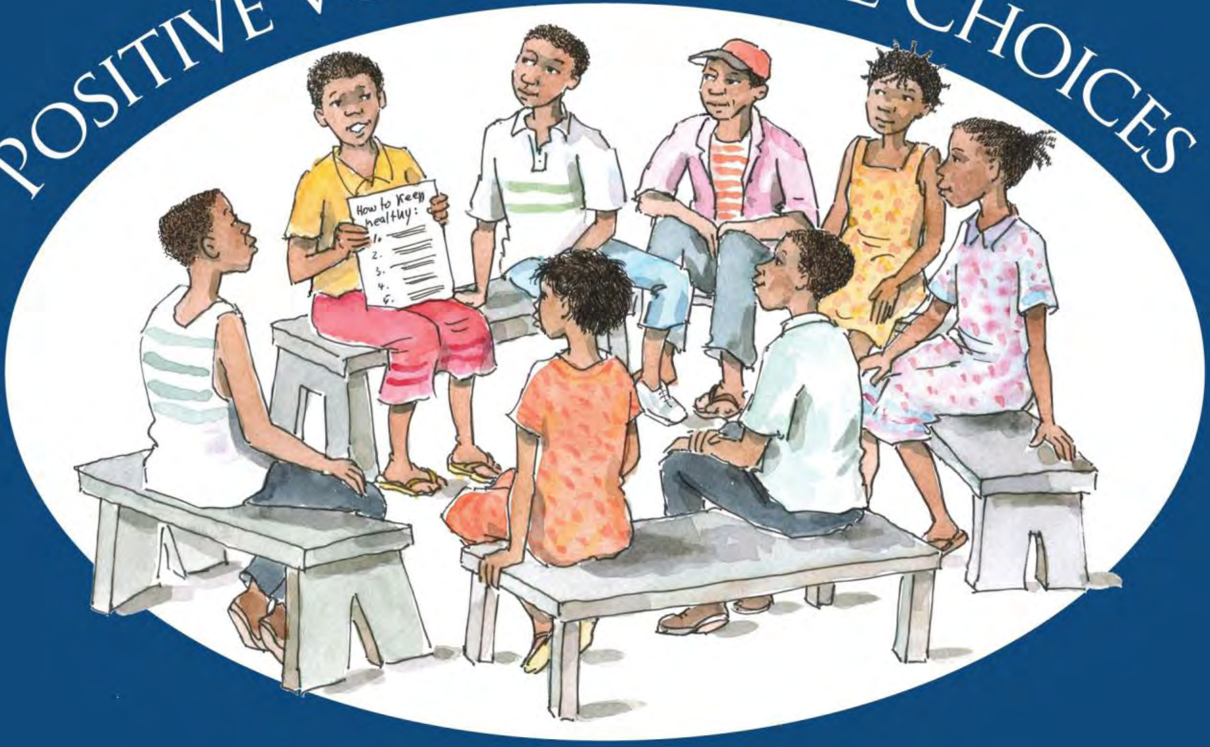
POSITIVE VOICES, POSITIVE CHOICES



A Comprehensive Training Curriculum for Adolescent Peer Educators

PARTICIPANT MANUAL

ICAP
Global. Health. Action.
COLUMBIA UNIVERSITY
Mailman School of Public Health

POSITIVE VOICES, POSITIVE CHOICES

A Comprehensive Training Curriculum for Adolescent Peer Educators

Participant Manual

2011

VERSION 1.0

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ICAP
COLUMBIA UNIVERSITY
Mailman School of Public Health

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Foreword

More than thirty years ago, I began my career as a pediatrician in Central Harlem in New York City. It was the very beginning of the HIV epidemic in the United States and children and adults were being diagnosed with unusual infections and illnesses that often led to death. We soon learned that the cause of this mysterious illness was a virus, ultimately identified as the human immunodeficiency virus (HIV). Since that time we have learned a great deal about this virus and the disease it causes— how it is transmitted, how to prevent its transmission, how to treat it, and, for millions of people, how to live healthy and productive lives with the infection.

When I first started my work, all of my patients were babies and young children. Many of them died from HIV/AIDS, but many have also survived. As we found treatments that worked to fight the virus, these children bravely took their medicines and engaged, often with their families, in their own fights to battle their infection and stay healthy. The majority of these children are now adolescents and adults. In the United States, most children born with HIV infection are in their teens and many have embarked on their adult lives with partners, jobs, and children of their own. This has been a truly remarkable journey, one that I look back on with pride and awe.

In my work I've been privileged to share the lives of countless children and youth living with HIV infection. A number of patients have generously and patiently taught me many things over the years. I've learned about the difficulties of having to take medications every day, of feeling different from your friends, and of living with an infection that has no cure. I've also learned that no one knows what adolescents need in their lives better than adolescents themselves. While parents, doctors, nurses, and counselors all care deeply, only with the voices of adolescents themselves are we be able to help them get good health care, make wise decisions, and lead strong, healthy lives.

Positive Voices, Positive Choices: A Comprehensive Training Curriculum for Adolescent Peer Educators was designed to help adolescents formally engage in the health care system and to train them to become peer educators. Peer educators are critical members of the multidisciplinary health care team because they represent the needs, interests, and feelings of adolescents receiving services at the clinic. This curriculum provides information for peer educators on adolescent health, HIV infection, HIV treatment, sexual and reproductive health, communication, counseling, and many other topics. It also builds on the strengths of adolescents as inquisitive, thoughtful, intelligent people with important experiences, knowledge, and insights. What you bring to the training is in many ways as important as what you are likely to gain.

This training program is a tribute to the children and youth I cared for in New York City who taught me to listen carefully to my patients. I look forward to hearing your collective voices as you continue the tradition of sharing and of educating other youth, health care providers, and communities about living positively with HIV infection.

Special Thanks

I would like to express my appreciation and gratitude to all of the individuals who contributed to the development of these materials. Special thanks go to Tayla Colton, independent consultant, for her technical support, expertise, openness, and inspired and informed approach to material development; Anne Schley, independent consultant, for her creative, sensitive, and intelligent approach to the special issues of adolescents and for her tireless work on these materials; Anne

Schoeneborn for her superb writing and editing skills; Beatriz Thome and Ruby Fayorsey, ICAP Clinical Officers, for their thoughtful contributions throughout the development process; Cristiane Costa, Regional Program Director, and Leah Westra, Project Officer, for their continued support throughout the development process; Petra Röhr-Rouendaal, artist, for her beautiful illustrations; Laurian Miles from Mantaray Design for designing many of the tools used in the curriculum; and Virginia Allread and her colleagues at François-Xavier Bagnoud Center (FXB), School of Nursing, University of Medicine and Dentistry of New Jersey, for producing a product that we can all be proud to share.

This work would not have been possible without the support of the MTCT-Plus Initiative. The MTCT-Plus Initiative was the first multi-country, family-centered HIV care and treatment program and it supported services in 14 centers in 9 countries in Sub-Saharan Africa and Thailand. Funding for the MTCT-Plus Initiative was provided by the Bill & Melinda Gates Foundation, the William and Flora Hewlett Foundation, the Robert Wood Johnson Foundation, the Henry J. Kaiser Family Foundation, the John D. and Catherine T. MacArthur Foundation, the David and Lucile Packard Foundation, the Rockefeller Foundation, the Starr Foundation, and the U.S. Agency for International Development. The MTCT-Plus Initiative was the first program providing the foundation for the formation of ICAP, an important partner in the global effort to expand access to quality HIV prevention, care, and treatment services. ICAP programs are funded by a variety of U.S. government and private sources, including the U.S. Centers for Disease Control and Prevention (CDC) under the President's Emergency Plan for AIDS Relief (PEPFAR), the U.S. Agency for International Development (USAID), the Department of Defense, and the National Institutes of Health.

