Foundation.

Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). *Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers*. Watertown, MA: Pathfinder International.

Orr, N. (2004). *Positive health*. Cape Town, South Africa: Double Story Books.

WHO (draft). (2005). *Participant manual for the WHO basic ART clinical training course, based on chronic HIV care with ARV therapy module*. Addis Ababa, Ethiopia: WHO.

SESSION 10.8: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- PLHIV can live full and healthy lives if they take care of themselves, access treatment and support and feel supported to make healthy choices.
- You play a key role in helping other PLHIV and their families live positively and follow the “recipe for positive living”:

KNOWLEDGE + DETERMINATION TO LIVE

with actions for a

HEALTHY MIND + HEALTHY BODY + HEALTHY SOUL

= A LONG, HEALTHY LIFE

- You can help clients keep their minds healthy by offering support and referring them to support groups, spiritual counselors and other groups.
- You should know the common signs of anxiety and depression. You should tell the clinical team if you think a client is anxious, depressed or wants to end her or his life.
- You can help people keep their bodies healthy by practicing safer sex, eating well, staying clean and keeping active (among other things).
- You should help people stay away from unhealthy things like alcohol, smoking, unsafe sex, eating sugary and fatty foods, and being isolated from other people.
- PLHIV and their partners should be counseled on safer sex to avoid spreading HIV and STIs, to avoid re-infection with a different strain of HIV and to avoid unwanted pregnancy.
- Safer sex means avoiding the passing of semen, vaginal fluids and blood from one person to another.
- One of the best ways to have safer sex is to use male or female condoms the right way, every time.
- You can give clients condoms and help clients negotiate condom use with their partners. Peer Educators should be safer sex role models.
- Having an STI makes it much easier to get or spread HIV.
- You can help clients prevent STIs by educating them on how to have safer sex, referring clients with signs of STIs and advising clients on what to do while treating an STI.
- You can help other clients advocate for themselves and their children, be involved and understand their treatment, ask questions and understand referrals and other aspects of their care.

MODULE 11: Stigma, Discrimination and Disclosure



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Define stigma and discrimination and discuss different types of stigma
- Describe how stigma and discrimination negatively affect people's access and adherence to HIV prevention, care and treatment services
- Implement strategies to deal with stigma and discrimination at the individual level, at the health facility and in the community
- Support clients to understand the advantages and disadvantages of disclosure in their lives
- Provide supportive counseling to clients to decide about and prepare for disclosure
- Discuss why it is important for children to know their HIV-status and help families prepare to disclose to children
- Provide follow-up counseling to clients and family members after disclosure



CONTENT:

- Session 11.1: Introduction: Our Own Experiences with Stigma
- Session 11.2: How Does Stigma Affect HIV Services?
- Session 11.3: Strategies to Deal with Stigma
- Session 11.4: Introduction to Disclosure
- Session 11.5: Disclosure Counseling
- Session 11.6: Classroom Practicum on Stigma and Disclosure Counseling
- Session 11.7: Module Summary

SESSION 11.1: Introduction: Our Own Experiences with Stigma

Key Definitions

Stigma: Having a negative attitude toward people we think are not “normal” or “right.” For example, stigma can mean not valuing PLHIV or people associated with PLHIV.

To stigmatize someone: Labeling someone and seeing them as inferior (less than, below) because of something about them.

Discrimination: Treating someone unfairly or worse than others because they are different (for example, because someone thinks a person has HIV). Discrimination is the action that often follows stigma.

You can help clients understand and deal with stigma and discrimination. You can work with the rest of the multidisciplinary team and the community to fight stigma and make sure people have access to the services they need without discrimination.

There are different kinds of stigma:

- **Stigma towards others:** Rejecting or isolating other people because they are different or perceived to be different.
- **Self-stigma:** People take cruel and hurtful views placed upon them by other people as their own views of themselves.
- **Secondary stigma:** People are stigmatized by their association with PLHIV.



There are different forms of discrimination:

- Not being able to get a job
- Being fired from a job
- Being isolated from the family or community
- Not having access to quality health care or other services
- Facing violence at home or in the community
- Being kicked out of school
- Not being able to attend school
- Being rejected from a church, mosque or temple

SESSION 11.2: How Do Stigma and Discrimination Affect HIV Services?

How can stigma and discrimination affect HIV prevention, care and treatment?

- They can prevent people from knowing their HIV-status, enrolling in care or getting a CD4 test, limiting their access to ART.
- They can cause feelings of hopelessness and depression that can make it hard for people to start or adhere to ART.
- They can cause fear that if a person takes ART, more people will know she or he is living with HIV.
- They can prevent or delay disclosure, forcing people to keep their status and their ART a secret. This will impact their adherence and the amount of support they receive.
- They can make it hard for people to negotiate condom use and safer sex practices.
- Children with HIV cannot get the care and treatment they need if there is stigma attached to their illness or if the family has not disclosed to others.
- They can cause people to be isolated from friends and family, which means they will not get support to take ART and adhere to care and treatment.
- Women—especially pregnant women—and young people are often the most stigmatized and discriminated against. This makes it even harder for these groups to access and adhere to care and treatment.
- Stigma and discrimination among health care providers can result in low quality services at health facilities, making people less likely to access the care they need.
- Stigma and discrimination can extend to caregivers of PLHIV as well, making it less likely that people will want to care for PLHIV or seek services themselves.

You have an important role to play in reducing stigma and discrimination among individuals, at the health care facility and in the community. Being a positive role model is one of the best ways to fight stigma and discrimination!

SESSION 11.3: Strategies to Deal with Stigma

At the individual level, you can counsel clients to do the following:

- Stand up for yourself and talk back.
- Educate people.
- Be strong and prove yourself.
- Talk to people you feel comfortable with.
- Ignore people who stigmatize you.
- Join a support group.
- Try to explain the facts.
- Avoid people you know will stigmatize you.

At the health facility, you can work with the team to do the following:

- Make sure people living with HIV (like Peer Educators) are part of the care team.
- Talk openly about your own attitudes, feelings, fears and behaviors with others.
- Share your experiences as a client.
- Encourage health care workers and other Peer Educators to be open about their status and for everyone to support one another.
- Report any discrimination you see towards people living with HIV or their families at the clinic to a manager.
- Listen to clients about their feelings and concerns about stigma and discrimination, and report these back to other health care workers.
- Work with the rest of the multidisciplinary team to identify where stigma and discrimination exist in the clinic and work together to make changes.

In the community, you can:

- Get community and NGO leaders involved in the fight against HIV.
- Work with community and religious leaders to acknowledge and accept that PLHIV are equal members of the community.
- Promote PLHIV as role models and active community participants.
- Organize community meetings and activities related to HIV.
- Conduct community sensitization and education on HIV, led by PLHIV.
- Get the community to support orphans and other children affected by or infected with HIV.
- Improve linkages between health facilities and the community.
- Conduct community education on caring for someone with HIV and being a treatment buddy.



With faith-based and religious groups, you can:

- Use churches, mosques and other religious institutions to discuss stigma.
- Get people to recognize their own stigmatizing behavior and correct it.
- Help religious leaders to lead efforts in stigma reduction and tolerance.
- Work with religious leaders to provide counseling that is non-stigmatizing and non-judgmental, such as pre-marital counseling.
- Support religious leaders living with HIV to be open about their status.

SESSION 11.4: Introduction to Disclosure

What is disclosure?

- Disclosure is when people tell one or more people about their HIV-status.
- **Disclosure is an ongoing process.** People may first want to disclose to only one person and then over time disclose to others. It is not a one-time event and PLHIV need continued support on disclosure.

Part of being a Peer Educator is openly disclosing your status to clients and people in the community. You can be a disclosure role model.

Advantages of disclosure may include:

- Avoiding the burden of secrecy and hiding
- Avoiding anxiety about accidental or unwanted disclosure
- Access to emotional and practical support
- Ability to talk about symptoms and concerns
- Easier access to health care
- Improving adherence to care and medication, and ultimately making people healthier and able to live positively with HIV
- Ability to discuss safer sex and family planning choices with one's partner(s)
- Ability to refer partners and children for HIV counseling and testing and to care and treatment if needed
- For pregnant women, ability to get support for safer infant feeding from family members and friends and to find linkages to food support programs when the mom wants to wean the baby
- Freedom to ask a friend or relative to be a treatment buddy
- Access to patient support groups and community organizations
- Serving as a role model for other people on disclosure



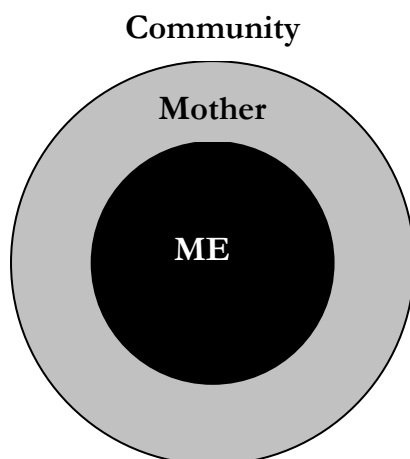
Disadvantages of disclosure may include:

- Blame by partner or family for “bringing HIV into the household”
- Distancing, fear, rejection or abandonment by partner, family or friends
- Loss of economic support from a working partner
- Discrimination in the community
- Discrimination at work, including possible loss of job
- Assumptions made about sexuality, promiscuity or lifestyle choices
- Rejection of children at school or in the community
- Reluctance on the part of partners to have more children
- Physical violence
- More self-stigma

Deciding about disclosure:

- A good way to understand disclosure and help people decide whom they will disclose to is by creating “disclosure circles” with your client.
- The center of the circle is the person her- or himself.
- The next circle out is a person or people the person is very close to, such as her or his mother, sibling or partner.
- The next circle includes larger groups of people that the person is not as close to, such as people at work or others in the community.
- There can be many layers to the circles of disclosure.
- Each layer of disclosure represents a process in itself – preparing for disclosure, the disclosure process and ongoing conversations after disclosure. Remember that the conversation does not end after disclosure.
- The goal is NOT that all people will eventually disclose to all of the people in the circles. Instead, the circles provide a way to discuss the disclosure process and risks and benefits of disclosing to different people.

Here is an example of a disclosure circle:



SESSION 11.5: Disclosure Counseling

Disclosure counseling:

- Should not include pressure for someone to disclose
- Is a confidential conversation that assists clients to work through the issues related to telling others about their HIV-status
- Is important to reduce stigma, enhance adherence to care and treatment, and reduce the spread of HIV
- Is intended to promote informed decisions about whether or not to disclose HIV-status and, if so, to whom
- Assists and supports people who have decided to disclose their status
- Enhances coping strategies following disclosure
- Is an ongoing process that requires preparation, practice and follow-up support

You can help prepare clients who choose to disclose by:

- Helping to decide whom to disclose to, when and where (using the disclosure circles discussed before)
- For parents or caretakers, deciding what type of information is most understandable for a child, given the child's age and development
- Planning for a good place and time to have the conversation (for example, when the children are asleep and when no one else can hear)
- Helping people weigh the advantages and disadvantages of disclosure to different people in their lives
- Assisting clients to anticipate likely responses
- Practicing disclosure through role-plays, including how they will start the conversation
- Providing practical suggestions, ongoing support and reassurance
- Planning the next steps and scheduling a time for follow-up counseling



Considerations when disclosing to children:

Note: There is more on disclosing to children in *Advanced Module 18*.

- Children have a right to know about their own health and we must work with caregivers to encourage disclosure.
- When we disclose to children, we must consider the needs, feelings and beliefs of the children, parents and caregivers, as well as the specific family situation.
- We need to involve all of children's caregivers and make sure everyone has the same messages and knows how and when children will be disclosed to.
- Keep in mind that disclosure to children depends on what stage of development they are in.
- Plan for follow-up support to the family, including children, after disclosure. Disclosure to children is not a one-time event and will require many conversations over time.

What are the reasons to disclose a child's HIV-status?

- Children have a right to know about their own health care.
- Children who have not been disclosed to may develop their own views about their illness, feel isolated, learn their HIV-status by mistake or have poor adherence.
- Orphaned or other vulnerable children may wonder why they have lost a parent or been rejected by the family. They need to know the truth. This will also help children seek the services they need, especially those who do not have regular caregivers.
- Children often want and ask to know what is wrong. Children are observant, smart and curious. They often know much more than we adults think.
- When children learn about their status directly from caregivers, it can provide comfort and reassurance. Too often, children overhear health care workers and caregivers talking about their health as if they were not in the room.
- Children who know their HIV-status can take an active role in their care and treatment plan and, when old enough, take steps to live positively and prevent new infections.

SESSION 11.6: Classroom Practicum on Stigma and Disclosure Counseling

Scenario for Start-Stop drama:

Actors: A pregnant woman, her mother and her sister (or brother)

- A pregnant woman named C___ wants to disclose her status to her mother and sister.
- C___ sits them down one evening after they have cleaned up the house and the other children are asleep. Her boyfriend is out at a bar with his friends.
- C___ is scared that her baby will be HIV-infected. She wants her mother and sister to help her stay healthy during the pregnancy. She isn't sure if she should tell her partner about her status and wants support and advice from her mother and sister.
- C___ tells her mother and sister that she found out at the clinic that she is HIV-positive.
- The mother will not accept her daughter's status. She says that the doctors are wrong and she should just take herbal medicines and she will feel better. She is completely in denial.
- The sister knows a bit more about HIV than the mother, but is worried about C___ taking ART during pregnancy because she thinks it will kill the baby. She is also worried because she is a teacher at the community school and she is afraid she might lose her job if everyone knows there is HIV in the family.

Case studies for small group work:

Case Study 1:

A woman named F___ is a counselor at the local HIV testing center. About one year back, she decided to get tested and found out she is living with HIV. Since then, F___ has not enrolled in the care and treatment program because she does not want anyone to know she is positive. F___ is feeling well, but has started losing weight lately and thinks some of her fellow counselors might be talking about how she has HIV. She feels so badly about herself and thinks she should have known better than to have unsafe sex. She comes to you for advice. How would you counsel her?

Case Study 2:

A married man named P___ with 2 children (aged 7 and 3) tested positive for HIV last week after having pneumonia and being referred for HIV testing. He wants to know if he has AIDS and he has not told anyone about his status because he is worried about their reactions. He started using condoms, but his wife is acting suspicious. He wants to talk about disclosure with you. What would you talk to him about? Lead P___ through a disclosure role-play.

Case Study 3:

A pregnant woman named V___ comes to talk with you. She is physically quite well, but just tested positive for HIV during an antenatal check up. She is scared to tell anyone and does not want to go to the ART clinic because someone might see her there and tell her family. Her husband can be violent when he gets upset, and she thinks he gave her HIV because he is the only person she has had sex with without condoms. She turns to you for help. How would you counsel V___?

Case Study 4:

A 19-year-old man named H___ tested positive for HIV about 2 years ago, but takes good care of himself and feels fine. He got tested because his girlfriend at that time found out she was HIV-positive. He has since changed girlfriends and has not told his new girlfriend about his HIV-status. He comes to the clinic for his regular appointment, but wants to talk with you about how to tell his girlfriend that he is living with HIV. He does not know how to use condoms and is afraid that if he starts using them with his girlfriend she will know he has HIV. How would you counsel H___?

Case Study 5:

A mother named J___ has been caring for her HIV-infected child for the last 6 years. The child is now ready to start school, but she is afraid to tell the teacher that her son has HIV. She is afraid he will be stigmatized in the school and that he will learn about his HIV-status from schoolmates or the teacher. Counsel J___ about disclosing to her son.