Elaine Abrams
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Acronyms

3TC	lamivudine
AIDS	Acquired Immune Deficiency Syndrome
ALHIV	Adolescent(s) living with HIV
ART	Antiretroviral therapy
ARV	Antiretroviral
AZT	zidovudine
CTX	cotrimoxazole
d4T	stavudine
EFV	efavirenz
FTC	emtricitabine
HIV	Human Immunodeficiency Virus
IUD	Intra-uterine device
MTCT	Mother-to-child transmission (of HIV)
NGO	Non-governmental organization
NVP	nevirapine
OI	Opportunistic infection
PCP	*Pneumocystis jiroveci* pneumonia
PLHIV	Person (or people) living with HIV
PMTCT	Prevention of mother-to-child transmission (of HIV)
TB	Tuberculosis
TDF	tenofovir
STI	Sexually transmitted infection
VCT	Voluntary counseling and testing
UNAIDS	Joint United Nations Program on HIV/AIDS
WHO	World Health Organization
YLHIV	Youth living with HIV
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: Why We Are Here: Review of Training Objectives

Session 1.3: Learning Needs Assessment

SESSION 1.1: Welcome, Introductions, Agenda, and Ground Rules

Suggested Training Agenda:

Week 1:

Time	Day 1	Day 2	Day 3	Day 4	Day 5
12:00-12:30	Lunch Official Opening	Lunch Review and recap of Day 1	Lunch Review and recap of Day 2	Lunch Review and recap of Day 3	Lunch Review and recap of Day 4
12:30-14:30	Module 1: Course Overview and Introduction Module 2: The Needs of Adolescents Living with HIV (ALHIV) and the Role of Adolescent Peer Educators in Meeting Them	Module 3: Review of HIV Basics	Module 4, continued	Module 5: Comprehensive HIV Care and ART	Module 6: Supporting Adherence to HIV Care and Treatment
14:30-14:45	TEA BREAK	TEA BREAK	TEA BREAK	TEA BREAK	TEA BREAK
14:45-16:45	Module 2, continued	Module 4: Communicating with your Peers	Module 4, continued	Module 5, continued	Module 6, continued
16:45 -17:00	Daily Summary and Closing	Daily Summary and Closing	Daily Summary and Closing	Daily Summary and Closing	Daily Summary and Closing

Week 2:

Time	Day 6	Day 7	Day 8	Day 9	Day 10
12:00-12:30	Lunch Review and recap of Day 5	Lunch Review and recap of Day 6	Lunch Review and recap of Day 7	Lunch Review and recap of Day 8	Lunch Review and recap of Day 9
12:30-14:30	Module 7: Providing Psychosocial Support	Module 8: Planning and Co-Facilitating Support Groups for ALHIV	Module 9: Understanding and Supporting the Disclosure Process	Module 10: Sexual and Reproductive Health	Module 11: Positive Living
14:30-14:45	TEA BREAK	TEA BREAK	TEA BREAK	TEA BREAK	TEA BREAK
14:45-16:45	Module 7, continued	Module 8, continued	Module 9, continued	Module 10, continued	Module 11, continued Module 12: Community Outreach, Education, and Linkages
16:45-17:00	Daily Summary and Closing	Daily Summary and Closing	Daily Summary and Closing	Daily Summary and Closing	Daily Summary and Closing

Week 3:

Time	Day 11	Day 12	Day 13	Day 14	Day 15
12:00-12:30	Lunch Review and recap of Day 10	SUPERVISED PRACTICUM – DAY 1 **Note: the suggested time for the supervised practicum is 3-5 days, but can be adjusted according to the program's needs and training requirements**	SUPERVISED PRACTICUM – DAY 2	SUPERVISED PRACTICUM – DAY 3	Module 15: Next Steps, Course Evaluation, and Graduation/Celebration
12:30-14:30	Module 12, continued Module 13: Record-keeping and Reporting				
14:30-14:45	TEA BREAK				
14:45-16:45	Module 14: Supervised Practicum (classroom preparation 60 minutes)				
16:45-17:00	Daily Summary and Closing				

SESSION 1.2: Why We Are Here: Review of Training Objectives

Training objectives

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

1. Work as an integral part of a clinic's multidisciplinary care team
2. Understand needs and challenges of adolescents living with HIV (ALHIV) and how to help make clinic services more youth-friendly
3. Give one-on-one peer education and assist with facilitation of group education to ALHIV so they better understand, use, and adhere to HIV prevention, care, and treatment services
4. Demonstrate knowledge about issues related to sexual and reproductive health and show that you are comfortable talking about them
5. Help address the psychosocial needs of ALHIV and caregivers
6. Disclose your own HIV-status to clients, support ALHIV through the disclosure process, and help members of the multidisciplinary care team support caregivers who disclose their perinatally-infected child's status
7. Be a role model for positive living, disclosure, and adherence to care and treatment
8. Help ALHIV and family members live positively with HIV
9. Link ALHIV to required health services or support services within the community and clinic settings
10. Keep basic records of daily and monthly activities

There is also a supervised practicum (Module 15) included in this training. By the end of the practical sessions – which will take place in the clinic setting, you will be able to:

1. Practice skills learned during the training in a health facility offering HIV prevention, care, and treatment services to young people
2. Show competency in the major skills taught during the training, with supportive supervision and mentoring
3. Identify skill areas where further on-the-job practice and mentoring are needed

Please note: For the purposes of this curriculum, we define “adolescents” as people between the ages of 10 and 19 years.

SESSION 1.3: Learning Needs Assessment

My notes:

MODULE 2: THE NEEDS OF ADOLESCENTS LIVING WITH HIV (ALHIV) AND THE ROLES OF ADOLESCENT PEER EDUCATORS IN MEETING THEM

LEARNING OBJECTIVES:

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

- Define adolescence
- Describe the developmental stages of adolescence
- Describe common barriers and challenges that ALHIV face, especially with HIV care and treatment
- Discuss the goals and objectives of the Adolescent Peer Educator program
- Discuss the many roles Peer Educators can play in improving access and adherence to comprehensive HIV prevention, care, and treatment services for ALHIV
- Discuss how Peer Educators work as part of the clinic's multidisciplinary care team to improve services and make them more youth-friendly

CONTENT:

SESSION 2.1: Introduction: The Needs of ALHIV and the Challenges They Face

How do we define adolescence?

- The meaning of "adolescence" is understood in different ways in different cultures. It is seen almost everywhere, however, as a time of transition between childhood and adulthood. It is a period characterized by lots of physical and mental changes associated with puberty and a period of preparation for adulthood.
- Many organizations define "youth" as people between the ages of 10 and 24 years. For the purposes of this curriculum, we define "adolescents" as people between the ages of 10 and 19 years.
- Adolescence is a unique phase and stage of development. Adolescents are not "big kids" and they are not "little adults."

The Changes of Adolescence

There are many physical and sexual changes that occur during adolescence:

In females:

- Menarche (getting your period)
- Breasts develop
- Hips widen
- Pubic and underarm hair grows
- The vulva and pelvis develop

In males:

- The penis, scrotum, and testicles grow
- Night-time ejaculation (wet dreams)
- Morning erections
- Back muscles develop
- Pubic and underarm, chest, and leg hair grows

In both females and males:

- Quicker growth
- Increased perspiration
- Acne (pimples)
- Face has characteristics of young adult
- Tone of voice changes
- Sexual desire is activated
- Initiation of sexual activities

My notes:

The Stages of Adolescent Development

Adolescence can be divided into 3 overlapping developmental stages: ages 10-15, 14-17, and 16-19 years. The overlap of ages is important because the changes are not fixed and happen at different ages and times for each adolescent.

In "Early Adolescence" (10-15 years old), an adolescent:

- Begins puberty (this is a time of quick physical growth)
- Begins to experiment
- Begins to think differently and more broadly
- Is influenced by people beyond his or her own family, especially peers
- Is very concerned with image and acceptance by peers

In "Middle Adolescence" (14-17 years old), an adolescent:

- Continues growing and developing physically
- Starts to challenge rules and test limits
- Develops more "thinking" or analytical skills
- Develops more understanding or awareness of the consequences of his or her behavior
- Is strongly influenced by peers, especially in terms of image and social behavior
- Has an increasing interest in sex; starts having romantic, intimate, or sexual relationships

In "Late Adolescence" (16-19 years old), an adolescent:

- Reaches physical and sexual maturity
- Develops a sexual identity
- Has a greater ability to express thoughts, feelings, and ideas
- Can increasingly make independent decisions
- Is concerned about and plans for the future, including career, family, marriage, etc.
- May become more comfortable with own body image
- May be less influenced by peers as opposed to individual friendships

Adolescents: Not Big Kids or Little Adults

Adolescence is a unique stage in life. Adolescents are very different from adults and children, and these differences have implications for HIV care and treatment. ALHIV are different from adults and children living with HIV because of the quick physical and emotional changes that happen throughout this stage of development.