Note: Some of the preceding information in this Module was adapted from the following sources:

The CHANGE Project & ICRW. (2003). *Understanding and challenging HIV stigma: Toolkit for action*. Washington, DC: The CHANGE Project, Academy for Educational Development.

Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). *Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers*. Watertown, MA: Pathfinder International.

The International HIV/AIDS Alliance. (2006). *Trainer's manual: Community engagement for antiretroviral treatment. Participatory tools and activities for civil society organizations working with people with HIV*. International HIV/AIDS Alliance.
Joint United Nations Programme on HIV/AIDS. (2003). *Fact sheet: Stigma and discrimination*. Geneva, Switzerland: UNAIDS.

Joint United Nations Programme on HIV/AIDS. (2007). *Reducing HIV stigma and discrimination: A critical part of national AIDS programmes. A resource for national stakeholders in the HIV response*. Geneva, Switzerland: UNAIDS.

SESSION 11.7: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- Stigma is a bad or negative attitude toward a person or group of people who are different from what we think is “right.” Stigma is often followed by discrimination – when a person is treated unfairly because they are thought to be “different” (for example, because they are living with HIV).
- Stigma comes in many forms – it can be from one person to another, a person stigmatizing her- or himself, or stigma by association. Programs can also stigmatize and discriminate against people, as well as communities and religious groups.
- Stigma and discrimination make it hard for people to accept, access and adhere to prevention, care and treatment services.
- You have an important role to play as positive role models, reducing stigma and discrimination among individuals, at the health care facility and in the community.
- You can work with the multidisciplinary care team to reduce stigma and discrimination at the health care facility.
- When you and other Peer Educators are very open about your own HIV-status, it helps to reduce stigma and discrimination.
- Disclosure can help a person access prevention, care, treatment and support; improve adherence; reduce stigma and discrimination by bringing HIV out into the open; and slow the spread of HIV by helping people protect themselves and their partners.
- You can help people weigh the advantages and disadvantages of disclosure and be a supportive counselor throughout the process. You can help prepare clients for disclosure and give follow-up support after disclosure.
- Disclosure is an ongoing process, not a one-time event.
- It is important for children to know about their HIV-status.
- You can work with parents, caregivers and children to understand why disclosure to children is important, prepare for disclosure and provide follow-up support.

MODULE 12:

Community Outreach, Education and Linkages



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Describe community- and home-based support services that PLHIV and their families may need and the importance of each
- Describe your role in linking clients with community-based support services
- List common challenges to strong facility-community linkages
- List key strategies to improve facility-community linkages and your role in strengthening these linkages
- Create a community resources map and an inventory of community services
- Discuss how you can serve as a community HIV educator and advocate



CONTENT:

- Session 12.1: Introduction: What Services Do Clients Need in Their Communities?
- Session 12.2: Linking Clients to Community Support Services
- Session 12.3: Community Resource Mapping
- Session 12.4: Being a Community Educator and Advocate
- Session 12.5: Module Summary

SESSION 12.1: Introduction: What Services Do Clients Need in Their Communities?

Common support needs of PLHIV and their families in the community and at home:

- Home-based care
- Home-based adherence support
- Income-generating activities
- Savings and loan programs
- Support groups
- Nutritional support
- Legal advice and support
- Spiritual guidance and support
- Disclosure support
- Transportation to get to the clinic
- Education and counseling for family members
- End-of-life care, including pain management
- Others



Remember: No one person or organization can provide all of the services and support PLHIV need. We must work together to provide a continuum of ongoing care and support in the health facility, in the community and at home!

SESSION 12.2: Linking Clients to Community Support Services

Some examples of community-based support and services for PLHIV and their families

Home-based care:

- Home-based care (HBC) programs usually involve trained health workers visiting PLHIV in their homes to provide care and support services to clients and families.

Support groups:

- Support groups are very important for PLHIV and their families. Support groups offer a chance for PLHIV to come together to discuss concerns, share information and provide emotional support to one another.
- There are many kinds of support groups for many different kinds of people. Some support groups may be held at health facilities and others may be held in the community.

Self-help and income-generating groups:

- Poverty is one of the most common challenges faced by PLHIV and their families. Many communities have organizations and groups to provide self-help and income generation to clients and families in need, including income-generating activities, skills training and savings and loan groups.

PLHIV associations:

- PLHIV associations can offer many services and support to PLHIV.

Food distribution and nutritional support:

- Many clients will need linkages to food and nutritional support in the short-term and over the long-term. This can include food distribution, community food donation programs, community gardens, animal rearing and others.

Legal support:

- PLHIV and their families often have their rights violated and may need legal support services. Some organizations provide these services for free or at reduced cost to PLHIV, often through PLHIV associations.

SESSION 12.3: Community Resource Mapping

Strategies to improve facility-community linkages:

- Always ask about clients' community and family situations and any support needs during visits.
- Meet with community leaders to talk with them about HIV care and treatment services and why they are important.
- Advocate that each health facility should have an updated list of community resources.
- Work with the rest of the multidisciplinary team to learn what community organizations and services are available in the area and meet with these organizations to set up a formal "two-way" referral system.
- Work with the rest of the multidisciplinary team to plan an afternoon for community organizations, community health workers and community leaders to come to your health facility for a tour, to meet the health care workers and to learn more about the services provided there.
- Participate in community meetings and community gatherings to discuss HIV and care and treatment.
- Existing community health workers can be trained to identify community members and refer them for testing, PMTCT, care and treatment.
- Involve community outreach workers with home-based follow-up of clients who have missed appointments at the hospital.
- Involve community members openly living with HIV to strengthen facility-community linkages.
- Start a support group at the health facility. Invite health care workers to the support group meetings to provide guidance and information.

Community resource maps and inventories:

- As a first step, you can work together with community organizations and community health workers to map resources available in the community for people and families affected by HIV.
- In some places, resource lists may already exist, so check in with your local PLHIV associations, district HIV teams, regional health bureaus or other coordinating organizations.

Peer Educators should carry an updated inventory of community support services at all times for easy reference and referral.



SESSION 12.4: Being a Community Educator and Advocate

How can you mobilize the community around HIV?

- Use your position as a Peer Educator to speak at community gatherings, community group meetings, religious services, women's and youth group meetings and other community events.
- Talk with families in your community about HIV, how to prevent HIV and what prevention, care and treatment services are available in the community.
- Talk to young people about how to protect themselves from HIV, STIs and unwanted pregnancy. Help young people living with HIV to get the care and treatment they need.
- Involve other community members in the fight against HIV. Talk with teachers, business leaders and political leaders about what they can do to help PLHIV and their families and prevent new HIV infections.
- Get involved in community events, such as World AIDS Day activities and HIV testing campaigns.



SESSION 12.5: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- Some common needs of PLHIV and their families at the community and home levels include home-based care, adherence support, poverty reduction and income-generating activities, support groups, nutritional support and many other services.
- A key component of Peer Education is advocating for strong linkages between health facilities and these community services.
- There are many ways to strengthen facility-community linkages, such as meeting with community leaders; orienting existing community organizations and health workers on PMTCT, ART and adherence; and having a strong two-way referral system between the health facility and community organizations.
- You should stay up-to-date on which services are available for PLHIV and their families in the community, have an inventory of these services and make referrals.
- You may be asked to speak to community groups or at community gatherings. Use your position of respect to educate and mobilize the community and advocate for the needs of PLHIV and their families. Speaking in the community can also help reduce stigma and discrimination.
- Be sure to plan ahead when speaking in the community and use good group communication skills.

APPENDIX 12A: SAMPLE COMMUNITY RESOURCES INVENTORY

Name of District or Community: _____

Name of Organization	Services Provided and Schedule (days/hours)	Catchment Area	Contact Person, Telephone and Address
1.			
2.			
3.			
4.			
5.			
6.			

MODULE 13:

Record-keeping and Reporting



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Explain the importance of record-keeping
- Understand how information collected and reported by Peer Educators can be used to make program improvements
- Fill in daily registers on individual counseling and group education activities
- Complete the monthly activity report



CONTENT:

Session 13.1: Introduction: Why Do We Need Records?

Session 13.2: Peer Educator Recording and Reporting Forms

Session 13.3: Module Summary

SESSION 13.1: Introduction: Why Do We Need Records?

Records are important because they can help us:

- Remember things we have done or need to do
- Plan what we need to do
- See what we have done
- See what we can do better
- Report to other people (such as our supervisor) what we have done
- See what the gaps are in our services and fill them

It is important for you to understand the records that are kept in HIV care and treatment programs and to fill registers each day and reports each month because they will:

- Show what you have done during the month
- Show your supervisor what you have done
- Help you plan for the next month
- Help you follow up with clients from month-to-month
- Show how effective Peer Educators can be in helping PLHIV



Session 13.2: Peer Educator Recording and Reporting Forms

There are at least 3 important forms for you to fill out and discuss with your supervisor:

- Daily register for individual counseling sessions
- Daily register for group education sessions
- Monthly summary report

In addition, and depending on the program, you also may need to fill in forms related to:

- Client follow-up (phone calls, home visits, etc.)
- Adherence and psychosocial support assessments
- Attendance records
- Others

Record-keeping basics

- Write neatly.
- Write in blue or black ink.
- Cross out mistakes neatly.
- Write corrections clearly.
- Keep forms and registers in a clean, dry place.
- If you have to hand in a report, always make a photocopy for your records.
- Ask another Peer Educator, a supervisor or another member of the multidisciplinary team for help.



SESSION 13.3: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- Keeping good records can help you show the work you have done, plan for what do next and follow up with clients.
- It is important for you to keep good records of your work and to submit monthly reports on time to your supervisor. These reports should be discussed and shared among you, your supervisors and the entire multidisciplinary team.
- There are at least 3 important forms for you to fill out on a regular basis:
 - Daily register for individual counseling sessions
 - Daily register for group education sessions
 - Monthly summary report
- Peer Educators should help each other fill out the forms and ask each other, their supervisor or other members of the multidisciplinary team if they have questions.

APPENDIX 13A: Sample Daily Register for Individual Counseling Sessions (adapt to your local setting)

Date	Client's Name	Age	Sex	ART # or ANC # or Under 5 clinic #	Type of Individual Counseling Session (tick "A" for adult client and "C" for child client)														Referrals and Linkages					
					Pre-ART adherence counseling		2 week review post ART initiation		Monthly ART review or refill		Post HIV test counseling and support		Missed appointment/lost to follow-up counseling		PMTCT		Counseling for caregivers of HIV-exposed or HIV-infected infants and children		Psychosocial support		Other		Pregnant woman walked to ART clinic	
					A	C	A	C	A	C	A	C	A	C	A	C	A	C	A	C	A	C	A	C
TOTALS:																								

APPENDIX 13B: Sample Daily Register for Group Education Sessions (adapt to your local setting)

Date of Group Session	Pre-ART session #1			Pre-ART Session #2			Pre-ART Session #3			PMTCT Session			Support Group Meeting			Other Group Session		
	Adults	Pregnant women	Children and Caregivers	Adults	Pregnant women	Children and Caregivers	Adults	Pregnant women	Children and Caregivers	Adults	Pregnant women	Children and Caregivers	Adults	Pregnant women	Children and Caregivers	Adults	Pregnant women	Children and Caregivers
	<i>write number of people</i>			<i>write number of people</i>			<i>write number of people</i>			<i>write number of people</i>			<i>write number of people</i>			<i>write number of people</i>		
TOTALS:																		

APPENDIX 13C: Sample Monthly Reporting Form (adapt to your local setting)

Name of Peer Educator:

Name of Health Facility:

Reporting Month:

Individual sessions Totals for the month	Pre-ART adherence counseling	Adult	
		Child	
	2 week review post-ART initiation	Adult	
		Child	
	Monthly ART review of refill	Adult	
		Child	
	Post HIV test counseling and support	Adult	
		Child	
	Missed appointments/lost to follow-up counseling	Adult	
		Child	
	PMTCT	Adult	
		Child	
	Counseling for caregivers of HIV-exposed or HIV-infected infants and children	Adult	
		Child	
Psychosocial support	Adult		
	Child		
Other	Adult		
	Child		
Referrals Totals for the month	Pregnant women walked to ART clinic		
	Children walked to ART clinic		
	People invited/referred to support group meeting	Adult	
Child			

Group sessions	Pre-ART Session #1	Total # of sessions		
		Totals for the month	Number of participants (in all sessions)	Adult
Pregnant				
Child				
Pre-ART Session #2	Number of participants (in all sessions)	Adult		
		Pregnant		
		Child		
Pre-ART Session #3	Number of participants (in all sessions)	Adult		
		Pregnant		
		Child		
PMTCT	Number of participants (in all sessions)	Adult		
		Pregnant		
		Child		
Support group meeting	Number of participants (in all sessions)	Adult		
		Pregnant		
		Child		
Other	Number of participants (in all sessions)	Adult		
		Pregnant		
		Child		

Comments and Notes:

Peer Educator's Signature:

Supervisor's Signature:

MODULE 14:

Supervised Practicum



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Practice skills learned during the training in a health facility offering HIV prevention, care and treatment services
- Demonstrate competency in the major skills taught during the training
- Identify skill areas where further on-the-job practice and mentoring are required



CONTENT:

Session 14.1: Practicum Preparation
Session 14.2: Supervised Practicum
Session 14.3: Practicum Debriefing

SESSION 14.1: Practicum Preparation

Now, you will be able to put the information and skills you have learned into practice at hospitals and health centers, with real clients, working as a member of a multidisciplinary team.



SESSION 14.2: Supervised Practicum

During the practicum, you will be mentored by one or more people and will have a chance to practice the skills learned during the Peer Educator training. This is a good time to ask questions and get as much practice as possible!

The preceptors will be looking for you to demonstrate a number of skills that we have learned in the training. They will give you constructive feedback on what was done well and what could be done better.

The preceptors will be using a checklist to document all of the skills you use during the practicum. See *Appendix 14A* for a copy of this checklist.



SESSION 14.3: Practicum Debriefing

Congratulations on a job well done!

Practicum debrief discussion questions:

- What was your overall experience during the practicum?
- What skills were the most difficult?
- What skills were the easiest?
- Which areas would you like more support on to make you the best Peer Educator possible?

APPENDIX 14A: Peer Educator Supervised Practicum Checklist

Instructions: Preceptors should complete one checklist for each Peer Educator during the practicum. As you observe a specific skill being demonstrated, tick your rating as GOOD, FAIR or POOR. If you want to make comments or recommendations, write in the right-hand column and be sure to share comments with the Peer Educator. Note that it is unlikely that all items on the checklist will be observed during the practicum. This extensive list of skills is intended to be a guide to preceptors and Peer Educators. At the end of the practicum, complete the final evaluation for each participant.

Name of Participant: _____

Name of Preceptor(s): _____

Dates of Practicum: _____

Name of Practicum Site: _____

Key Skill Area	Preceptor's Rating (Tick One)			Comments
	Good has mastered the skill	Fair needs more practice	Poor needs more training	
General Communication and Counseling Skills with Individuals				
Greets clients properly				
Introduces self and role as a Peer Educator				
Ensures privacy and maintains confidentiality				
Uses good non-verbal communication:				
Makes eye contact				
Sits next to and faces the client				
Smiles				
Minimizes distractions and writing				
Asks open-ended questions to get more information				
Uses active listening skills:				
Uses a calm, non-directive tone of voice				
Allows the client to express emotions				
Does not interrupt				
Shows a respectful, non-judgmental attitude				
Reflects back what the client is saying				
Shows empathy (not sympathy) towards the client				
Uses non-judgmental words that build confidence and give support				

Key Skill Area	Preceptor's Rating (Tick One)			Comments
	Good has mastered the skill	Fair needs more practice	Poor needs more training	
Helps the client set goals and realistic next steps				
Summarizes the counseling session				
General Communication Skills with Groups				
Chooses location with privacy and limited distraction				
Sets up participants in a semi-circle				
Speaks loudly and clearly				
Introduces self to the group, identifies self as a PLHIV				
Introduces group session goals and content areas				
Engages participants in the discussion vs. lecturing				
Tailors session according to what participants already know				
Makes eye contact with participants				
Regularly checks participants' comprehension				
Engages quiet participants				
Uses visual aids to complement discussion				
Summarizes the session				
Offers follow-up counseling to participants				
Basic Communication about HIV and Reproductive Health				
Explains the difference between HIV and AIDS				
Explains how HIV affects the immune system				
Explains the function of CD4 cells and meaning of CD4 cell count				
Describes the functions of reproductive and sexual body parts				
Explains the different ways HIV is transmitted:				
Sexual transmission				
MTCT				
Blood-blood transmission				
Use of unsafe objects				
Clarifies the way HIV is NOT transmitted				
Explains the different ways HIV can be prevented:				
Prevention of sexual transmission – the ABCs				

Key Skill Area	Preceptor's Rating (Tick One)			Comments
	Good has mastered the skill	Fair needs more practice	Poor needs more training	
Male circumcision				
PMTCT				
Prevention of blood-blood transmission				
Prevention of unsafe object use				
Asks clients about family members (health, HIV testing, enrollment)				
Comprehensive HIV Care				
Describes components of comprehensive HIV care				
Provides post-HIV test support				
Mobilizes clients' family members for HIV testing				
Explains why HIV care is important, even if a person is not on ART				
Explains the most common OIs and other complications, their signs and symptoms, prevention and treatment				
Tuberculosis				
Pneumonia/PCP				
Mouth sores or pain				
Skin problems				
Malaria				
STIs				
Weight loss				
Explains the benefits and dosing of CTX				
Provides TB education				
Uses the TB screening tool to identify possible TB cases and refer				
Provides support to people with TB to take medications correctly				
Helps clients seek referrals within the health facility				
Effectively communicates with the multidisciplinary team				
ART				
Explains who needs ARVs and ART				
Explains the goals and benefits of ART				
Identifies first-line regimen, dosage, timing and possible side effects				
Provides advice on preventing and managing ARV side effects:				
Rash and skin problems				

Key Skill Area	Preceptor's Rating (Tick One)			Comments
	Good has mastered the skill	Fair needs more practice	Poor needs more training	
Numbness or tingling				
Nausea and vomiting				
Headache				
Diarrhea				
Trouble sleeping or nightmares				
Tiredness				
Long-term side effects (changes in body shape, etc.)				
Recognizes dangerous side effects and provides immediate referral				
Advises not to stop taking ARVs without coming to the clinic				
HIV Prevention, Care and Treatment for Pregnant Women and Their Children				
Explains the ways HIV can be transmitted from mother to child				
Explains that not all babies will become HIV-infected				
Articulates the 4 main PMTCT concepts:				
Keep moms healthy				
Reduce risk of MTCT at every stage of pregnancy and after				
All pregnant women living with HIV need ARVs				
All babies of mothers living with HIV need ARVs				
Discusses the motto of "saving 2 lives"				
Explains PMTCT strategies before pregnancy				
Explains PMTCT strategies during pregnancy				
Explains PMTCT strategies during labor and delivery				
Explains PMTCT strategies after the baby is born				
Strategies focused on the mother's health				
Strategies focused on the baby's health				
Safe infant feeding				
Assists pregnant women to understand and access ART services				
Explains follow-up services for HIV-exposed babies, including CTX				
Explains HIV testing for HIV-exposed babies <18 months old				
Explains HIV testing for infants >18 months old				
Explains the importance of identifying HIV-infected babies and starting them on care and treatment right away				

Key Skill Area	Preceptor's Rating (Tick One)			Comments
	Good has mastered the skill	Fair needs more practice	Poor needs more training	
Adherence and Psychosocial Support				
Explains the importance of adhering to the specific care plan				
Records/updates the client's complete contact information correctly				
Effectively conducts pre-ART group education session #1				
Effectively conducts pre-ART group education session #2				
Effectively conducts pre-ART group education session #3				
Effectively conducts individual pre-ART adherence counseling				
Conducts an ART readiness assessment				
Provides individualized counseling to make an adherence plan				
Conducts a psychosocial assessment				
Provides individualized counseling and support to address psychosocial needs and concerns				
Asks about adherence at follow-up visits or refill appointments				
Counsels clients who are having adherence challenges				
Provides referrals for community adherence and psychosoc. support				
Identifying and Tracing People Who Do Not Return to the Clinic				
Demonstrates understanding of the facility's policies and procedures to identify and follow up with clients				
Asks clients for consent to follow up by phone or home visit				
Records clients' follow-up preferences				
Uses the clinic's appointment book correctly				
Uses the clinic's appointment reminder cards correctly				
Helps create lists of clients who miss appointments				
Effectively contacts client who has missed an appointment by phone				
Effectively communicates with a community health worker to arrange a follow-up home visit				
Conducts a home visit with a client who has missed an appointment and provides necessary counseling				
Records the outcome of the follow-up attempt				
Provides adherence counseling when clients return to the clinic				

Key Skill Area	Preceptor's Rating (Tick One)			Comments
	Good has mastered the skill	Fair needs more practice	Poor needs more training	
Positive Living				
Describes the importance of positive living				
Gives practical support to keep the mind healthy				
Provides support to clients with anxiety and/or depression				
Understands when to make mental health referrals				
Explains healthy and unhealthy behaviors for PLHIV				
Describes ways to practice safer sex and prevent HIV				
Demonstrates male and female condom use				
Describes useful strategies to negotiate condom use				
Describes the common signs and symptoms of STIs				
Advises on complete treatment of STIs for self and partner				
Counsels on how clients can be involved in their own care				
Stigma, Discrimination and Disclosure				
Provides support to cope with and fight stigma and discrimination				
Freely discloses own HIV-status to clients and health care workers				
Provides disclosure counseling for adults				
Provides disclosure counseling for caregivers and children				
Community Outreach, Education and Linkages				
Demonstrates knowledge of available community resources				
Refers clients to needed resources in the community				
Speaks about HIV prevention, care and treatment at a community meeting or event (optional)				
Record-keeping and Reporting				
Correctly fills in daily activity records for individual sessions				
Correctly fills in daily activity records for group sessions				
Correctly completes monthly summary report				

Final Evaluation by Preceptors:

Name of participant: _____

Tick one:

____ Demonstrated a majority of skills effectively and is ready to start work as a Peer Educator

____ Demonstrated some skills effectively, but still needs more practice before becoming a Peer Educator

____ Unable to demonstrate most skills and should participate in the training course again before becoming Peer Educator

Additional comments:

Preceptor(s) Signature: _____

Date: _____

MODULE 15:

Next Steps, Course Evaluation and Graduation



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Review and reflect on the overall learning objectives of the Peer Educator training
- Discuss your vision and hopes for the Peer Education Program and your future as a Peer Educator
- Agree on next steps for when you return to your respective health facility
- Complete a final learning assessment
- Complete a training evaluation
- Graduate from the training



CONTENT:

Session 15.1: Reflection on Learning Objectives

Session 15.2: Next Steps for Peer Educators

Session 15.3: Final Learning Assessment/Post-
Test

Session 15.4: Training Evaluation

Session 15.5: Graduation and Closing

SESSION 15.1: Reflection on Learning Objective

At the beginning of the training, we agreed on a number of learning objectives.

By the end of this basic training course, you will be able to:

1. Work as an integral part of facility multidisciplinary care teams, specifically at PMTCT and HIV care and treatment clinics
2. Provide one-on-one counseling and group education to clients and their families so they better understand, use and adhere to HIV prevention, care and treatment services
3. Assist clients and their families to access different services within the health facility, such as ART, PMTCT, VCT, TB diagnosis and treatment, STI treatment, maternal and child health, and family planning
4. Help prioritize pregnant women for HIV care and treatment services
5. Follow up HIV-exposed babies and provide basic information to clients on caring for their HIV-exposed and HIV-infected babies and children
6. Implement family-focused care by encouraging clients to disclose to family members and bring them to the clinic for counseling, testing, care and treatment
7. Serve as a role model for positive living and adherence to care and treatment
8. Help clients, family members and community members live positively with HIV and prevent new HIV infections
9. Identify and trace clients who have missed appointments or have discontinued treatment in order to bring them back into care
10. Assist clients and their families to access community-based services, such as support groups, PLHIV associations, food support and income-generating activities
11. Conduct community mobilization and sensitization around HIV and prevention, care and treatment services
12. Keep records of daily, weekly and monthly activities

SESSION 15.2: Next Steps for Peer Educators

During this Module, we will spend time discussing what the next steps are in preparation for your work as a Peer Educator. Please take your own notes in the space below.



SESSION 15.3: Final Learning Assessment/Post-Test

We will now do a final learning assessment to evaluate how effective the training was in developing knowledge and skills. The assessment is similar to the needs assessment you completed at the beginning of the training.



SESSION 15.4: Training Evaluation

To improve how the training was conducted, we would like your honest feedback and evaluation. This will help the trainers know what went well and what can be done better at future trainings.

Discussion questions:

- What did you like best about the training?
- What didn't you like about the training?
- What do you think could be done better in future trainings?

SESSION 15.5: Graduation and Closing

Thank you for your hard work and commitment to helping people living with HIV and their families!

Congratulations on a job well done!



ADVANCED MODULE 16:

Sexuality, Childbearing and Family Planning Basics



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Reflect on your biases and values about particular sexual behaviors
- Understand the importance of being non-judgmental when counseling clients about sexual and reproductive health
- Identify and describe the basic functions of sexual and reproductive body parts in men and women
- Explain how conception happens
- Work as part of the multidisciplinary team to support clients with their childbearing decisions
- Work with members of the multidisciplinary team to provide information on family planning methods and make referrals for family planning services
- Counsel clients on dual protection from STIs, HIV and unwanted pregnancy



CONTENT:

- Session 16.1: Introduction: Let's Talk about Sex
- Session 16.2: Different Sexual Behaviors: Okay for Me?
- Session 16.3: Parts of the Body Involved in Sex and Reproduction
- Session 16.4: Conception and Childbearing Choices
- Session 16.5: Types of Family Planning Methods
- Session 16.6: Dual Protection and Condom Use
- Session 16.7: Classroom Practicum on Conception, Childbearing and Family Planning Counseling
- Session 16.8: Module Summary

SESSION 16.1: Introduction: Let's Talk about Sex

Sex is a normal part of life. HIV is mainly spread through unsafe sex. Unsafe sex is any kind of sex that puts ourselves or our sexual partners at risk of getting a sexually transmitted infection, including HIV, or unwanted pregnancy. In order to help people protect themselves and their families, you must make sure people have the facts.

Sometimes, it can be uncomfortable to talk about sex, sexuality and reproduction. You need to be able to talk openly with people to help them practice safe sex, understand reproduction and make informed choices about having children.



SESSION 16.2: Different Sexual Behaviors: Okay for Me?

Remember:

- In many places, “sex” is often thought to mean only penis-vagina sex between a man and a woman. But sexual behaviors include much more than penis-vagina sex.
- We all have value judgments when it comes to sex and sexual behaviors, but you should not put your values on clients. Clients should feel comfortable talking about their sexual behaviors with you no matter what.
- If you do not talk about sex and sexual behaviors with clients, they may not get the information, skills and supplies they need to protect themselves and their partners and reduce risks of HIV, STIs, sexual violence, discrimination and unwanted pregnancy.

SESSION 16.3: Parts of the Body Involved in Sex and Reproduction

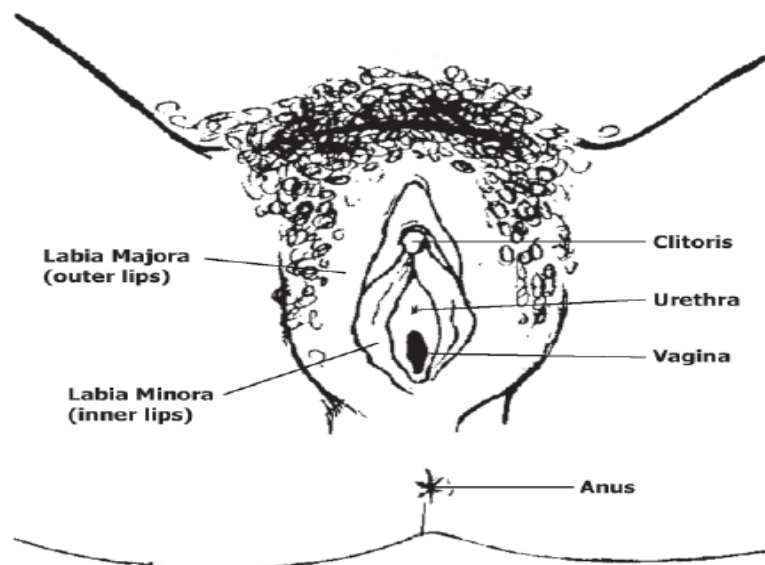
The information below is a review of material from *Module 3*.

Female Sexual and Reproductive Body Parts

External female body parts (parts you can see):

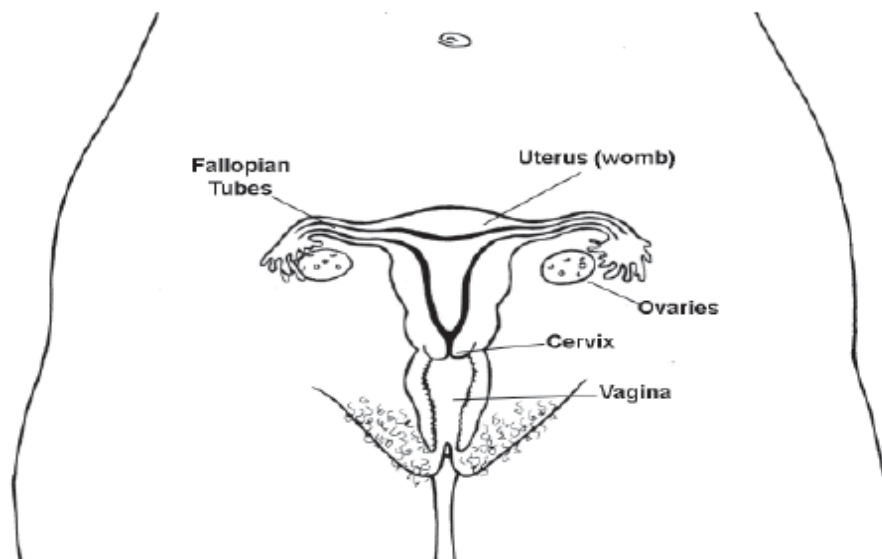
- **Urethra:** where urine (pee) comes out of the body
- **Vagina:** where the penis or fingers enter during sex and also where a baby comes out. The vagina is the opening to the cervix and the uterus, which is where babies grow.
- **Anus:** where stool (poop) comes out of the body and where the penis or fingers enter the body during anal sex
- **Labia minora** and **labia majora:** sometimes called the “lips” around the vagina and urethra
- **Clitoris:** where women can have strong pleasure and orgasm

Some women may have experienced genital cutting, where the clitoris and labia may have been removed in part or completely. Some women may also have had parts of their vaginas sewn up. It is important not to judge women that have or have not undergone these procedures.