How are ALHIV different from children living with HIV?

- Often, blame is placed on ALHIV (especially those who acquire HIV behaviorally) because of their "risky behavior." This results in stigma and discrimination, whereas small children living with HIV are usually treated as "innocents" or "victims."
- Adolescents need to take an active role in their own adherence to both clinical care and medicines.
- Adolescents are often dealing with their physical, psychosocial, emotional, and sexual development, which can cause confusion.
- Adolescents are more vulnerable to unintended pregnancy and sexually transmitted infections (STIs).
- It can be more difficult to find and bring young people into care because of the need for parental consent and/or involvement (however, this parental involvement may be a very positive factor).
- Outreach is more difficult for adolescents because they are scattered and it is harder to bring them into care.
- Adolescents will eventually have to transition to adult care and treatment and, without adequate planning, support, and follow-up, they can be lost in the system during this transition.
- Adolescents can demand their rights while young children cannot.

My notes:

How are ALHIV different from adults living with HIV?

- Some people think that ALHIV are "not supposed" to be having sex. As a result, adolescents may hide their sexuality.
- Adolescent clients are more likely to lack the skills to understand medicine side effects, treatment options, and regimen requirements.
- Adolescents have different ways of thinking that require different communication approaches.
- Younger adolescents often have to rely on a parent or caregiver to take medicines and adhere to both care and treatment.
- Adolescent clients often depend on their parents or caregivers (for money and housing, etc.) and can therefore not always make independent decisions.
- Adolescents may just be starting to think about their future careers, getting married, and having a family, whereas some adults may have made these decisions already and may have their own families and children.
- Condom and contraceptive use may be more difficult for adolescents.
- Adolescents usually have less stable relationships than adults.
- Adolescent clients face peer pressure and often want to be the same as their peers, even though this may be difficult.
- Not all adolescent clients know or understand their legal rights to access health services that ensure privacy and confidentiality.

Adolescent Vulnerabilities

How are adolescents physically vulnerable?

- It is easier for adolescents, in particular young women, to get STIs (including HIV). This is because their cervixes are still forming and growing, and are more susceptible to infection.
- Young adolescent males may be more vulnerable to STIs, including HIV, if they are not circumcised.
- Adolescents are growing quickly and need a nutritious diet. Because of their increased energy needs, adolescents are susceptible to nutritional deficiencies.
- An adolescent's physical and mental development can be affected by HIV and other infections and diseases.

How are adolescents emotionally vulnerable?

- Adolescence is a time mental illnesses can emerge.
- ALHIV may be especially susceptible to mental health problems.
- Adolescents often lack assertiveness and good communication skills, making it difficult for them to express their needs to adults and also to deal with peer pressure.
- Adolescents may feel pressure to "fit in" with their peers and to adopt the same behaviors as their peers.
- Adolescents are more vulnerable than adults to sexual, physical, and verbal abuse because they are less able to prevent these shows of power.
- Sometimes communication and relationships between adolescents and adults are challenging because adults may still see adolescents as children.
- Adolescents may not have the maturity to make good, rational decisions.

How are adolescents socially vulnerable?

- During adolescence, young people’s need for money often increases, yet they typically have little access to money or employment. This may lead adolescents to feel that their only option is to work in dangerous situations. For example, young women may have transactional or commercial sex to earn money (for food, school fees, etc.) or in exchange for goods.
- Poverty and economic hardships can increase health risks because of poor sanitation, lack of clean water, and the inability to afford/access health care and medicines.
- Disadvantaged adolescents are at greater risk for substance abuse.
- Young women often face gender discrimination that affects food how food is shared, access to health care, adherence to care, the ability to negotiate safer sex, and education and employment opportunities.
- In many societies, a girl’s status is only recognized when she marries and has a child. Some young women marry very young to escape poverty but, as a result, they may find themselves in another difficult situation.
- Some young people are particularly vulnerable, like street children, sex workers, child laborers, refugees, young criminals, those orphaned because of AIDS and other circumstances, and other neglected and/or abandoned youth.

My notes:

Youth-Friendly Services

ALHIV have a difficult time accessing health care because they may not have the financial resources, they may not trust health care professionals, and there may not be enough providers with expertise in both HIV and adolescents. Young people may also be scared because they are worried about the level of confidentiality.

You can help make clinics and health facilities more "youth friendly" and can help link ALHIV to HIV care and treatment services by doing the following:

- Getting involved in how the program is designed
- Giving inputs and feedback from the adolescent clients' point of view
- Making sure all clients are welcomed and treated equally (boys, girls, married, unmarried, street youth, etc.)
- Working with the multidisciplinary care team to make sure that peer support groups and group education sessions/discussions are available to adolescent clients
- Making sure adolescents know about the services offered at the clinic
- Assisting with referrals by walking with the client to the referral point and making sure he or she does not have to wait a long time
- Explaining educational materials or health-related information in easy-to-understand language that young people can "hear"
- Helping the clinic to form linkages with schools, youth clubs, and other youth-friendly institutions

SESSION 2.2: Overview of the Adolescent Peer Education Program

Key terms:

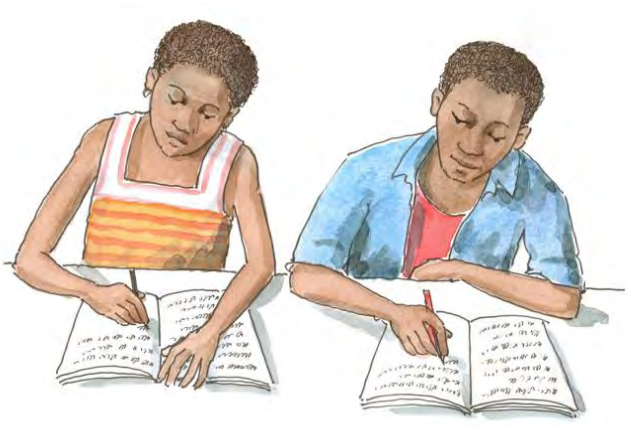
- The English term **"peer"** refers to *"one that is of equal standing with another; one belonging to the same group especially based on age or status."* In modern times, the term has come to mean, more generally, an equal or a match.
- **Education** refers to the development of a person's knowledge, attitudes, beliefs, or behavior that results from the learning process.
- **Peer education** is the transfer of knowledge and skills to members of a social group by others within the same group.
- **Adolescent Peer Educators** are people who are themselves enrolled in HIV prevention, care, and/or treatment services; have a good understanding of HIV, care, treatment, and adherence; and have the skills to help other adolescents with their care and treatment. Usually, Peer Educators are volunteers.

Background of the Peer Education program:

- The program was started in ____________________ (month, year).
- The program was started by __________________________ (organization/s).

The Peer Education program goal is to:
(fill in)

Partners in the Peer Education program include:
(fill in)



SESSION 2.3: Roles and Responsibilities of Adolescent Peer Educators

You are expected to:

- Spend at least 2-3 days per week at the clinic
- Participate as an active member of the multidisciplinary care team in the clinic, including going to meetings and trainings if required
- Openly disclose your HIV-status to clients
- Help conduct/co-facilitate support groups and other psychosocial support activities for ALHIV of different ages and stages
- Conduct Peer Education sessions (one-on-one, with members of the multidisciplinary team, and in groups) with ALHIV and provide support on the following topics:
  - Basic information about HIV and HIV care and treatment
  - Adherence to HIV care and treatment
  - Disclosure
  - Positive living
  - Safer sex
  - Basic emotional and psychosocial support
  - Others, as decided by the program
- Help ALHIV with referrals within the health facility
- Help link ALHIV with needed community support services
- Be role models to other ALHIV
- Act as a link between clients and the multidisciplinary care team
- Keep basic records and compile monthly reports