Internal female body parts (parts you cannot see):

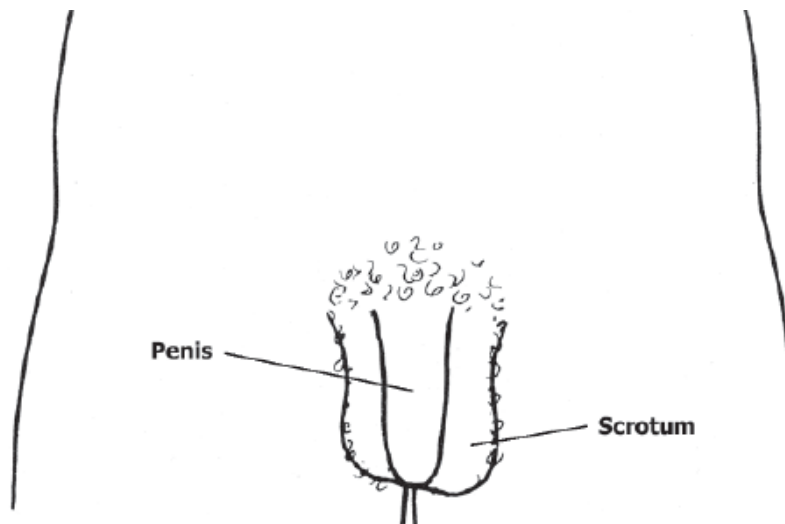
- **Uterus** or **womb**: where a baby grows and where monthly bleeding comes from
- **Ovaries**: where a woman's eggs are stored
- **Fallopian tubes**: attached to the uterus. The eggs travel through the fallopian tubes to get from the ovaries to the uterus.
- **Cervix**: "mouth" of the uterus. Sperm enters the uterus through the cervix and the baby comes out of the uterus through the cervix.
- **Vagina**: where the penis or fingers enter during sex and also where a baby comes out. The vagina is the opening to the cervix and the uterus (where babies grow).



Male Sexual and Reproductive Body Parts

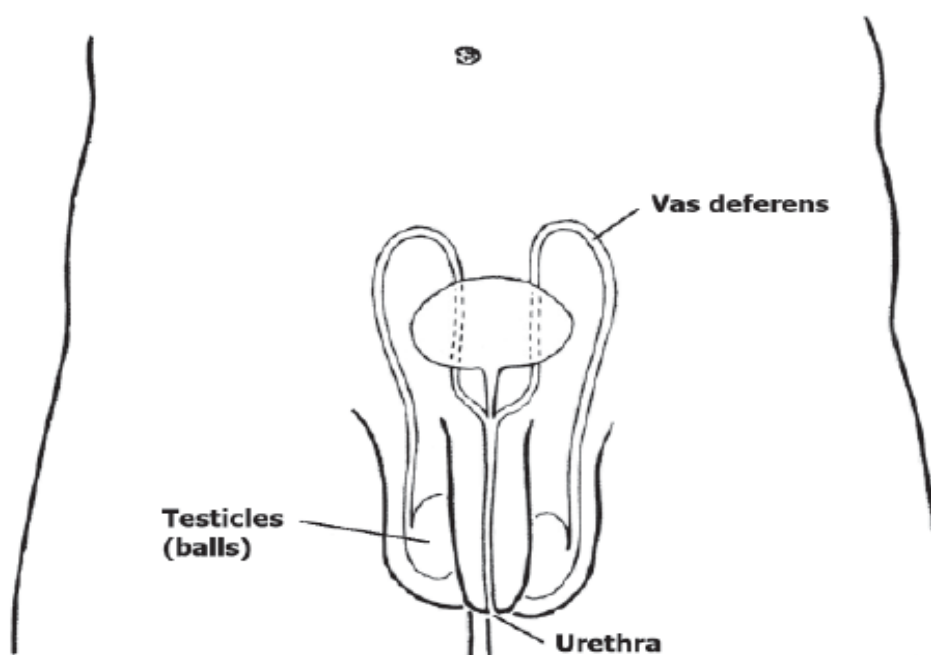
External male body parts (parts you can see):

- **Penis:** the main body part for sex and pleasure. The penis delivers the sperm that can make a woman pregnant during sex. The tip of the penis may have foreskin or, if the man has been circumcised, there will be no foreskin.
- **Scrotum:** sack that holds the testicles (balls)
- **Anus:** where stool (poop) comes out of the body and where the penis or fingers enter the body during anal sex. Note that the anus is not shown in the diagram below, but is located in the same place as in a female.



Internal male body parts (parts you cannot see):

- **Testicles** or **balls**: where sperm are made and stored. Sperm live in a fluid called semen (cum), which is what comes out when a man ejaculates. Semen can contain STIs and HIV.
- **Vas deferens**: attached to the testicles. Sperm travel through these tubes to get to the urethra.
- **Urethra**: the opening on the end of the penis where urine (pee) and semen (cum) containing sperm come out. Note that urine and semen do NOT come out at the same time.



SESSION 16.4: Conception and Childbearing Choices

You can help people in the community understand how women get pregnant and give people information to make choices about if, and when, they want to become pregnant.

Remember: You should always work with other members of the multidisciplinary team, as you are not trained family planning counselors or educators. Good referral linkages between Peer Educators like yourself and other health care workers are very important.

Conception:

- A girl is born with all the eggs she needs in her lifetime. The eggs are stored in the ovaries. After the girl reaches puberty (around age 14-15), the ovary will release one egg each month, until she stops having her period (the time each month that women bleed) around age 45-50. About 2 weeks before monthly bleeding, the ovary releases one egg, which travels down the fallopian tubes to the uterus. This process is called **ovulation**.
- If the girl or woman has sex with a man during the time of ovulation, the sperm from the man will enter into the cervix, travel through the uterus and into the tube where it can join the egg. When a sperm from a man joins the egg of a woman, this is called **fertilization**. A woman will not always get pregnant if she has sex with a man (without a condom) while she is ovulating because every woman's cycle is a little bit different.
- The joined egg and sperm travel back down the tube into the uterus. It buries into the woman's uterus lining and a baby will start to grow.
- After about 2 weeks, a **placenta** starts to grow. This is a sack that holds the baby inside the woman's uterus and helps it get nutrients. Blood and food from the woman travel through the placenta and help the baby grow for 9 months until it is ready to be born.
- If the woman does NOT have sex with a man (or uses a condom) during ovulation, the egg will pass out of the woman's body during monthly bleeding. There is no monthly bleeding during pregnancy because the woman's body needs that blood to nourish the baby.

Other key terms

- **Contraception:** The use of a method or more than one method to prevent pregnancy when a man and a woman have sex.
- **Family planning:** Having the number of children you want, when you want them. Often this includes using a contraceptive method to prevent or space births.
- **Birth spacing:** When people plan their births far enough apart so the woman and the baby are not at risk of the health problems that can occur when babies are born too close together. At least 3 years between children is recommended.

Childbearing choices:

All people, including people living with HIV, have the right to decide if they want to have children or not and, if they do, how many children they want to have. It is very important that you are not judgmental of a person's decisions about having children.

You can work with other members of the multidisciplinary team to ask their clients about their childbearing preferences:

For women, discuss:

- *Is she pregnant now?*
- *When was her last period (monthly bleeding)?*
- *If she is not pregnant, does she want to have children now? In the future? When?*
- *Is her partner living with HIV or HIV-negative?*
- *Is she using a contraceptive method?*

For men, discuss:

- *Does he have a female partner?*
- *Is she pregnant now?*
- *Do they want to become pregnant now? In the future? When?*
- *Is his partner living with HIV or HIV-negative?*
- *Are they using a contraceptive method?*

For clients who want to prevent or space pregnancy, you can provide information and referrals:

- Provide basic family planning information and referrals.
- Talk about the importance of dual protection, to protect against both pregnancy and HIV/STIs (there is more on this in the next session).
- Give condoms and show the person how to use them.



For women living with HIV who want to have a baby, you can work with other members of the multidisciplinary team to talk with them about the safest times to get pregnant:

- When their CD4 cell count is high
- When they do not have any major illnesses, including TB
- When they are on ART (if eligible)

You can remind women about the importance of long term adherence to care and treatment so that they can stay healthy for their own well-being and that of their children.



For women living with HIV who are currently pregnant, you can work with other members of the multidisciplinary team to:

- Make sure they enroll in a PMTCT program.
- Counsel them on different PMTCT services.
- Encourage them to take ART if they are eligible, or ARVs during the pregnancy if not.
- Talk to them about their pregnancy desires after the baby is born and provide basic family planning information and referrals for family planning services.

For men living with HIV who wish to have a child with their partner, you can work with other members of the multidisciplinary team to:

- Encourage them to take and adhere to ART, if eligible.
- Encourage them to practice safer sex with condoms during the times of the month when their partner is NOT ovulating (see below) – men should also always use condoms during sex with other partners.
- Counsel them to prevent and treat any STIs and to bring their partner(s) for treatment as well.

You can also provide childbearing information to discordant couples where one person is living with HIV and the other person is HIV-negative.

- Encourage discordant couples who wish to become pregnant to practice safer sex when the woman is NOT ovulating (this is usually during the 7 days after she has her monthly bleeding and the time during her monthly bleeding). This will help prevent the spread of HIV to the HIV-negative partner (the man or the woman). Then, the couple can try and conceive when the woman is ovulating (this is usually around days 8-20 of her monthly cycle) – not using condoms during this time.
- Counsel the couple about how important it is for the partner living with HIV to be enrolled in care and, if eligible, take ART. Good adherence to ART can lower the amount of HIV in the person's body and help reduce the chance that the HIV-negative partner will be infected.
- Counsel the couple on preventing and treating STIs.
- Encourage the HIV-negative partner to get regular HIV tests – especially before, during and after pregnancy.



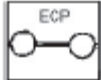







SESSION 16.5: Types of Family Planning Methods




You should work with other members of the multidisciplinary team to provide family planning information to clients and, if needed, referrals for family planning services. Make sure you know which methods are available within your health facility and at other health facilities in your area.



Family Planning Methods

Family Planning Method	Protection From Pregnancy	Protection from HIV/STIs	Possible Side Effects	Other Important Information
Condoms 	Effective ✓ ✓ ✓	Good	Latex allergy	<ul style="list-style-type: none"> Condoms should only be used ONE time and then thrown away. It is good to use lubricant with condoms. They are the best method to prevent STIs/HIV, but they must be used correctly, every time.
Oral Contraceptive Pills 	Very effective ✓ ✓ ✓ ✓	None	Nausea, headaches, weight gain, breast swelling and tenderness, or changes in monthly bleeding	<ul style="list-style-type: none"> One pill must be taken by mouth at the same time every day. Women taking some TB medicines should use another method. It is usually safe to take ART and the pill, but it is important for a woman to talk with a doctor or nurse to make sure. Some oral contraceptives cannot be used when a woman is breastfeeding.
Emergency Contraceptive Pills (ECP) 	Effective within 5 days of unprotected sex ✓ ✓	None	Nausea, vomiting, changes in monthly bleeding	<ul style="list-style-type: none"> ECP should just be used in emergencies or when other methods fail. It has to be taken within 5 days of unprotected sex. The earlier it is taken, the more effective it is. Women should consult with a doctor or nurse to see what kind and how many pills to take if ECP is needed. ECP is NOT an abortion.

Injectables 	Very effective ✓✓✓✓✓	None	Weight gain, sore or tender breasts, nausea, changes in monthly bleeding	<ul style="list-style-type: none"> • The woman must see a health provider every 2-3 months to get an injection (usually in her upper arm). • The woman does not have to do anything before sex because the injectable works all the time. • No one can tell if a woman is using injectables. • They are safe to use when breastfeeding.
Implants 	Very effective ✓✓✓✓✓	None	Weight gain, sore or tender breasts, nausea, changes in monthly bleeding	<ul style="list-style-type: none"> • Implants can prevent pregnancy for 3-7 years. A trained nurse or doctor has to put in the implants (in the arm) and remove them. • The woman does not have to do anything before sex since the implants work all the time. • Implants are safe to use during breastfeeding.
Intra-Uterine Device (IUD) 	Very effective ✓✓✓✓✓	None	Pain in the uterus and cramping, long and heavy monthly bleeding, spotting (light bleeding).	<ul style="list-style-type: none"> • An IUD can safely stay inside the uterus for 10 years once it has been inserted by a doctor or nurse. • The IUD is very safe and women will not feel it inside. • It is important that women are checked for STIs before getting an IUD. • IUDs are generally safe for PLHIV. People with advanced HIV or AIDS or with STIs should NOT use IUDs.
Diaphragm 	Effective ✓✓✓✓	Some	Urinary tract infections	<ul style="list-style-type: none"> • Diaphragms should be used with spermicide. • Women must see a doctor or nurse, who will fit the diaphragm to the woman's size.
Spermicides 	Not very effective ✓	None	Irritation in the vagina or on the penis	<ul style="list-style-type: none"> • Spermicides can irritate the skin and cause cuts and sores. This may increase the risk of HIV. • They must be put into the vagina 1 hour or less before sex and left in the vagina for 6 hours after sex.

Sterilization (women and men) 	Very effective ✓✓✓✓	None		<ul style="list-style-type: none"> • Sterilization is best for men and women who never want to have children or have had all the children they want in life because it is a permanent method. Sterilization in men is called vasectomy. Sterilization in women is called tubal ligation. • These procedures have to be done by a trained nurse or doctor.
Lactational Amenorrhea Method (LAM) 	Somewhat effective ✓✓✓	None		<ul style="list-style-type: none"> • A woman must give her baby only breast milk and her monthly bleeding must not have returned. It is best to use condoms during breastfeeding and start another method before the baby is 6 months old or the woman stops exclusively breastfeeding.
Standard Days Method (SDM) 	Somewhat effective ✓✓✓	None		<ul style="list-style-type: none"> • It is important to remember that many women do not have control over when they have sex with their partner, so the SDM and other natural methods may not be useful in protecting her from pregnancy. • Women's cycles are different and it is difficult to tell for sure exactly when a woman is ovulating. This makes natural family planning methods, like SDM, less reliable than "modern" methods.
Withdrawal	Not very effective ✓	Almost none		<ul style="list-style-type: none"> • Withdrawal should only be used as a last resort as it is not an effective method of preventing pregnancy or STIs/HIV. It also means that the woman has to rely on the man for protection.

General Points on Family Planning Counseling

- You should always work with doctors, nurses and other members of the multidisciplinary team when providing family planning education or counseling to clients.
- It is important for clients to know all the methods that are locally available to them so they can make an informed decision about if they want to use a method and which type of method is best. You should know which family planning methods are available at different health facilities in your working areas.
- Never tell clients which methods are best for them. A woman, man or couple should be informed completely about the different methods available and the benefits and drawbacks of each so they can choose without pressure or confusion.
- As with all counseling, make sure there is privacy and confidentiality when talking with clients about family planning methods.
- Encourage clients to discuss family planning methods with their partner so they can both take responsibility for protection from unwanted pregnancy and STIs/HIV.
- Be aware that discordant couples (where one person is living with HIV and the other is HIV-negative) may face special challenges when making decisions about pregnancy and family planning.
- Clients who choose hormonal methods should be provided with adherence counseling about the importance of taking oral contraceptives on time each day (including planning reminder cues), never missing pills and the importance of returning to the clinic.
- Always remind clients to come back to see a health care worker if they have any questions, concerns or are having side effects.