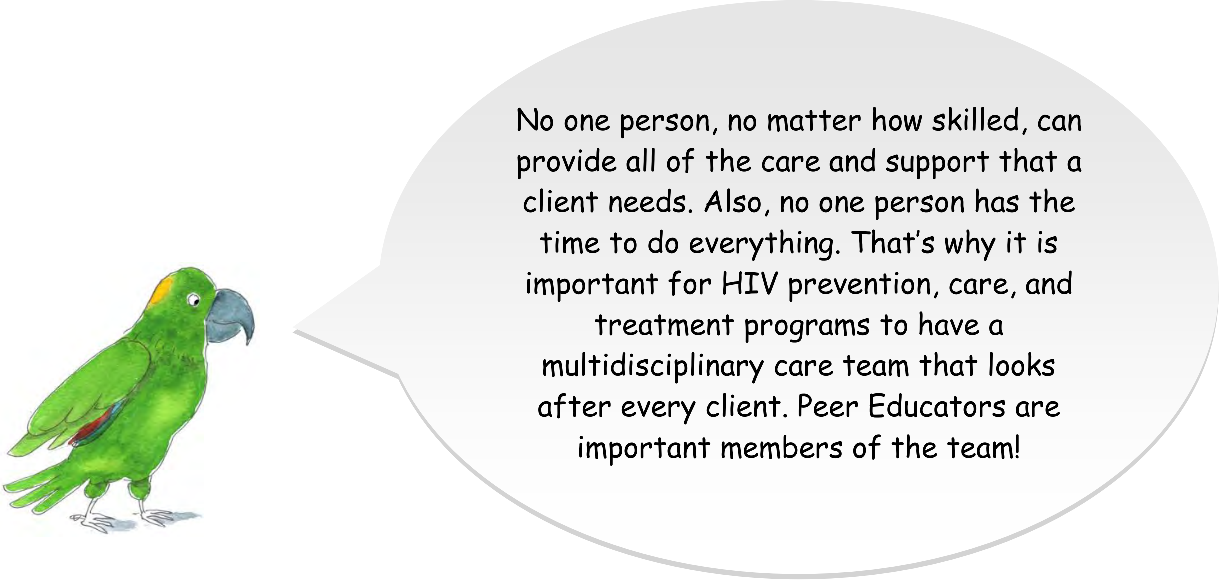
Peer Educators never work alone:

- No one person, no matter how skilled, can provide all of the care and support that a client needs. We all have different training, skills, and personal strengths. Also, no one person has time to do everything. This is why it is important for HIV prevention, care, and treatment programs to have a multidisciplinary care team that looks after every client. You are important members of this team.

> **"Multidisciplinary" means a mix of different professionals and volunteers—doctors, nurses, counselors, peer educators, administrative staff, and others—working as members of a team.**

Depending on the specific site, other members of the multidisciplinary care team can include:

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



My notes:

Note: Some of the preceding information in this Module was borrowed and/or adapted from the following sources:

Centers for Disease Control and Prevention. (2009). *Sexual risk behaviors.* Retrieved from http://www.cdc.gov/HealthyYouth/sexualbehaviors/index.htm

Colton, T., Costa, C., Twyman, P., Westra, L., & Abrams E. (2009). *Comprehensive peer educator training curriculum, Trainer manual, Version 1.0.* New York: ICAP.

Pathfinder International. (2000). *Programmatic issues for youth friendly programs.* Retrieved from http://www.pathfind.org/pf/pubs/focus/RPPS-Papers/OverviewKE.html

Senderowitz, J., Solter, C., & Hainsworth, G. (2004). *Comprehensive reproductive health and family planning training curriculum. 16: Reproductive health services for adolescents*. Watertown, MA: Pathfinder International.

World Health Organization. (2010). *IMAI One-day orientation on adolescents living with HIV, Facilitator guide.* Geneva, Switzerland: WHO Press.

SESSION 2.4: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- "Adolescence"—the period between 10 and 19 years of age—is seen as a time of transition between childhood and adulthood.
- Adolescents are a very "mixed" group that includes young people of different ages, needs, and stages of development.
- Adolescent are not "big kids" or "little adults." They have their own set of needs and challenges.
- Adolescents may be more vulnerable to mental health problems and other medical problems, like sexually transmitted infections.
- Adolescents are dealing with many rapid physical, mental, emotional, and sexual changes, which can cause changes in their relationships, problem solving abilities, and general ways of thinking.
- ALHIV differ from adults and children living with HIV because of the quick physical and emotional changes that occur during this stage of development.
- Peer Educators have important jobs. They are both providers and recipients of HIV prevention, care, and treatment services.
- Peer Educators have many important roles and responsibilities in supporting ALHIV, including providing adolescent clients with emotional support, sharing their own experiences with care and treatment, and acting as good role models.
- ALHIV can have difficulty accessing health care. Peer Educators can help make clinics and health facilities more "youth friendly" and they can help ALHIV by linking them to HIV care and treatment services.
- Peer Educators are important members of the multidisciplinary care team.

My notes:

MODULE 3: REVIEW OF HIV BASICS

LEARNING OBJECTIVES:

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

- Discuss common myths and rumors about HIV, AIDS, and ALHIV
- Discuss the difference between HIV and AIDS
- Discuss how HIV affects the immune system
- Recall the ways HIV is transmitted and prevented
- Identify behaviors that increase risk of HIV transmission and discuss the challenges young people face in reducing risk

CONTENT:

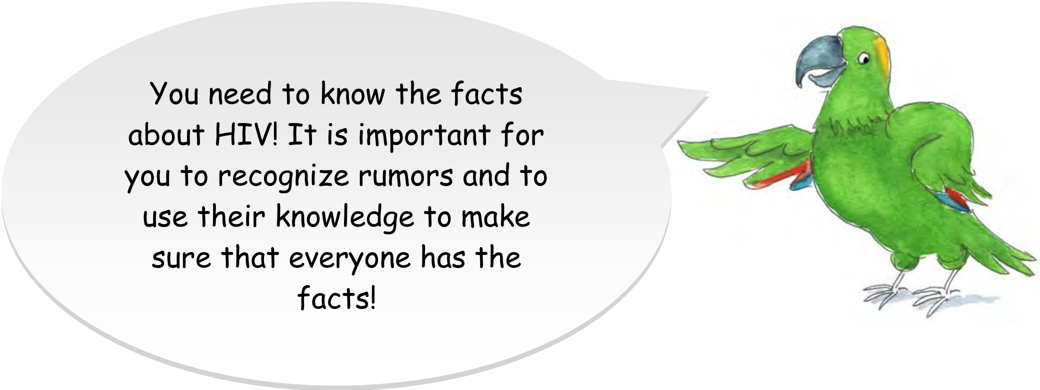
Session 3.1: Introduction: Myths and Rumors about HIV, AIDS, and ALHIV

Session 3.2: From HIV to AIDS—What HIV Does to the Body

Session 3.3: HIV Transmission and Prevention

Session 3.4: Module Summary

SESSION 3.1: Introduction: Myths and Rumors about HIV, AIDS, and ALHIV



My notes:

SESSION 3.2: From HIV to AIDS—What HIV Does to the Body

HIV stands for **Human Immunodeficiency Virus**:

H	Human (refers to us)
I	Immunodeficiency (means the body cannot fight diseases and protect itself from getting sick)
V	Virus (a type of germ in the body that cannot be cured and causes diseases)

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 collection of signs and symptoms of disease)

Basic Definitions

- **HIV** is the virus that gets into the body.
- **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. Having a CD4 count below 200 also means a person has AIDS, even if he or she is not sick.
- **HIV-infected** is when HIV has entered a person's body. A person who is HIV-infected might be very healthy and may not have any signs of illness for a long time. The time it takes for HIV to develop into AIDS varies from person to person. This time can be as long as 10 years for some people or as short as 1-2 years for others. This is why the only way to tell if a person has HIV is with a blood test (and why you cannot tell just by looking at them.
- **HIV-exposed** usually refers to an infant born to a mother infected with HIV and exposed to HIV during pregnancy, childbirth, or breast-feeding.
- Babies and children with HIV infection develop AIDS much faster than adults.
- HIV kills important cells in the body that fight disease. These cells are called **CD4 cells**. Eventually, HIV attacks so many of the CD4 cells that the body cannot fight infections anymore and the person develops AIDS. If a person's CD4 count is below 200, he or she is diagnosed as having AIDS.
- The body of a person who is HIV-infected is more likely to be attacked by infections and diseases. These infections are called **opportunistic infections (OIs)** and can include pneumonia, tuberculosis, meningitis, as well as others. OIs can make people living with HIV—especially babies, children, and people not taking ART—sick because their body's immune or defense system is weakened. Participants will learn more about OIs in *Module 5*.
- HIV can result in other severe life-threatening infections, such as some forms of cancer, problems in the nervous system, and brain diseases. Encephalopathy is a term used to describe a number of different conditions, all of which affect the brain.

My notes:

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, keeping the person healthy. CD4 cells are one type of blood cell in the immune system that fight infection. We can say that CD4 cells are the "guardian angels" that protect us from disease.
- When a person is infected with HIV, HIV enters the blood stream and starts to attack CD4 cells.
- HIV makes more copies of 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 the virus 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 a person more likely to get infections and makes it harder for his or her 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 who, without treatment, will die.
- HIV affects babies/children very quickly—much quicker than it affects adults—because a baby's immune system is still developing.
- Taking ART the right way, at the same time, every day will prevent the HIV from becoming stronger in the body and making the person sick. Taking ART will keep the person's CD4 cells from dying (and keep their CD4 count up).

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.

CD4 cells are our "guardian angels" and protect our bodies from infections that can make us sick. **The higher a person's CD4 count. the better!**

My notes:

SESSION 3.3: HIV Transmission and Prevention

HIV is most easily transmitted in these body fluids:

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

HIV is not usually transmitted in these body fluids, unless there is also blood:

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

My notes:

Ways HIV is transmitted

Sexual transmission:

- Unprotected sexual intercourse with an infected person—this includes male-female sex, male-male sex, and female-female sex
- Direct contact with the body fluid of an infected person (blood, semen, or vaginal secretions)
- Most HIV transmission worldwide is sexual transmission
- 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 (because at this time there is a lot of HIV in the blood)
  - One or both people are eligible for ART and are not taking it or have poor adherence

Remember: Taking ART the right way, every day lowers the chance of transmitting the virus to sexual partners and babies.

Mother-to-child transmission (MTCT):

- During pregnancy
- During labor and delivery (most MTCT happens at this stage)
- During breastfeeding

Blood-to-blood transmission:

- Transfusion with infected blood
- Direct contact with infected blood/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:

- Wearing someone else's clothing
- Sharing food, cups, and plates with a person with HIV
- Swimming in a swimming pool, river, or waterhole with a person or people with HIV
- Travelling on crowded buses with a person or people with HIV
- Sharing a latrine/toilet
- Using condoms
- Mosquitoes or insect bites—even if they carry human blood, HIV cannot live outside of humans
- Living with or sleeping in the same room as a person with HIV
- Hugging
- Kissing
- Shaking hands
- Coughing or sneezing
- Caressing, massaging
- Masturbation

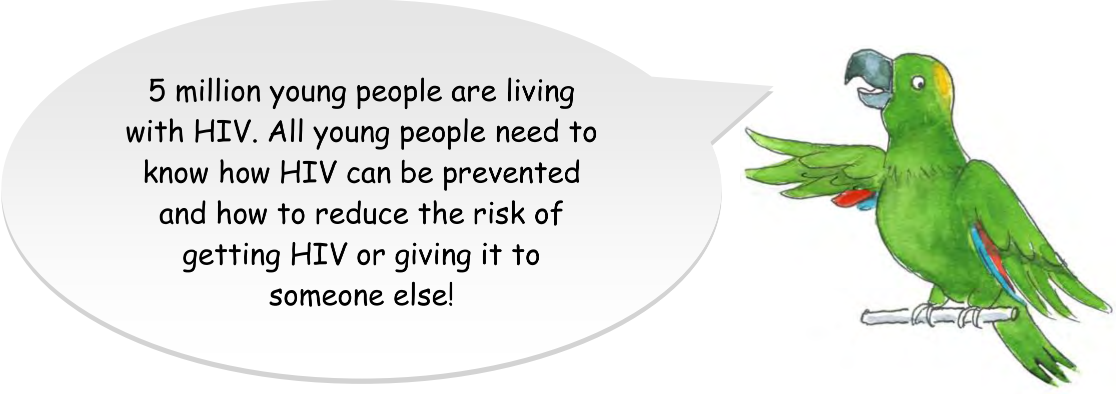
Suggestions for participant activity on HIV Transmission Behaviors

- Kissing on cheeks
- Sleeping in the same room as someone living with AIDS
- Having an injection with a new needle at a local pharmacist's or clinic
- Being tattooed
- Using a public latrine
- Oral sex without condoms
- Anal sex without condoms
- Having sex within marriage
- Hugging someone who is infected
- Having a blood transfusion with HIV
- Using someone else's toothbrush
- Being bitten by bedbugs
- Ritual circumcision
- Swimming in a pond with someone living with HIV
- Caring for someone living with AIDS
- Being bitten by a mosquito
- Having many sexual partners and using condoms with most of them
- Having your ears pierced
- Tongue kissing
- Witchcraft

My notes:

Facts About Youth and HIV

- Almost half of all new HIV infections in the world are among people under 25.
- Estimates show 2,500 young people become infected with HIV every day.
- Globally, 5 million young people are living with HIV.
- Young women under age 25 are at increased risk of becoming infected with HIV, and make up 60% of infected youth.
- Young people remain the most vulnerable group to HIV infection.



HIV Prevention: The ABCs of preventing sexual transmission of HIV:

A#1: Abstinence (not having sex at all)—this approach works best for younger adolescents

A#2: Adherence to ART—take your ART the right way, every day. Keeping your viral load (the amount of HIV in your body) low protects your sexual partner from HIV infection. There is more about "treatment as prevention" in ***Module 10.***

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 initiation of sexual intercourse.

E: Early and complete treatment of STIs

F: Free and open communication between partners about sex

G: Get to know your HIV-status.

Prevention of mother-to-child transmission:

- Prevention of unwanted pregnancies in the first place (good family planning and communication about family planning between couples)
- Providing lifelong ART to all eligible pregnant women and providing ARVs to women not eligible for lifelong ART during pregnancy and breastfeeding
- HIV testing before deciding to become pregnant
- Good, early antenatal care
- HIV testing as part of antenatal care
- Counseling for mothers and fathers on PMTCT
- Safer sex during and after pregnancy
- Safe, normal delivery at a facility
- Providing ARVs for all babies exposed to HIV (at birth and during breastfeeding)
- Safe infant feeding
- Regular follow-up of mother and baby

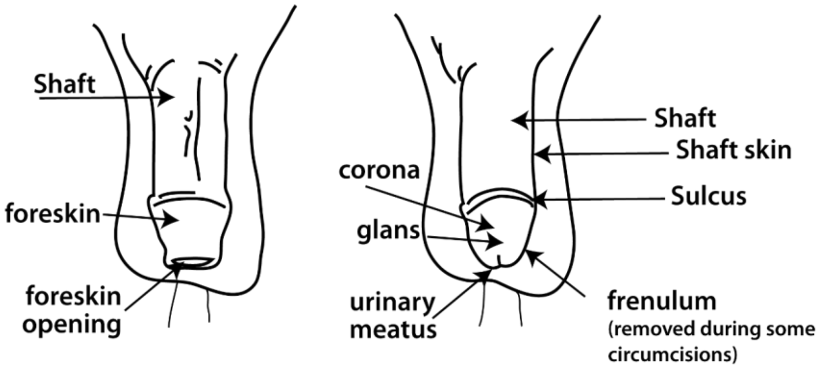
My notes:

Male Circumcision

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. Circumcision involves removal of the foreskin on the penis, as shown in the drawing below. Babies or adults can be circumcised but the procedure 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.
- Studies are still being done to see if circumcision affects male-male sexual transmission of HIV.
- Circumcision is not recommended for men living with HIV.
- It is important for a man to use condoms and to get tested for HIV even if he is circumcised.

Uncircumcised Penis **Circumcised Penis**



Future HIV prevention options:

Microbicides and **"PrEP"** are new interventions that can protect HIV-uninfected individuals when they are exposed to HIV.

- **Microbicides** refer to a new type of product being developed that people could use in their vagina or rectum to protect themselves from HIV, and possibly other STIs. A microbicide could be produced in many forms, including gels, creams, suppositories, films, or as a sponge or ring that releases the medicines over time. Microbicides are still being tested in clinical trials and are not for sale yet.
- **PrEP** stands for "pre-exposure prophylaxis." It means using medicine in advance (before you are exposed to something) to prevent yourself from getting a disease or condition, in this case HIV. When we talk about PrEP for HIV, we are referring to the idea of HIV-negative people taking certain ARVs in order to reduce their risk of becoming infected with HIV if they are exposed to it. Although recent studies have shown that PrEP works in preventing new HIV infections, we are still waiting to see how research findings will be translated into guidelines and use for the general public. Until we know more about how to implement PrEP, it will not be available for general use.