SESSION 16.6: Dual Protection and Condom Use

Dual Protection

Dual protection means preventing STIs, HIV infection and unwanted pregnancy at the same time. Dual protection includes:

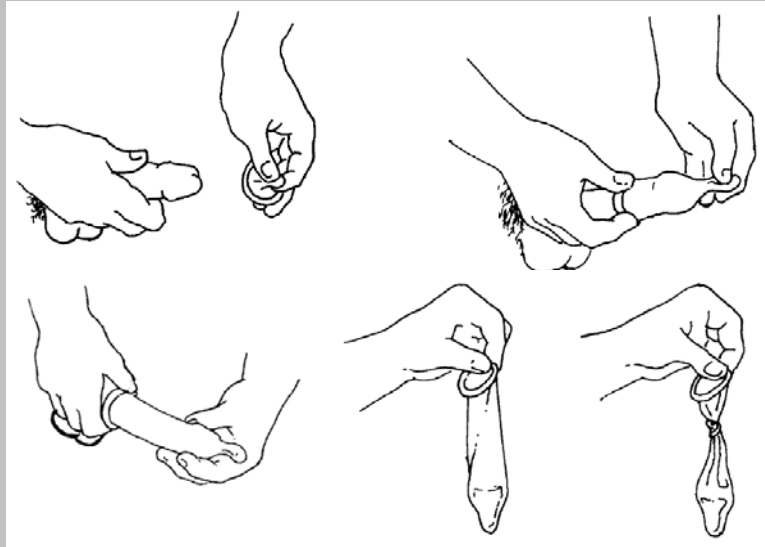
- Using male or female condoms in combination with another contraceptive method
- Using male or female condoms alone
- Abstinence (not having sex at all)
- Avoiding all forms of penetrative sex

Condoms:

Not having sex at all is one way to be completely safe. But this is not practical or enjoyable for most people. Using condoms is one reliable way to practice safer sex and prevent STIs, HIV and unwanted pregnancy.

How to use a Male Condom

These are the basic steps you should know for using, and demonstrating how to use, a male condom. If penis models are not available, you can use a bottle, banana or corn. Only condoms made out of **latex** protect against HIV.



Steps to use a male condom:

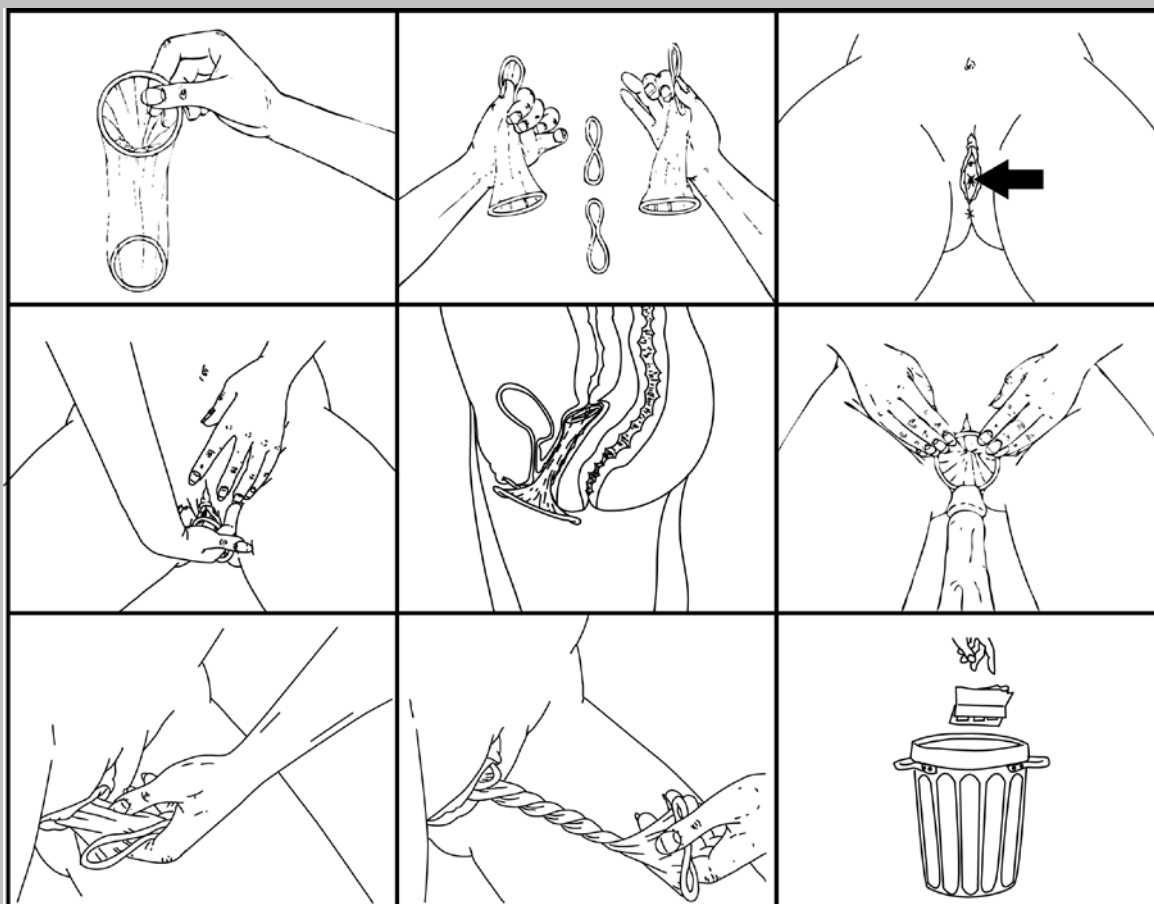
1. Look at the condom package and check the date to make sure it is still good and that the package does not have any damage.
2. Open the packet on one side and take the condom out. Do not use your teeth to open the package.
3. Pinch the tip of the condom to keep a little space at the tip. This will hold the semen and prevent the condom from breaking.
4. Hold the condom so that the tip is facing up and it can be rolled down the penis.
5. Put it on the tip of an erect (hard) penis (only use condoms on an erect penis) and unroll it down to the bottom of the penis.
6. After ejaculation (coming), hold the rim of the condom while the man removes his penis without spilling the semen. The penis must be removed while it is still hard to make sure the condom does not fall off.
7. Remove the condom and tie it in a knot to avoid spilling. Throw it away in a latrine or bury it.
8. Use a new single condom every time!

Also, it is important to:

- Use only lubricants made out of water (not oils).
- Store condoms in a cool, dry place, out of the sun. Do not keep them in a wallet.
- Do not use condoms that seem to be sticky, a strange color, or damaged in any way. Throw them away.

How to Use a Female Condom

Some women really like the female condom because it gives them more control over their own bodies and over sex. Some men like it, too, because they do not have to use a male condom. The female condom is becoming more affordable and available to women in many countries. These are the main steps for using a female condom. If no vaginal model is available to demonstrate its use to people, you can use a box with a round hole cut in it or your hand.



Steps to use a female condom:

1. Open the packet. Do not use your teeth.
2. Find the inner ring at the bottom, closed end of the condom. The inner ring is not attached to the condom.
3. Squeeze the inner ring between the thumb and middle finger.
4. Guide the inner ring all the way into the vagina with your fingers. The outer ring stays outside the vagina and covers the lips of the vagina.
5. When you have sex, guide the penis through the outer ring. It has to be **INSIDE** the ring.
6. After the man ejaculates (comes), before the woman stands up, squeeze and twist the outer ring to keep the semen inside the pouch and pull the pouch out.
7. Put the used condom in a latrine or bury it. Do not put it in a flush toilet.

SESSION 16.7: Classroom Practicum on Conception, Childbearing and Family Planning Counseling

Case Study 1:

A___ is a 25-year-old woman living with HIV. She is on ART and is feeling very well. She does not have a regular partner, but does have a couple of different boyfriends. She does not want children right now, but may want them in the future. How would you counsel her?

Case Study 2:

B___ and G___ are a married couple. They are both living with HIV and are on ART. They have 3 healthy children and do not want to have any more. How would you counsel B___ and G___?

Case Study 3:

T___ is a 35-year-old woman. She is HIV-negative, but her husband is living with HIV. Her husband usually uses condoms, but not all the time. She is afraid of getting HIV and becoming pregnant, but she is also afraid to talk to her husband about family planning because she knows he wants more children. How would you counsel her?

Case Study 4:

P___ and her boyfriend N___ visit you at the clinic. P___ just learned that her CD4 cell count is 250 and the doctor wants to start her on ART. N___ is HIV-negative. They want to have a baby soon and ask you if it is safe. How would you counsel this couple?

Note: Some of the preceding information in this Module was adapted from the following sources:

Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). *Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers*. Watertown, MA: Pathfinder International.

EngenderHealth. (2002). *Integration of HIV/STI prevention, sexuality, and dual protection in family planning counseling: A training manual*. New York, NY: EngenderHealth.

SESSION 16.8: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- We all have value judgments when it comes to sex and sexual behaviors. But in order to be good Peer Educators, we must not put our values on clients.
- You need to talk openly with people to help them practice safer sex, understand reproduction, and make informed choices about if they want to have children, and how many children to have.
- It is important for you to know all of the body parts involved in sex, sexuality and reproduction in women and men.
- You can help people in the community understand how women get pregnant and help people make choices about if/when they want to become pregnant. You can provide non-judgmental information on family planning and childbearing.
- You should always consult with doctors, nurses, counselors and other members of the multidisciplinary team when providing clients with information on conception, childbearing and family planning. You can also provide clients with referrals for more counseling or services.
- All people, including PLHIV and discordant couples, have the right to decide if they want to have children or not and if they do, how many children they want to have. It is very important that, as Peer Educators, you not be judgmental of a person's or couple's decisions about having children.
- You are not a trained family planning provider, but you can give clients basic information on family planning methods and make referrals for these services.
- It is important for clients to know all the family planning methods that are available to them so they can make an informed decision about if they want to use a method and which type of method is best.
- Dual protection means preventing STIs/HIV and unwanted pregnancy at the same time. The key to practicing dual protection is to use condoms, either alone or with another contraceptive method, such as pills, injectables or clinical methods.

ADVANCED MODULE 17:

Nutrition Education and Counseling



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Discuss the relationship between nutrition and HIV and how nutrition is part of comprehensive HIV care and treatment
- Understand why PLHIV sometimes do not eat enough healthy foods
- Know the basic food groups and what locally available foods belong to each group
- Provide basic nutrition education and counseling to adults, pregnant and breastfeeding women and caregivers of children living with HIV
- Provide practical information to address common nutrition and eating problems in coordination with other members of the multidisciplinary team and as part of the comprehensive HIV care and treatment plan
- Identify ways to help or refer clients and their families when there is not enough food to eat



CONTENT:

- Session 17.1: Introduction: The Relationship between Nutrition and HIV
- Session 17.2: The Basic Food Groups
- Session 17.3: Providing Basic Nutrition Education and Counseling for Adults and Children
- Session 17.4: Common Nutrition and Eating Problems among PLHIV
- Session 17.5: What to Do if There Is Not Enough Food
- Session 17.6: Classroom Practicum on Nutrition Education and Counseling
- Session 17.7: Module Summary

SESSION 17.1: Introduction: The Relationship between Nutrition and HIV

Good nutrition is important for PLHIV because it can:

- Make muscles, skin and bones healthy
- Provide energy
- Protect against infections
- Prevent weight loss
- Help medicines absorb into the body
- Help prevent or reduce side effects of some ARVs
- Decrease the amount of time it takes to get better after an illness
- Help women who are pregnant and breastfeeding to stay healthy
- Help children living with HIV grow well

Poor nutrition can lead to:

- Weakened immune system
- Increased number and seriousness of infections and illness
- Slower healing process
- Getting sicker more often and faster
- Poorer response to treatment
- Poor growth in children

Many PLHIV may not be able to eat enough nutritious foods. This can be because of:

- Poverty and loss of household income, or the person is too sick to tend the farm or garden
- Eating problems, such as sores in the mouth, diarrhea and vomiting
- Changes in the way food tastes (due to medicines or illnesses)
- Feeling tired, alone or depressed, which could lead to loss of appetite
- Discrimination and uneven food distribution within the household
- HIV and infections can affect the way the body absorbs and uses the foods we eat. This can lead to weight loss and malnourishment.



You can help clients understand why good nutrition is important to their own and their family's health and how eating well is part of comprehensive HIV care and treatment. You can also help clients learn what kinds of locally available and affordable foods they can eat as part of a balanced diet.

SESSION 17.2: The Basic Food Groups

Eating a balanced diet means eating many different types of foods and eating enough foods every day. No one food or group of foods can give us all the nutrients that we need to stay healthy.

The basic food groups:

- **“GO” foods** give us energy and make us GO. These include rice, bread, pasta and other grains. These foods should make up the biggest part of the meal.
- **“GROW” foods** provide protein and help build our bodies and keep muscles strong. These include meat, fish, eggs, beans, nuts and dairy. Note that PLHIV should try and eat legumes every day (such as beans, lentils, peas and nuts). These are usually cheaper than meat and provide a good source of protein.
- **“GLOW” foods** provide vitamins and minerals to help the immune system stay strong and fight off infections. These include all kinds of fruits and vegetables.
- **Fats and sugars** can help give energy, help us gain weight and can make foods taste better, but they should be eaten with other healthy foods and in moderation. “Good fats” include things like avocados, nuts and palm oil.
- **“Junk Food”**: Sometimes when we are very busy or do not have time to prepare food, we eat pre-prepared foods and “junk foods” that have no nutritional value and can even be harmful to our health. You should help clients understand why they should avoid “junk foods” like soda, candy and potato chips – they cost a lot of money and do not give us any good nutrition. Fresh, natural foods are always the best, and they are usually cheaper than packaged and pre-prepared foods.



It is important for you to help clients learn which locally available and affordable foods to eat in order to have a balanced diet and get the energy and nutrients needed to stay healthy and prevent infections.

SESSION 17.3: Providing Basic Nutrition Education and Counseling for Adults and Children

Adults Living with HIV

Nutritional needs:

- PLHIV should try and take more food each day and eat snacks during the day to get more energy.
- PLHIV with advanced HIV or AIDS need to eat more food than asymptomatic PLHIV to keep weight on and stay healthy. PLHIV with advanced HIV or AIDS should eat another full meal each day.
- Remember that all adults living with HIV should start ART as soon as they are eligible.

Counsel your clients to:

- Eat a balanced diet with foods from all of the groups.
- Eat up to another full meal each day if possible. Try to eat small snacks during the day.
- Choose foods according to what is available and affordable.
- Use local foods and eat fresh foods instead of processed or fried foods.
- Make GO foods (starches) the biggest part of the diet.
- Try and eat GROW foods (proteins) with every meal (including non-animal proteins, like legumes).
- Eat many GLOW foods (fruits and vegetables) every day. Use fats and oils in small amounts (unless the person needs to gain weight, in which case fats and oils can be used more).
- Do not eat too much sugar and avoid junk foods.
- Try to eat small, frequent meals throughout the day.
- Take a daily multivitamin.
- Store and prepare food safely.
- Drink at least 8 glasses of clean, boiled water each day.
- Treat any worms or parasites right away.
- Try and get some exercise every day. Even a short walk and some stretching will help build muscles, increase appetite, improve digestion and relieve stress.