See *Module 10* (page 10-14) for more information on treatment as prevention, microbicides, and PrEP.

My notes:

Other ways young people can prevent transmission of HIV:

Young people should have information about and be encouraged to:

- **Delay sexual activity.** Abstain from sex until married or in a stable relationship.
- **Know their partner's HIV-status.**
- **Learn how to use condoms and use them correctly.** Adolescents should practice using condoms before becoming sexually active. If young people are already sexually active, it is important to make sure they know how to use condoms correctly.
- **Stick with one partner or limit the number of partners you have.**
- **Avoid high-risk partners.**
- **Adhere to HIV care and treatment**, including taking ARVs the right way, at the same time, every day. Good adherence helps keep the viral load (the amount of HIV in the body) low, and can protect sexual partners from getting HIV. But remember, it's always important to also use condoms during sex.
- **Recognize symptoms of STIs.** If a person has burning with urination (peeing), discharge from the penis/vagina, and/or genital sores, he or she and his or her partner should not have sex and should come to the clinic for treatment.
- **Discuss sexual issues with your partner.** Young men and women must feel comfortable communicating with their partners about sex and their sexual histories.

Why are adolescents more at-risk for HIV infection?

Adolescents are more physically at-risk of getting infected with HIV:

- The bodies of young women are still maturing and growing. Their genital tract is more susceptible to infection.
- Women often do not show symptoms of chlamydia and gonorrhea (the most common STIs). A person is more likely to become infected with HIV when he or she has unsafe sex if he or she has another STI. Adolescent females become infected with HIV at twice the rate that adolescent males do.

Adolescents are more socially and economically at-risk of getting infected with HIV:

- Adolescents lack basic information about the symptoms, transmission, and treatment of STIs.
- Adolescents often have multiple, short-term sexual relationships and do not consistently use condoms.
- Adolescents sometimes face dangerous practices like genital cutting, anal intercourse to preserve virginity, and scarification.
- Gender inequality: in some cultures, girls are not empowered to say no.
- Sexual violence, lack of formal education (including sexuality education), inability to negotiate with partners about sexual decisions, and lack of access to reproductive health services put young women at especially high risk.
- Sexual intercourse is often unplanned and spontaneous.
- Adolescent males may have their first sexual experiences with sex workers.
- Adolescent females may have their first sexual experiences with older men.
- Adolescents often do not have accurate knowledge about their bodies, sexuality, and sexual health.
- Adolescents often have little access to income and may do sex work for money or favors.
- Adolescents are more likely to use alcohol, tobacco, and other drugs. When a person is under the influence of drugs or alcohol, he or she is more likely to have unprotected sex.
- Homeless adolescents are at high risk for HIV infection if they are exchanging sex for drugs or money.

Adolescents are very vulnerable to HIV, especially young women. ALHIV need to understand how they can prevent new HIV infections. You need to know about and tell others how to practice the ABCs of HIV prevention, including practicing safer sex!

My notes:

SESSION 3.4: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- Peer Educators should know the facts about HIV and AIDS and help correct myths and rumors among clients, caregivers, family members, 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 get tested so they know their HIV-status.
- HIV attacks a person's immune system and makes it hard for the body to fight off diseases and infections.
- Specifically, 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.
- If they are not on ART, babies and children with HIV usually progress from HIV to AIDS very quickly.
- It is very important that Peer Educators know all the ways HIV can and cannot be passed from person to person and that they 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, through blood-to-blood contact, and through sharing needles, knives, and other sharp objects.
- Adolescents are more physically and socially vulnerable to HIV infection than adults.
- Peer Educators should know the ABCs of preventing sexual transmission of HIV:

  A#1: Abstinence (not having sex at all)—this approach works best for younger adolescents

  A#2: Adherence to ART—take your ART the right way, every day. Keeping your viral load (the amount of HIV in your body) low protects your sexual partner from HIV infection.

  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

D: Delay initiation of sexual intercourse.

E: Early and complete treatment of STIs

F: Free and open communication between partners about sex

G: Get to know your HIV-status.

- Adolescents can prevent HIV transmission by delaying sexual activity, knowing their partners' status, using condoms, limiting the number of partners, avoiding high-risk partners, adhering to their HIV care and treatment, and recognizing the symptoms of sexually transmitted infections (STIs) and getting treatment for themselves and their sexual partner.
- Taking ART the right way, at the same time, every day, lowers the risk of passing HIV to sexual partners and babies.
- Microbicides and "PrEP" are new interventions that can protect HIV-uninfected individuals when they are exposed to HIV. We know from research studies that these interventions work to prevent HIV, but we are waiting to see how they can best be used in the general population. For now, microbicides and PrEP are not available for use in the general

My notes:

MODULE 4: COMMUNICATING WITH YOUR PEERS

LEARNING OBJECTIVES:

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

- Discuss your own attitudes, values, and beliefs and how these may affect communication with other ALHIV
- Describe the importance of effective communication skills as a Peer Educator
- Discuss the basic principles of counseling and behavior change
- Discuss the challenges to building trust and rapport with young clients and how you can overcome them
- Recall what is meant by shared confidentiality and why it is important for Peer Educators
- List the 4main stages of a one-on-one Peer Education session
- Demonstrate the 7 essential communication skills required of Peer Educators
- Practice using the Talking Tree to facilitate Peer Education sessions and help clients come up with their own solutions and make decisions

CONTENT:

Session 4.1: Introduction: The Story of the Monkey and the Fish—Understanding Yourself and Others

Session 4.2: Understanding the Basic Principles of Counseling and Behavior Change

Session 4.3: Let's Talk!: Key Communication Skills for Adolescent Peer Educators

Session 4.4: Classroom Practicum on Communication

Session 4.5: Module Summary

SESSION 4.1: Introduction: The Story of the Monkey and the Fish—Understanding Yourself and Others

The Story of the Monkey and the Fish

> *Once upon a time, in a land far, far away, there lived a monkey. This monkey actually lived on an island. One day it began to rain and rain. The rain never seemed to end and the island began to flood. The rain and the waters kept coming and coming until, one day, the monkey was left with only a little bit of land and one tree. As he was sitting up in his tree, he noticed another animal in the water. It was moving back and forth. The monkey was so worried about the little animal and wanted to rescue it. So, the monkey risked its own life to go out to the end of one of the tree's branches and snatch the animal out of the water to prevent it from drowning. He put the animal on the ground to dry out under the sun and get warm. The animal flopped around and the monkey thought it looked so happy, it must be jumping around in excitement. Then, the animal lay perfectly still and the monkey thought it looked so peaceful. Of course, the animal was a fish.*

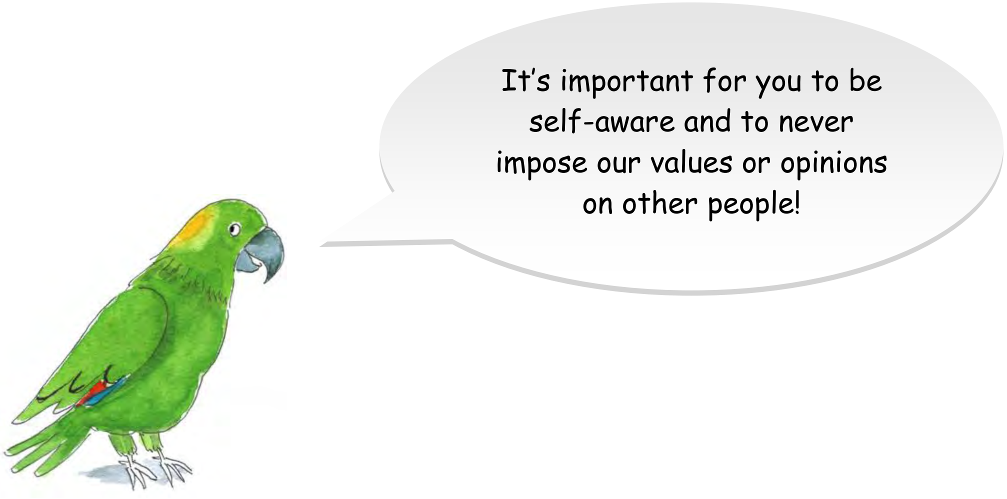
You should always:

- Remember that everyone is different and never assume anyone is "just like us."
- Think about the issues related to your own attitudes, values, and prejudices and how these issues affect your ability to give effective support services to clients.
- Be sensitive to the culture, values, and attitudes of your clients, even if they are different from your own.
- Make all people feel comfortable and that it is "safe" to talk with you openly and honestly.

Key terms:

- **Attitudes and values** are feelings, beliefs, and emotions about a fact, thing, behavior, or person. For example, some people believe that having multiple sexual partners is okay as long as you practice safer sex, while other people believe that this is wrong.
- **Prejudices** are negative opinions or judgments made about a person or group of people before knowing the facts. For example, assuming that an adolescent with HIV must be promiscuous is a prejudice.
- **Being self-aware** means knowing yourself, how other people view you, and how you affect other people.

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



My notes:

SESSION 4.2: Understanding the Basic Principles of Counseling and Behavior Change

You should understand the
basics about counseling and
behavior change so you can be
an effective helper!

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 goal of counseling is not to solve every problem but to improve the client's 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
- Talking about options and alternatives
- Helping people to see and build on their strengths
- Helping people to develop a positive attitude toward life
- Respecting everyone's needs, values, culture, religion, and lifestyle

Counseling does not include:

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

Always remember to be respectful and non-judgmental when communicating with clients and other community members!

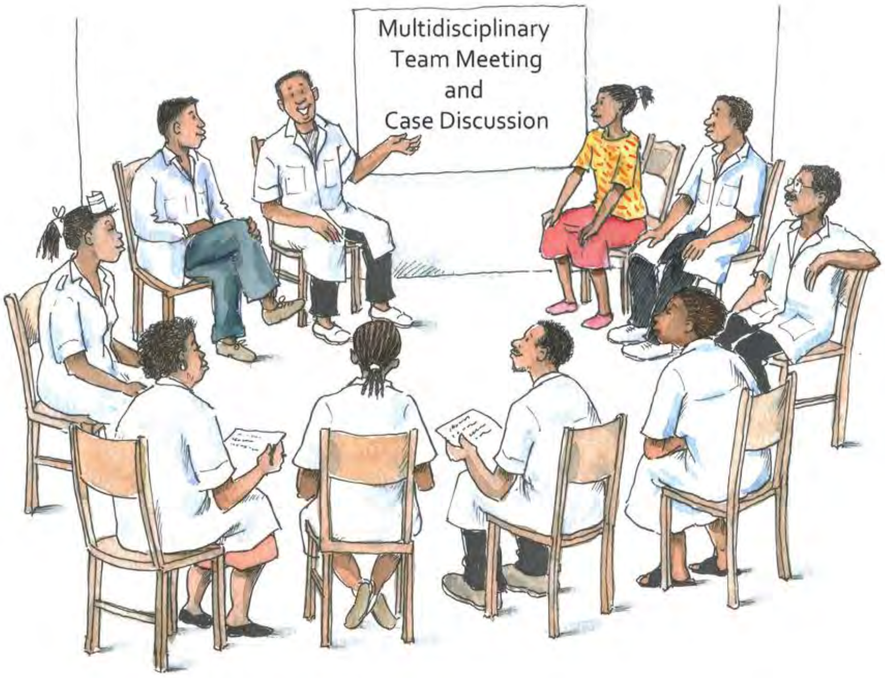
My notes:

Behavior Change

- Behavior change is a step-by-step process of change from one behavior to another.
- Usually a person moves from being uninterested in changing, to considering a change, to deciding and preparing to make a change.
- Behavior change happens gradually over time; it is a process. It does not happen overnight, and setbacks are normal and part of changing behavior.
- We often realize we should change our behavior after getting new information—but information alone is usually not enough to cause us to change our behavior.
- Often, we actually begin to change as a result of a personal experience or crisis that motivates us to try to change our behavior or lifestyle.
- When trying to change a behavior, almost all of us stumble along the way, either because of our own personal obstacles or because of obstacles that others put in our way.
- To succeed in changing a behavior, most of us receive some form of support, either from something we find within ourselves or from our peers, family, or others who are important to us.
- As Peer Educators, we must be patient with our clients as they try to change their behaviors.

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 HIV-positive, or any other information about the client. Confidentiality is especially important in HIV programs because of the stigma surrounding HIV and the discrimination against ALHIV in the home, at work, at school, and in the community.

Because multidisciplinary care teams take care of clients, sometimes they need to discuss a client's needs and health status with one another so they can provide the best care possible to the client. This is called **shared confidentiality.**



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 care team, a community health worker, a treatment supporter, etc.—***with the client's consent.***

Peer Educators often come from the same community as their clients. This might make some people who know them uneasy, especially in the beginning. You need to tell clients that you will NOT discuss their concerns, health, or problems with people in the community.

Privacy:

PRIVACY is a very important part of quality counseling. Even though space is a challenge in many clinics, it is important that the multidisciplinary care team work 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 counseling is taking place.

ALWAYS tell your supervisor or a member of the multidisciplinary team (e.g. nurse or social worker) IMMEDIATELY if your client:

- ✓ **Talks about suicide**
- ✓ **Talks about wanting to hurt someone**
- ✓ **Reports any kind of physical or sexual abuse**
- ✓ **Talks about abusing drugs or alcohol**
- ✓ **Shows any signs of severe behavioral, emotional, or mental health problems (like if a client reports hearing voices)**
- ✓ **Tells you about a new or worsening medical condition or problem**
- ✓ **Acts aggressive or threatening**
- ✓ **Asks for information you do not have or know**

Always review client information with your supervisor and/or the multidisciplinary care team after the individual session to ensure the best possible care for your client!

My notes:

SESSION 4.3: Let's Talk!: Key Communication Skills for Adolescent Peer Educators

Phases of a One-on-One Peer Education Session

There are 4 main phases in a one-on-one Peer Education session:

1. Establishing the Relationship
2. Understanding the Client's Needs
3. Creating an Action Plan
4. Ending the Session

1. Establishing the Relationship

- To establish a relationship, you must quickly build trust with the person. Smile, introduce yourself, and give a short explanation of your role. Choose a space or room to talk that is private and where people do not walk through so that there are few, if any, interruptions or disturbances. For younger children, you may want to sit on the floor.
- Confidentiality: explain that what is discussed in counseling is confidential, which means that it is not talked about with other people—it is private. Explain, however, that sometimes there may be a need to talk about a client's health information with someone else in the clinic to ensure the best possible care for the client. Explain that Peer Educators may only talk about this information in the clinic with other health workers and never in the community.
- Ways to begin a counseling session after introducing yourself and explaining confidentiality: *"Can you tell me why you came here today?"*
- If you show a positive and caring attitude from the beginning, this will help you develop a trusting relationship with clients.

2. Understanding the Client's Needs

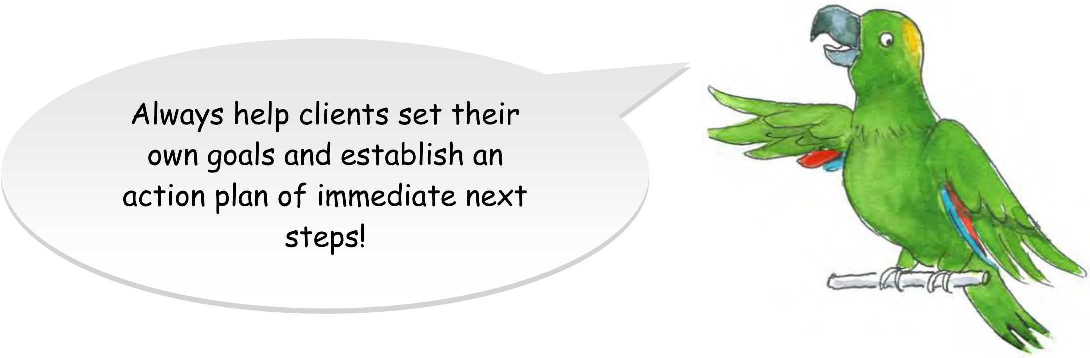
- Be patient and let the client describe what is happening. Listen as the person talks about his or her thoughts, feelings, and actions around the situation he or she is in.
- Use the 7 essential communication skills to encourage conversation.
- There may be different problems or points to address. Help the client decide which is the most important.