Pregnant and Breastfeeding Women Living with HIV

Nutritional needs:

- During pregnancy and breastfeeding, women need to eat more healthy foods so that they stay healthy, gain weight, and so that the baby develops. Good nutrition is also important for the woman to produce breast milk.
- ALL pregnant and breastfeeding women should eat more healthy foods during these times.
- Pregnant women should eat foods high in Vitamin A and they also need foods high in iron to prevent anemia.
- Pregnant women with advanced HIV or AIDS need to eat even more healthy foods than usual, including more GROW foods (proteins), if possible.
- Remember, all pregnant women living with HIV need to take ARVs or ART.

Encourage your clients to:

- Eat a balanced diet including all of the food groups.
- Eat more food than usual during pregnancy and breastfeeding.
- Eat more GROW foods (proteins) high in iron. This is to prevent anemia. Examples are green leafy vegetables, fish, red meat, chicken, liver, eggs, seeds, dried fruit, beans, millet and sorghum.
- Eat more foods high in Vitamin A, such as green, red, yellow and orange vegetables, egg yolks, liver, sweet potatoes and yellow maize.
- Take daily multivitamins, iron and folic acid as directed by a health care worker.
- Get more rest, especially during the last 3 months of pregnancy.
- Avoid harmful foods or traditional practices during pregnancy and breastfeeding.
- Try to prevent and treat diarrhea, nausea, vomiting, loss of appetite and mouth and throat problems right away.
- Prepare and store foods safely.
- Use iodized salt. This will help prevent iodine deficiency and goiter.
- Treat any worms or parasites right away.
- Try to get some exercise every day. Even a short walk and some stretching will help build muscles, increase appetite, improve digestion and relieve stress.



Infants and Children (HIV-exposed or HIV-infected)

Nutritional needs:

- Good nutrition can help young children gain weight, grow and develop.
- Good nutrition can also decrease illnesses like diarrhea and vomiting and keep the child healthy and well longer.
- Children with HIV need to eat more healthy foods than children without HIV to grow, develop and stay healthy.
- If a child has advanced HIV or AIDS, they should eat more at each meal if possible and try to eat an extra meal during the day.
- Remember, all HIV-infected children under the age of 2 years should start ART (according to national guidelines) and the doctor should check children for ART eligibility regularly.

Counsel clients with infants aged 0-6 months to:

- Make informed infant feeding decisions.
- Exclusively breastfeed for as long as possible up to 6 months, if that is the infant feeding choice.
- Initiate breastfeeding as soon as possible, if that is the feeding choice.
- Remember that, during breastfeeding, either she or her child will need to take ARVs or ART every day.
- Use a cup and spoon to feed the baby, not a bottle.
- Avoid mixed feeding (breast milk and other liquids or foods).
- Avoid traditional medicines and remedies, unless the doctor or nurse says they are safe.
- Look for mouth and tongue sores and get treatment right away.

Counsel clients with children aged 6-24 months to:

- Continue breastfeeding and taking their own/giving the baby ARVs, and add complementary foods. These should be foods rich in energy and other nutrients, like porridge enriched with milk, sugar, pounded groundnuts, bean powder or soya bean oil.
- Wean the baby off the breast at 12 months of age if enough replacement food is available, and can be safely prepared.
- Remember that, during breastfeeding, either she or her child will need to take ARVs or ART every day.
- Give children foods from the basic food groups at least 3 times a day.
- Try to identify which foods the child likes and give these foods often. Offer food in small amounts many times during the day if possible, especially after the child is sick.
- Add a small amount of margarine or oil to food to increase energy intake (only if the child does not have diarrhea or vomiting).
- Give the child mashed fruits and vegetables like ripe bananas, avocados, boiled and mashed pumpkin and boiled sweet potato as often as possible.

- De-worm children every 4-6 months starting when they are 1 year old.
- Give Vitamin A supplements and multivitamins starting when the child is 6 months old.
- Encourage the child to be active and play. This will help build muscles and also help with digestion.

Malnutrition:

Malnourished children living with HIV have a high chance of becoming very ill and dying. To prevent malnourishment, counsel mothers and caregivers on the importance of:

- Regular growth monitoring for children, even when they are healthy
- Good nutrition for children
- Good hygiene at home

Signs of Malnutrition

- Not gaining weight or not gaining enough weight (in children and pregnant women)
- Developmental delays (in children)
- Behavior changes (for example, the person could be irritable or not responsive)
- Tiredness
- Decrease in body fat, especially on the legs, arms, buttocks and face (especially in children, but also in adults)
- A big, swollen belly (especially in children, but also in adults)
- Swelling in other parts of the body
- Dry or peeling skin
- Changes in skin color
- Changes in hair color
- Nails become brittle and change shape
- Vision problems
- Changes in hair (for example, hair could become thinner, easily pulled out, dull brown or red color)
- Poor healing of wounds
- Goiter (large, swollen area on the throat, mostly seen in adults)

You should always refer adults and children with signs of malnutrition to a health care worker right away!

Safely preparing foods:

The way we store and prepare food is just as important to our health as the kinds of foods we eat. You can educate clients on ways to store and prepare food at home as part of nutrition counseling.

Tips to safely prepare and store food

- Always wash and dry hands before and after touching food.
- Wash and dry all cooking and eating utensils well.
- Wash and dry all raw vegetables and fruits with clean water before cooking or serving. If possible, peel the skin off before cooking or serving fruits and vegetables.
- Wash and cook all meats and animal products until there is no blood or pink and red areas.
- Do not prepare raw and cooked foods on the same surface because germs will be spread from the raw food to the cooked food.
- Hard boil or cook eggs well. They should not be runny.
- Try not to overcook vegetables because this takes away their nutrients. You can steam, fry or boil them for about 5 minutes. If you boil vegetables, the leftover water can be used for cooking, such as making a soup.
- Always keep food covered and away from flies and insects.
- Serve food right away after it is cooked. Do not let it cool too much.
- Do not eat leftover food unless it has been kept cold, such as in a refrigerator. If you do eat leftover food, be sure to reheat it to kill any germs that may have grown.
- Always filter or boil water used for cooking and drinking.

SESSION 17.4: Common Nutrition and Eating Problems among PLHIV

Common nutritional and eating problems and advice for clients:

As Peer Educators, you should work with doctors, nurses, nutritionists and other members of the multidisciplinary team to support clients with nutritional problems. You should always refer clients with these problems to a doctor or nurse for care. You should also support clients to adhere to their care and treatment plan, including ART, which can help reduce these symptoms.

Major weight loss – advise clients to:

- Eat small meals often. Try to include “GROW” foods with each meal.
- Eat snacks during the day if possible (such as peanuts, boiled eggs and avocados).
- Eat more “GO” foods (like rice, ugali, chapatti, bread and porridge).
- Eat more beans, lentils, peas and nuts.
- Try to eat more meat, fish and eggs.
- Use more fats and oils in food, especially “good fats” like avocados and nuts.
- Eat more dairy foods, like milk and yogurt.
- Add dry milk powder to foods, like porridge and cereals.
- Add sugar, honey, syrup or fruit jam to foods.
- Try to eat more of person’s favorite foods.
- Also, adhere to the care and treatment plan, including ART.



Diarrhea – advise clients to:

- Eat soups and drink safe water, rice water, thin porridge and weak tea to avoid dehydration.
- Drink oral rehydration solution (ORS).
- Eat small amounts of food many times a day.
- Eat foods like millet, bananas, peas and lentils to help retain fluids.
- Eat foods like rice, bread, millet, maize, porridge, boiled potatoes, sweet potatoes and crackers that are easy to digest.
- Eat soft foods like bananas, squash, cooked and mashed green bananas, paw-paws, mashed sweet potatoes and mashed carrots.
- Eat eggs, chicken or fish for protein.
- Also, adhere to the care and treatment plan, including ART.

Stay away from:

- Strong citrus fruits (like oranges and lemons)
- Dairy products (like milk) – try fermented products instead (like yogurt)
- Coffee and strong tea
- Alcohol
- Fried foods
- Very sugary foods
- Extra oil, butter or lard
- Gas-forming foods (like cabbage, onions and carbonated soft drinks)

Anemia (due to lack of iron in the diet) – advise clients to:

- Try to eat more meat, legumes, fish, eggs, green leafy vegetables, dried fruits and whole grains.
- Avoid coffee, tea, milk or cocoa while eating – these reduce how the body processes iron.
- Eat fruits and vegetables with lots of Vitamin C (like oranges, lemons and green leafy vegetables) to increase how the body processes iron.
- Go to the health facility to treat malaria, hookworm or other parasites.
- Take a multivitamin with iron and iron tablets.
- Also, adhere to the care and treatment plan, including ART.

Nausea and vomiting – advise clients to:

- Drink fluids, especially clean water, to prevent dehydration.
- Eat bland soups.
- Eat fruit, such as bananas.
- Eat lightly salty and dry foods, such as crackers or bread, to calm the stomach.
- Drink herbal teas and lemon juice in hot water.
- Eat small amounts of food many times a day.
- Also, adhere to the care and treatment plan, including ART.

Stay away from:

- Spicy or fatty foods
- Coffee and tea
- Alcohol

Mouth and throat sores or infection – advise clients to:

- Eat soft mashed foods, such as scrambled eggs, cooked carrots, sweet potatoes, bananas, soup, paw-paws and porridge.
- Eat cold foods or foods at room temperature.
- Drink liquids, such as beef broth, lentil or pea soup.
- Rinse the mouth with clean, warm salt water before and after eating.
- Use cinnamon tea as a mouthwash.
- Suck on clean ice, if available, to relieve pain.
- For thrush, eat fermented foods, like plain yogurt. Sucking on a lemon and eating garlic can also help.
- See the nurse or the doctor, and adhere to the care and treatment plan, including ART.

Stay away from:

- Spicy or salty foods that can irritate mouth sores
- Strong citrus fruits and juices that can irritate mouth sores
- Sugary foods and drinks
- Rough foods like toast and raw vegetables
- Alcohol

Loss of appetite – advise clients to:

- Eat small frequent meals throughout the day.
- Eat nutritious snacks between meals.
- Take walks before meals if possible – the fresh air helps to stimulate appetite.
- Avoid smoking – it reduces appetite.
- Add seasonings, especially herbs, to food to give more flavor.
- Try rinsing out the mouth after meals.
- Use lemon, raw tomatoes or tonic water to stimulate the taste buds.
- Chew food well and move it around the mouth to stimulate taste buds.
- Avoid strong-smelling foods.
- Eat with others as much as possible.
- Also, adhere to the care and treatment plan, including ART.

Taste changes (can sometimes be caused by ARVs and other medications) – advise clients to:

- Change sweetness, saltiness or sourness of food by adding sugar, salt, jam or lemon to increase the taste.
- Try different herbs and spices.
- Eat more fish or chicken, as meat can often have a metallic taste.
- Eat lentils, beans or split peas.
- Brush teeth after eating to remove any aftertaste.
- Also, adhere to the care and treatment plan, including ART.

Foods, herbs and spices that can help relieve common eating problems

Certain foods, herbs and spices can help relieve common eating problems. Remember that food is not a substitute for medicine. Herbs and spices should not be used in place of healthy, balanced eating or in place of medications (including ART). **You should always refer clients with nutritional and eating problems to the doctor or nurse.**

Basil: helps relieve nausea and helps digestion. It can be added to foods or chopped and mixed with water and gargled.

Raw carrots: very high in Vitamin A and can help clear the digestive system of worms and parasites. They can be added to other foods or eaten directly.

Cayenne pepper: helps improve appetite, fights infections and can help heal ulcers. It can be sprinkled on foods or added to fruit juice or water.

Cloves: help improve appetite, digestion and relieve diarrhea, nausea, and vomiting. They can be used in soups, fruit juice and tea.

Garlic: helps digestion and weakness, relieves diarrhea, throat and ear infections, and relieves oral and vaginal thrush. It can be eaten raw, used in tea or used when cooking other foods.

Ginger: helps with digestion and can relieve diarrhea and nausea. It also can help improve appetite and be used to treat coughs and sore throats. It can be added to food, chewed raw or made into tea.

Lemons and limes: help fight bacteria, help digestion and dry the mouth. They can be added to foods or drinks or sucked on directly.

Mint: helps digestion and can sooth mouth sores. Use in tea or chew the leaves to help with digestion.

Neem: helps bring down fever. It can be boiled to make tea or bark can be chewed directly.

Parsley: helps improve appetite. It can be added to raw or cooked foods.

Pumpkin seeds: help the digestive system clean itself of worms and parasites. Seeds can be dried in the sun and eaten.

Thyme: helps relieve coughing and helps with digestion and growth of good bacteria in the stomach. It can be made with tea or used as a mouthwash.



SESSION 17.5: What to Do if There Is Not Enough Food

One of the best things you can do to help families who do not have enough food is to make sure they get HIV care and treatment. With ART, people can get healthy and stay healthy enough to work or tend a farm or garden.



Some ways you can help PLHIV and their families get enough good foods to eat:

- Work with the rest of the multidisciplinary team to have formal linkages between the clinic and food support organizations, including distributing food to clients at the health facility level.
- Link clients with nutrition support programs in the community.
- Link clients with animal husbandry, agricultural and other income generating activities in the community.
- Provide practical counseling and education to clients and family members on good nutrition, locally available foods, as well as storing and preparing food.
- Make sure clients take multivitamins.
- Help families learn to make sack gardens or start community or school gardens.
- Help organize market workers, restaurant and store owners to donate food to households affected by HIV.
- Help organize community members to help take care of other people's gardens when they are ill or need to go to the facility for an appointment.
- Help organize food banks through community and faith-based organizations.

SESSION 17.6: Classroom Practicum on Nutrition Education and Counseling

Case Study 1:

L___ is a 30-year-old woman living with HIV. She started ART about 1 year ago, but has recently stopped. The nurse refers L___ to you for more counseling. You learn that her husband died and that, without his income, she is very poor and does not have enough food to eat. She says she stopped taking ART because she knows it has to be taken with food, but she does not always have food to eat. How would you counsel her? What other information would you want to know? What practical nutritional advice would you provide to L___ ?

Case Study 2:

D___ is a male client living with HIV. Recently, he has been feeling ill and has lost a lot of weight. The nurse refers him to you for counseling. D___ says that he does not have meat to eat anymore since he lost his job at the factory. You also learn that he is taking CTX, but not ART. What other information would you want to know? How would you counsel D___? What practical nutrition advice would you provide, including on locally available and affordable foods that could help him gain weight?

Case Study 3:

R___ is a 20-year-old woman living with HIV. You meet her in the clinic waiting area. She is unwell and says that she does not like to eat anymore. She tells you she has very painful sores in her mouth and that it hurts to eat. Also, she says food does not taste the same. How would you counsel R___? What practical nutrition advice would you provide?

Case Study 4:

B___ and her boyfriend N___ visit you at the clinic. They are both living with HIV. B___ is pregnant. The nurse said she is not gaining enough weight during the pregnancy and refers her to you for more counseling. How would you counsel B___ and N___? What information would you want to know? What practical nutrition advice would you provide?

Case Study 5:

F___ is the caregiver of a 2-year old girl named V___. V___ is living with HIV and is on ART. F___ brings V___ to the clinic because she has very bad diarrhea. The doctor notes that V___ is losing weight. How would you counsel F___? What practical nutrition advice would you provide?

Note: Some of the preceding information in this Module was adapted from the following sources:

Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. (2006). *Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers*. Watertown, MA: Pathfinder International.

WHO/Food and Agriculture Organization (FAO). (2002). *Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS*. Geneva, Switzerland: WHO/FAO.

SESSION 17.7: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- Good nutrition is part of comprehensive HIV care and treatment, including ART.
- Good nutrition is important for all PLHIV, even if they are not ill, because it can help maintain weight and fight off infections and illnesses.
- Eating a balanced diet means eating many different types of foods and eating enough foods every day. We need to eat a variety of foods to help us get the energy we need (to “go,” to “grow” and to keep our immune system strong, or “glow”).
- It is always best to eat foods that are grown at home or produced locally instead of imported or processed foods, which do not have as many nutrients.
- PLHIV with advanced HIV or AIDS should try to eat another full meal each day.
- ALL pregnant and breastfeeding women should eat more healthy foods during these times.
- Pregnant women with advanced HIV or AIDS need to eat even more healthy foods than usual, including more GROW foods (proteins), if possible.
- Proper nutrition can help young children gain weight, grow and develop. Good nutrition can also decrease illnesses like diarrhea and vomiting and keep the child healthy and well longer.
- Mothers should be supported to make informed infant feeding decisions.
- Mothers should exclusively breastfeed for as long as possible up to 6 months, if that is the infant feeding choice.
- After the baby is 6 months old, caregivers should be encouraged to continue breastfeeding and taking their own/giving the baby ARVs, and add complementary foods. These should be foods rich in energy and other nutrients, like porridge enriched with milk, sugar, pounded groundnuts, bean powder or soya bean oil.
- The baby can be weaned off the breast at 12 months of age if enough replacement food is available, and can be safely prepared.
- Remember, during breastfeeding, either the baby or the mother will need to take ARVs or ART every day.
- Children with HIV need to eat more healthy foods than children without HIV to grow, develop and stay healthy.
- Adults and children who are malnourished need immediate medical care.
- It is important to teach clients and their family members how to safely store and prepare foods at home.
- You, along with other members of the multidisciplinary team, can help clients come up with practical solutions to common nutritional and eating problems, like weight loss, diarrhea, mouth sores and loss of appetite.

(KEY POINTS, CONTINUED)

- One of the most common challenges people living with HIV and their families face is lack of food. You can help link PLHIV and their families with community-based and health facility-based nutrition support.

ADVANCED MODULE 18: Pediatric HIV Care and Treatment



LEARNING OBJECTIVES:

By the end of this Module, you will be able to:

- Discuss why it is important to give special attention to HIV-exposed and HIV-infected babies and children in health facilities and in the community
- List different ways HIV-exposed and HIV-infected babies and children can be found and brought into care and treatment
- Understand when and how HIV can be diagnosed in infants and children
- Provide information to mothers and caregivers on the care HIV-exposed and HIV-infected children need
- Understand what ARVs are commonly available for children
- Work with other members of the multidisciplinary team to help prepare families for disclosure to children and offer follow-up support
- Work as part of the multidisciplinary team to prepare families for ARV adherence and to provide on-going support for adherence to care and treatment in children



CONTENT:

- Session 18.1: Introduction: The Importance of Pediatric HIV Care and Treatment
- Session 18.2: Identifying HIV-exposed and HIV-infected Infants and Children
- Session 18.3: Caring for HIV-exposed and HIV-infected Babies
- Session 18.4: Pediatric ART
- Session 18.5: Pediatric Disclosure
- Session 18.6: Pediatric Adherence
- Session 18.7: Classroom Practicum on Pediatric HIV
- Session 18.8: Module Summary

SESSION 18.1: Introduction: The Importance of Pediatric HIV Care and Treatment

Important points about pediatric HIV:

- Children are not little adults. Adults can live many years with HIV before they get sick. But children, particularly babies, are not as strong and are much more likely to get sick very quickly once infected with HIV.
- 50% of babies with HIV will die before their second birthday without care and ART.
- Caring for sick children and having a child die can be very hard emotional experiences for families.
- Children are our future and we need to keep them healthy to build strong communities and a strong nation.
- Babies and children with HIV who are in care and take ART can live long, healthy lives and grow up to be healthy adults.



There are many challenges to pediatric HIV care and treatment. You have an important role to play in helping parents, caregivers and children overcome these challenges and get the care and treatment they need!

SESSION 18.2: Identifying HIV-exposed and HIV-infected Infants and Children

Places to find babies and refer them for HIV care and treatment:

- PMTCT programs
- Under-5 clinics
- Pediatric inpatient wards
- Adult ART clinics
- Health centers and hospital outpatient departments where babies are taken when they are sick
- Emergency rooms
- Homes with adults living with HIV
- Community health workers and community-based organizations, especially those working with orphans
- Traditional healers and traditional birth attendants who may be a first point of contact for sick babies



In places where many people are living with HIV, you can encourage HIV testing and counseling for **ALL** children. This way, more children can get the lifesaving care and treatment services they need.

Common signs of HIV in babies and children:

- Losing weight
- Not gaining weight or growing according to plan
- Lots of ear, throat and other infections
- Diarrhea
- Fever
- Coughing
- Skin problems
- Thrush (white spots) in the mouth
- Swollen glands

HIV Testing in Babies and Children

HIV testing in babies under 18 months of age:

- The only way to know for sure if a child under 18 months of age is HIV-infected is through a virological test, such as DNA PCR testing. A sample of the baby's blood is put on filter paper and dried. This is called dried blood spot, or DBS. The DBS sample is then tested for HIV.
- Rapid HIV tests used in adults can be used to test babies, but they will only tell us if the baby is exposed to HIV, not if the baby is definitely HIV-infected.
- Once the baby is 6 weeks old, a small amount of blood can be taken from the baby's heel and a test conducted to see if the baby is HIV-infected (this is for the DNA PCR test).
- You can help the mom think about her support system – who will help her if the baby is HIV-infected? Who will help come to clinic appointments?
- You can make sure mothers understand that the results will take time and schedule an appointment for the mother and baby to return to the clinic to pick up results.
- Follow up if the mom or caregiver does not come back to pick up the results of the child's HIV test.
- **If the result of the test is positive**, the baby is HIV-infected and most babies should start ART right away. Help the mom and the baby go to the ART clinic to get the child enrolled as soon as possible. If the mom is breastfeeding, she should continue to breastfeed.
- **If the result of the test is negative** and the mom is still breastfeeding, she should keep breastfeeding, make sure the baby is brought to the clinic for regular visits and then retest the baby 2-3 months after she has stopped breastfeeding completely. The baby is still at risk of becoming HIV-infected as long as it is breastfeeding. This is because there is HIV in breast milk. Remember, there is less HIV in the breast milk if the woman is receiving ART. If the mother is not receiving any ART when she is breastfeeding, the baby will need to take NVP every day until he/she is weaned.



HIV testing in children over 18 months of age:

- Once children are 18 months old, they can be tested for HIV with the standard rapid test used on adults.
- If children are still breastfeeding, they should be retested after the mother has completely stopped breastfeeding.
- Be sure to follow your national guidelines on HIV testing in babies and children and always work with other members of the multidisciplinary team.

SESSION 18.3: Caring for HIV-exposed and HIV-infected Babies

Remember: It is important to explain follow-up care to mothers and families and to make sure that they continue to get the medical attention they need after the baby is delivered. There is a lot that can be done to keep the baby healthy when it has been exposed to HIV.



Caring for babies exposed to HIV:

Right away after babies are delivered to mothers with HIV:

- The doctor or nurse should give the baby single-dose NVP at birth. In some places, NVP is given to the mother to take home during her pregnancy so that the mother can give the dose to the baby right away after delivery. Babies delivered at home should be seen at the clinic as soon as possible for a check-up and for ARVs.
- Starting after birth the baby will continue to get either NVP daily or AZT twice daily from birth to 4 to 6 weeks.
- If the baby is breastfeeding, either the mother will need to take ART or the baby will need to take NVP daily, until 1 week after breastfeeding is stopped.

At 4-6 weeks of age:

- If the baby is breastfeeding, either the mother will need to take ART or the baby will need to take NVP daily, until 1 week after breastfeeding is stopped.
- All exposed babies should start taking CTX. Babies exposed to HIV or with confirmed HIV infection should take CTX EVERY DAY.
- The dose of CTX will depend on the baby's weight, so the baby needs to come back to the clinic very often to be weighed so the mother knows how much medicine to give.
- Where available, babies should be tested for HIV with DNA PCR as soon as possible after 6 weeks of age.

Ongoing:

- If the baby is HIV-infected, he/she needs to start taking ART as quickly as possible.
- If the baby is HIV-infected, a CD4 test needs to be done.
- Babies should keep taking CTX until it is definite that they are not HIV-infected and they are no longer breastfeeding.
- Make sure babies go for check-ups and get immunizations on schedule.

- Health care providers should look for and treat infections.
- Make sure babies are getting good nutrition and growing well. Doctors or nurses will weigh, measure and examine babies at every visit to see if they are growing and developing normally. Babies' height, weight and head measurement should be recorded on a growth chart at each visit. This is one of the best ways to see if babies are healthy.

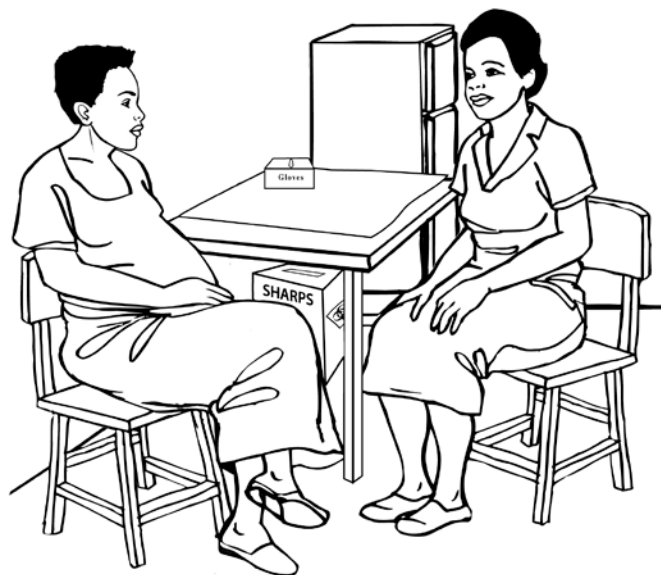
Error!

6 key points about caring for babies exposed to HIV:

- Come back to the clinic often. If the baby is sick, come in right away.
- Go for early HIV testing.
- Give ARVs to the baby every day for the first 4-6 weeks (all babies) and every day until 1 week after breastfeeding has stopped (babies whose moms are not taking ARVs/ART).
- Give CTX to the baby every day.
- Weigh and measure the baby at every visit.
- Focus on the whole family.

Focus on the family:

- Having a sick baby and knowing that the baby may have HIV can be a very hard thing for parents and caregivers.
- It is important for you to spend time talking with families about how they are feeling and making sure they understand what is happening with babies (tests, medicines, side effects, etc.).
- HIV is a family disease and parents of sick babies will often themselves be sick and in need of care and treatment and support to adhere, disclose to others or seek community services.
- Parents and caregivers should be active in the baby's care and monitoring as they often know best when "something is not right" with the baby. Whenever the baby is not doing well, parents and caregivers should be encouraged to trust their instincts and bring the baby to the clinic right away.
- You should also ask about all caregivers of the baby, as they often change. All caregivers should know what is going on with the baby's health and care and treatment plan.



SESSION 18.4: Pediatric ART

Pediatric ART:

ART can help keep babies and children living with HIV healthy, strong and able to live a whole lifetime when they adhere to their care and medication regimens.

You can help families understand and access pediatric ART and the care and treatment services they need to have healthy families and communities.

First-line ART regimens for infants and children:

(write in the first-line regimens for children in your country here):

Common ARV names

AZT or ZDV = zidovudine

3TC = lamivudine

NVP = nevirapine

EFV = efavirenz

d4T = stavudine

LPV/r = Kaletra

ABC = Abacavir



Key issues for pediatric ART:

- Most babies and young children with HIV will need ART since they get sick quickly and are at great risk for illness and death.
- All HIV-infected babies and children need CTX.
- WHO recommends that **all HIV-infected children under 2 years of age start ART**. It is important to follow your national guidelines.
- Once the doctor or nurse decides the child should start ART, the caregivers need to be prepared for the challenges ahead.
- You can help caregivers understand pediatric HIV and make an ART adherence plan with the multidisciplinary care team.
- Success with pediatric ART depends on a partnership among the caregiver(s), the child, the multidisciplinary care team at the clinic and the community.
- All members of the family and all caregivers must be prepared to give the child ART at the same time, the right way, every day.
- The child must cooperate and be involved in their treatment as well.
- The dose of different ARVs will change often in children because it depends on their weight.
- If the parent or caregiver has not disclosed their HIV-status, it makes it hard to tell people about the child's HIV-status.
- As children get older, they should know about their own HIV-status. What we tell children about HIV depends on their age and maturity.

SESSION 18.5: Pediatric Disclosure

Children have a right to know about their own health care. Children who have not been disclosed to may develop their own views about their illness, feel isolated, learn their HIV-status by mistake or have poor adherence.

Some key points on disclosure to children:

- Children – even very young children – have feelings, concerns and questions.
- It is important to talk with children openly and honestly. It is never good to lie to a child or hide information that the child wants to know.
- Parents and caregivers should start talking about health issues with children at an early age.
- Disclosure is more than telling children their HIV-status.
- Disclosure is an on-going process – it is not a one-time event.
- When to say “HIV” varies with the child and the family, but most children should know they have HIV by the time they are school-aged.
- Let the child be the guide – children will naturally ask questions.
- Consider the child’s age, developmental stage, maturity, coping skills and family situation.

How can Peer Educators help families with disclosure?

You can support parents and caregivers during the disclosure process, but you yourself should not disclose to the child. You should work with doctors, nurses, counselors and other members of the multidisciplinary team to support families with disclosure to children.

You can work with other members of the multidisciplinary team to:

- Help families prepare for disclosure.
- Help educate families about disclosure and pediatric HIV.
- Help families plan for disclosure (remember, it is an on-going process).
- Offer on-going support and follow-up to the family and the child.

Some tips on talking with children about HIV:

- The best place to tell children about their HIV-status is usually at home. However, some families may prefer that some of the disclosure process happens at the health facility with the support of a counselor, social worker, nurse or doctor.
- The best person to tell children about their HIV-status is usually a trusted parent, caregiver or family member. Some families may want to have a counselor or other health professional give support during some of the disclosure process.
- Many of the listening and learning skills for adults apply to children as well.
- When talking with children, adults should be at the same level (such as sitting on the floor together).
- Make sure there is privacy.
- Listen to children and show that you are listening.
- See what concerns children have before giving information.
- Allow children time to talk without being interrupted.
- Use play and drawing to help learn how children are feeling.
- Always give children correct information – never lie.
- Children do not always need to know how they got HIV.
- Help children understand their choices and empower them to make decisions.
- Remind children that they can come to you any time to talk or ask questions. Disclosure is not a one-time event, but rather an on-going conversation.

SESSION 18.6: Pediatric Adherence

You can help caregivers and children receiving ART in many ways. You can work with other members of the multidisciplinary team to provide adherence education, counseling and ongoing support.

Providing adherence education:

- Identify children's primary caregivers. When possible, work with more than one caregiver and make sure that each new caregiver is educated and counseled on pediatric HIV care and treatment.
- Hold separate group education sessions for caregivers and children.
- Work with the parents and all caregivers to understand what is meant by adherence, including:
 - Understanding the diagnosis and the care and treatment plan
 - Coming to the clinic for appointments
 - Never missing a dose and not taking any breaks
 - Taking medicines the "right" way
- Explain the importance of adherence to children's health.
- Talk about the need for open, honest communication with the health care team.

Providing individual adherence counseling to caregivers:

- Take time to prepare caregivers and children.
- Encourage all of children's main caregivers to come to the clinic for adherence education and preparation sessions.
- Conduct an adherence and psychosocial support assessment to learn more about the family's situation and specific needs.
- Work with caregivers to make the medication schedule fit with the family's life.
- Help caregivers manage problems, such as when children refuse, vomit or spit out medicines.
- Help make the health facility child-friendly, such as having a space for children to play.

Addressing the WHO, WHAT, WHEN and HOW of the medications:

- **WHO** will give the medications?
- **WHAT** medications will be given?
- **WHEN** will the medications be given?
- **HOW** will the medications be given? Include demonstration and practice for caregivers.

Providing on-going adherence monitoring and support:

- Ask clients to be honest and open about adherence challenges.
- Ask about adherence at every visit and work as part of the multidisciplinary care team to support adherence.
- Offer on-going support to children and caregivers, especially around disclosure.
- Offer information on, or refer to, children's support groups and caregiver's support groups.
- Use adherence tools, such as labeled syringes, pill boxes and medication calendars (in the appointment book that the patient keeps).

You can work with other members of the multidisciplinary team to help with adherence challenges:

- Get detailed information about the adherence problems.
- Review the WHO, WHAT, WHEN and HOW of medications.
- Observe how caregivers administer medicine to children if possible.
- Work with children and caregivers to identify specific adherence challenges.
- Try to solve problems related to these barriers.
- Be aware of **“adherence fatigue”**:
 - As with adults, do not assume “once adherent, always adherent.”
 - This is especially true for children, as they will have different adherence challenges at different developmental stages.
 - With time, children may get tired of taking medications.
 - With time, caregivers may get tired of giving medications.



SESSION 18.7: Classroom Practicum on Pediatric HIV

Case Study 1:

I___ is a 12-year-old female orphan with HIV who lives with her maternal aunt and uncle. Her aunt, M___, monitors her ARV medication and reports very good adherence. When asked to consider disclosure of HIV-status, M___ starts crying. She is not sure how to explain HIV to I___ in a way that she will understand. She is also concerned that I___ *“will feel different from other kids.”* At school, I___ has already learned about HIV. No one has told her anything about why her parents died, but she is worried that her parents had HIV and that she will die soon too. She has only been told that the medication she takes is to “keep her strong.” How would you counsel I___ and M___?

Case Study 2:

P___ brings N___, a 5-year-old boy who has been on ART for the past 8 months, to the clinic. The pharmacist is concerned that there is more medication left than there should be if the medication was given properly. When you speak to P___, she is not able to say about how much medication N___ takes or how he takes it. You figure out that P___ is not the same caregiver who brought the child to the ART clinic last time.

Case Study 3:

A 28-year-old mother named R___ and her 5-month-old baby named C___ come to the clinic. The mother is living with HIV and is exclusively breastfeeding the baby. The baby is taking CTX and is getting immunizations on schedule. The mother is happy with the child’s growth and development. The mother’s 2-year-old daughter is also at the clinic. Neither of the children has been tested for HIV. Talk to the mother about testing, care and treatment for both children.

Case Study 4:

You meet a 15-year-old girl named B___ who tested positive for HIV last year, but did not go for any follow-up care. You counsel her and she agrees to get a CD4 test. The doctors say she needs to start ART. B___ lives with her mother and her younger brother – they both know she is HIV-positive, but since she is healthy, the family believes she does not need ART. They do not want anyone in the community to know she is living with HIV. What would you talk with B___ and her family about?

Case Study 5:

L___ is a 6-year-old girl living with HIV and taking ART. She lives with her mother M___, maternal uncle and 5 older half-siblings and cousins. Each time L___ comes to the clinic, she gets very upset when she gets blood drawn and recently has been asking, “*Why do I need to take medications*” and “*Why am I always sick*”? Today, L___ is very upset at the clinic. When you ask, you find out that M___ has not told L___ anything about her HIV-status or the reasons she has to come to the clinic so much. How would you counsel L___?

Note: Some of the preceding information in this Module was adapted from the following sources:

The Adherence Networking Group. (2006). *Kids count: Children’s ART adherence resource pack*. South Africa: Adherence Networking Group.

WHO (2010). *Guidelines on HIV and infant feeding*. Geneva, Switzerland.

WHO (2010). *Antiretroviral therapy for HIV infection in adults and adolescents. Recommendations for a public health approach*. Geneva, Switzerland: World Health Organization.

WHO (2010). *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: towards universal access*. Geneva, Switzerland: World Health Organization.

WHO (2010). *Antiretroviral therapy of HIV infection in infants and children: towards universal access*. Geneva, Switzerland: UNAIDS.

SESSION 18.8: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- With care and treatment, children with HIV can become healthy adults.
- Without treatment, most children with HIV will die before their second birthday.
- HIV makes babies and children sick quickly, so we need to identify HIV-infected children early and get them enrolled in care and treatment as soon as possible.
- The only way to tell for sure if a baby under 18 months old is HIV-infected is through DNA PCR testing, which can be done when the baby is 6 weeks old.
- The 6 key points to remember with following HIV-exposed and infected children:
 - Come back to the clinic often. If the baby is sick, come in right away.
 - Go for early HIV testing.
 - Give ARVs to the baby every day for the first 4-6 weeks (all babies) and every day until 1 week after.
 - Give CTX to the baby every day.
 - Weigh and measure the baby at each visit.
 - Focus on the whole family.
- The WHO recommends that ALL HIV-infected children under age 2 begin ART as soon as possible.
- Pediatric ART depends on a partnership among parents and caregivers, children and the multidisciplinary care team.
- There are special ARVs for babies and children. They should not be given adult ARVs unless prescribed by the doctor.
- The type and dose of ARVs for children depends on age and weight. This will change often over time so clients need to come back to the clinic regularly.
- Disclosure to children has many benefits.
- Disclosure for children requires attention to the child's age, developmental stage, coping skills, as well as the beliefs of the parents or caregivers and the family situation.
- Disclosure is an on-going process that takes place over time and after careful preparation. You can work with other members of the multidisciplinary team to help prepare for, support and follow up with disclosure.
- You can work with other members of the multidisciplinary team to help caregivers prepare to give ART to babies and children and adhere to the care and treatment plan in the long term.
- You can also provide emotional support to caregivers, as caring for sick children and/or giving children medicine every day is not easy.

(KEY POINTS, CONTINUED)

- Adherence needs and barriers will change over time, especially with children as they age and go through different developmental stages.
- The entire multidisciplinary team should be involved in supporting children and their families with adherence, disclosure and psychosocial support.

ADVANCED MODULE 19:

PLHIV Support Groups



LEARNING OBJECTIVES:

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

- Discuss the overall goals and objectives of peer support groups
- Understand different types of support groups that may be helpful for PLHIV and their families
- Plan a support group meeting, including making an agenda and working with co-facilitators
- Effectively facilitate a support group meeting



CONTENT:

- Session 19.1: Introduction: Why Do We Need Support Groups?
- Session 19.2: Planning Support Group Meetings
- Session 19.3: Facilitating Support Group Meetings
- Session 19.4: Classroom Practicum on Support Groups
- Session 19.5: Module Summary

SESSION 19.1: Introduction: Why Do We Need Support Groups?

In peer support groups, members help each other to improve and better manage their situation, share challenges and discuss solutions. Members support each other to implement decisions made in order to meet their psychological, social, physical and medical needs.

Here are some of the different types of support groups:

- Adherence support groups
- Mothers support groups
- Parents and caregivers support groups
- Adolescent support groups
- Play groups for children
- Couples support groups
- Post-test clubs
- Groups for other specific populations



SESSION 19.2: Planning Support Group Meetings

Planning a Support Group Meeting – Key Steps:

- 1. Learn what support groups already exist in the community and at health facilities.**
- 2. Consult with key informants.**
- 3. Decide who the support group is for:**
 - Who will be invited to attend?
 - What is the ideal number and type of participants?
- 4. Define the goals and objectives of the support group:**
 - What is the purpose of the support group?
 - What will members gain from the support group?
- 5. Make a plan to recruit support group members:**
 - How will you let people know about the support group?
 - Will members of the multidisciplinary team at the health facility refer people to the support group?
- 6. Decide on the location of the support group meetings:**
 - Consider the location of the support group.
 - If support group meetings are held at a health facility, will members be able to get HIV services before/after the meeting?
- 7. Select convenient days and times for the support group and decide how often the group will meet.**
- 8. Decide who will lead the support group meetings:**
 - What will be the role of the support group members? (It should be participatory.)
 - If you are facilitating, what are you going to say at the beginning?
 - Will there be a secretary to record decisions made at the meeting?
 - Will there be guest speakers?
- 9. Plan the logistics of the meeting:**
 - Is there privacy at the meeting space?
 - Are there enough places for people to sit?
 - Can the room be arranged so participants are in a semi-circle?
 - Will you arrange for tea or snacks for the meeting?

10. Make an agenda for the meeting. Suggested agenda items for support group meetings:

- Registration/sign-in
- Refreshments (tea, coffee, snacks, etc.)
- Welcome/opening (song, prayer, dance, etc.)
- Introductions
- Overview of the agenda
- Reminder about confidentiality
- Health talk by invited guest or facilitator
- Testimonials by members related to the specific topic
- Questions and answers
- Open discussion and sharing
- Review of key messages
- Plan for the next meeting
- Closing (song, prayer, dance, etc.)



Case studies for *Session 19.2* and *19.4*

Case Study 1:

You and another Peer Educator are starting a support group at your health facility. You have learned that most of your clients do not belong to a support group, but that they would be interested in joining one. The group will meet once per month.

Discussion questions and tasks for small groups:

1. What steps would you take to plan the support group?
2. What are the goals of the group? Who is the group for?
3. What do you want members to gain from participating in the group?
4. How will you recruit support group members and advertise the first support group meeting?
5. How will you work with other members of the multidisciplinary team?
6. Develop an agenda for the first support group meeting, which will be held in the training room of the health facility where you work.

Case Study 2:

The PMTCT nurse at your health facility notices that many of her clients are not coming back to the clinic on time for their appointments, especially after they deliver their babies. The nurse comes to you because she wants you to help organize a mothers support group at the clinic. She wants the member mothers to support one another during and after pregnancy and she also thinks it would be helpful to include a short, 15-minute health talk during each of the support group meetings.

Discussion questions and tasks for small groups:

1. What are some of the things you would want to discuss with the nurse? What about with PMTCT clients?
2. What are the goals of the mothers support group?
3. What do you want the members to gain from the group?
4. How would you recruit support group members?
5. Develop an agenda for the first mothers support group meeting, which will be held in the antenatal clinic waiting area. Include a short health talk on a specific topic.

Case Study 3:

A local PLHIV association has monthly support group meetings in their office. The president of the support group asks you to come to lead the next meeting, which will focus on adherence to HIV care and treatment. About 25 men and women are expected to attend the meeting.

Discussion questions and tasks for small groups:

1. What information would you want to know from the support group president?
2. How would you plan for the meeting?
3. What do you hope members will gain from this meeting?
4. Develop an agenda for the meeting (the meetings last about 90 minutes).

Case Study 4:

You and another Peer Educator try to learn more about support groups in the community so you can refer your clients. You learn that there was a strong support group in the community run by a local church. The support group had about 30 active members, but in the past year, the group has not met regularly and members often miss meetings. After talking with other members of the multidisciplinary team and some of your clients, you decide that you should try to work together and improve this community support group instead of starting a new one.

Discussion questions and tasks for small groups:

1. What things would you want to find out about the support group and its members?
2. What are some of the reasons you think the support group is not as active as it used to be?
3. What steps would you take to improve the support group?
4. How will you convince people to return to the support group?
5. Develop an agenda for a support group meeting.

SESSION 19.3: Facilitating Support Group Meetings

These are suggestions to help you prepare for support group facilitation.

When planning support group meetings, make an agenda and stick to it!

- Careful planning is key to the success of support groups in the long-term.
- Make sure meetings start and end on time.

Make sure to plan new learning opportunities for support group members:

- Make sure each support group meeting offers something useful to members.
- Get feedback from support group members on topics they would like to discuss during the meetings and incorporate these into the agenda.

Set up the room so that everyone is comfortable and can participate:

- Encourage participants to sit in a semi-circle to make it more comfortable to talk and less like a classroom.
- Facilitators should not stand behind a desk or other furniture.
- If possible, provide tea or a light snack for members and facilitators.

Remind participants about confidentiality:

- Support group members will only feel open to discuss their experiences and feelings if they know there is confidentiality.
- It is always a good idea to remind support group members at the start of each meeting that what is said during the meeting is not repeated in the community. Facilitators should always respect this as well!



Be a good facilitator:

- Create a safe and welcoming environment for support group members.
- Be sure to plan the meeting agenda ahead of time and practice what to say.
- Lead an introductory activity so participants feel more comfortable.
- Review the agenda with support group members and ask if there are questions. Always ask for inputs for the next meeting agenda.
- Interact with participants and engage them by moving around the room, asking questions and asking people to share personal stories.
- Encourage participants to share their own experiences and concerns.
- Make eye contact with all members of the group.
- Pay attention to people who seem shy or quiet.
- Try to discourage people from dominating the discussion. If this is happening, you could say, *“You have shared so many helpful ideas and experiences with us – let’s hear from some other members now.”*
- Stick to the agenda and keep time!

Offer on-going support and referrals to participants:

- Encourage participants to speak with you or another facilitator in private afterwards if they have concerns they do not want to share with the group.
- Know what support and services are available in the community and at nearby health facilities so you can make referrals.
- If the meeting takes place at a health facility, try to time it so members can seek services after the meeting.
- Seek support and inputs from other multidisciplinary team members and other experts on topics that you are unsure about, you are uncomfortable with or are beyond your area of expertise.
- If you think a support group member needs assistance (for example, if they are mentally distressed, suicidal, violent or the victim of violence), tell other members of the multidisciplinary team about these issues right away.

Keep records of the meeting:

- Always keep an attendance record. Remember that this should be kept confidential.
- Ask someone to take simple notes at the meeting. Note what topics were discussed, key concerns of members and any next steps. Also note the date, time and location of the next meeting.

SESSION 19.4: Practicum on Support Groups

See the case studies in *Session 19.2*.



Note: Some of the preceding information in this Module was adapted from the following sources:

The Republic of Uganda Ministry of Health. (2006). *National guidelines for implementation of family support groups in prevention of mother-to-child transmission of HIV*. Kampala, Uganda: Republic of Uganda Ministry of Health.

SESSION 19.5: Module Summary



THE KEY POINTS OF THIS MODULE INCLUDE:

- You play an important role in starting support groups in the health facility or in the community, facilitating support group meetings and helping others organize and recruit members for support groups.
- While there are many different types of support groups, they all should aim to provide psychosocial and emotional support to their members.
- In peer support groups, members help each other to improve and better manage their situation, share challenges and discuss solutions. Members support each other to implement decisions taken in order to meet their psychological, social, physical and medical needs.
- Careful planning is one of the keys to successful support groups. This includes having clearly defined goals and objectives for the groups and an agenda for each meeting.
- Including short health talks as part of support group meetings is one way to share information with members and encourage them to seek health services. This is also a way to get other multidisciplinary team members involved in the support group.
- Support group meetings should always be participatory and everything that is said during the meeting should be kept confidential.
- Good facilitation skills are important to successful support group meetings.
- It is important to provide support group members with information and referrals for ongoing psychosocial support, clinical care and other services.

Illustration Credits

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