3. Creating an Action Plan

- You should give the client practical information, referrals, or perhaps just emotional support (i.e. make a plan to visit the ART clinic together, refer the client to a peer support group, etc.).
- It is very important that the decision-making come from the client. You can help the client explore the options, but in the end it is up to the client to make a decision.
- Write down the client's decision and immediate next steps (e.g. make a plan to visit the ART clinic together, go to a support group for ALHIV, etc.).
- **Remember: you may need to get assistance from the Peer Education Supervisor or a member of the multidisciplinary care team if the client's situation is serious or complicated (e.g. if the client is very down and thinks about suicide).**

4. Ending the Session

- Summarize what was discussed during the session, including the next steps and action points.
- Talk about any future Peer Education sessions and make needed appointments for the client.



My notes:

Case study for role play:

S__ is a 15-year-old young woman and a client at the HIV clinic. She comes to you and says: *"I just started seeing this guy. We have spent quite a bit of time together and I really like him. We have been really careful and had protected sex. He knows I have HIV and is pretty accepting. It has been about 2 months and now my boyfriend does not want to use a condom. He says that if I trust him, I should not ask him to use a condom. I am so confused. I do not know what to do."*

There are 7 essential communication skills that you should practice and use in their work when speaking to individuals and in front of groups:

- Skill 1: Use helpful non-verbal communication
- Skill 2: Actively listen and show interest in your client
- Skill 3: Ask open-ended questions
- 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 Peer Education session

The 7 essential communication skills are not only helpful at the clinic, but also in life and in all of our relationships with family members, friends, partners, and community members!

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 conversation with a client, unless you are writing down 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.

Role play **Non-verbal communication**	
What NOT to do **Non-verbal communication**	**What to do** **Helpful non-verbal communication**
Client walks in	Client walks in
Peer Educator: Hi. My name is _________ *(name).* (Peer Educator is filling in the register from behind a desk)	**Peer Educator:** Hello. My name is _________ *(name).* (Peer Educator is filling in the register from behind a desk)
Client: Um, I have some questions about how a person gets HIV.	**Client:** I have some questions about how a person gets HIV.
Peer Educator: Yeah, cool..... (speaking in a hurried fashion). What do you want? (Peer Educator still looking at the register)	**Peer Educator**: (Looks at client, stops writing in the register, and moves chair so that it is not behind the desk) Would you like to sit down? What were your questions? (Leans forward, not crossing legs)
Peer Educator: (No response and still filling in the register)	**Peer Educator:** (Looks warmly, yet with concern, at client. Optional: demonstrate appropriate touch)
Client: Well, I'm worried about giving my girlfriend HIV.	**Client:** Well, I'm worried about giving my girlfriend HIV.

Peer Educator: (No response and still filling in the register)	**Peer Educator:** (Looks warmly, yet with concern, at client. Optional: demonstrate appropriate touch)
Client: (Clears throat to get Peer Educator's attention)	----
Peer Educator: Oh sorry (she finally stops writing and looks at watch). Yeah, go ahead, you said that you are concerned that your sister might be infected? (Peer Educator's hands are folded, legs crossed and facing away from client, looking across the room with expression of disinterest)	**Peer Educator:** You look really concerned, why do you think she might get infected? (Peer Educator looks at client, leaning forward and not crossing legs)
Client: Well no, actually it was my girl…, actually, it's okay. Don't worry, sorry to have bothered you.	**Client:** (Proceeds to tell her story)

Skill 2: Actively listen and show interest in your client

Active listening skills:

- Listen in a way that shows respect, interest, and caring.
- Show the client you are listening by saying "*okay*" or "*mmm hmm.*"
- Use a calm tone of voice.
- Listen to the content of what the client is saying.
- Listen to how they are saying it—do they seem worried, angry, etc.?
- Allow the client to express her or his emotions. For example, if she is crying, allow her time for this.
- Never judge clients or impose your own values on them. Use non-judgmental language. Avoid saying, "*You should...*" Instead say, "*You can...* " or "*You may want to think about...*"
- Keep distractions to a minimum and try to find a private place to talk.
- Do not do other tasks while talking to a client.
- Do not interrupt the client.
- Ask questions or gently probe if you need more information.
- Don't be afraid of silence. Silence gives the client time to think about what to say next.

Listening carefully is one of the best ways you can help with a client's problems. Use your body language and tone of voice to show clients you are listening well and that you are interested!

Role play **Active Listening**
Peer Educator: What do you think your best friend's reactions might be if you told her that you have HIV?
Client: There's no way I could tell her. She would think all sorts of bad things about me.
Peer Educator: Mmm hmm (*nods sympathetically*).
Client: I think she would stop talking to me.
Peer Educator: You are afraid she won't understand or support you?
Client: Yeah, she'll think I got it because I slept around with a bunch of guys.
Peer Educator: Yeah, I understand. It must be really tough for you. It sounds like you could use some extra support since disclosing to your best friend sounds like something you're scared about doing.

My notes:

Skill 3: Ask open-ended questions

- Ask questions to help you clearly understand the client's problems or worries and to help the client get a deeper understanding of what is going on.
- Questioning should be centered around the concerns of the client and not around your curiosity.

These are the different types of questions:

Closed Questions

- A closed question limits the response of the client to a one-word answer—usually "yes" or "no."
- For example:
  - *"Do you practice safe sex?"*
  - *"Do you know how to use a condom?"*
- Closed questions do not give the client an opportunity to really think about what they are saying.

Open-ended questions

- An open-ended question requires more than a one-word answer.
- They invite the client to continue talking.
- For example:
  - *"If you were to tell your status to your girlfriend, how do you think she would react?"*
  - *"If your boyfriend found out from your best friend that you were pregnant, what do you think would happen?"*
  - *"If you asked your brother to help with the cooking, what do you think his response would be?"*

Leading questions

- A leading question is one that already suggests the answer.
- For example:
  - *"You do practice safe sex, don't you?"*
  - *"Do you agree that you should always use a condom?"*
- These questions are usually judgmental. Try not to use them.

Additional Practice on Closed- and Open-Ended Questions	
Closed-ended questions	**Open-ended questions**
Do you have safer sex with your boyfriend?	How do you have safer sex with your boyfriend?
Do you have more than one partner?	There are a lot of ways to reduce risk for HIV—like not having sex, being faithful to your partner, and using condoms. Which would work best for you based on your situation?
Do you use condoms?	What challenges do you have using condoms with your partner?
Do you know how to prevent HIV?	Can you tell me the ways you know of to protect yourself from HIV?
Are you taking your ARVs?	Tell me more about how it's going with your medicines. What are some of the challenges you are having? What is working well?

Role play Open-ended questions	
What NOT to do **Closed-ended questions**	**What to do** **Open-ended questions**
Client walks in	Client walks in
Peer Educator: Hi, how are you? I'm ____ *(name)*. I am a Peer Educator. I'd like to talk with you about taking your medicines.	**Peer Educator:** Hi, how are you? I'm ____ *(name)*. I am a Peer Educator. I'd like to talk with you about taking your medicines.
Client: OK	**Client:** OK
Peer Educator: Did you take all of your pills this month?	**Peer Educator:** How was it taking you medicines this month?
Client: Yeah, I think so.	**Client:** Well, it went pretty well but sometimes remembering to take my pills after school was hard.
Peer Educator: OK, great. And did you have any problems or side effects?	**Peer Educator:** Were there times this past week when you forgot to take your pills?
Client: Um, no, I don't think so.	**Client:** Ok, yesterday I remembered to take my medicines in the morning. But after school, I stayed out with my friends and forgot completely. My mother was at my grandmother's house. There was no one at home to help remind me.
Peer Educator: OK, cool. So it seems like things are fine. I'll see you next time you come to the clinic.	**Peer Educator:** Lets review your adherence plan together and think of ways you can remember to take your medicines.

Skill 4: Reflect back what your client is saying

- Summarize briefly what the client told you by paraphrasing his or her words
- Try to understand the client's feelings and let him or her know that you have understood these feelings

Reflecting can:

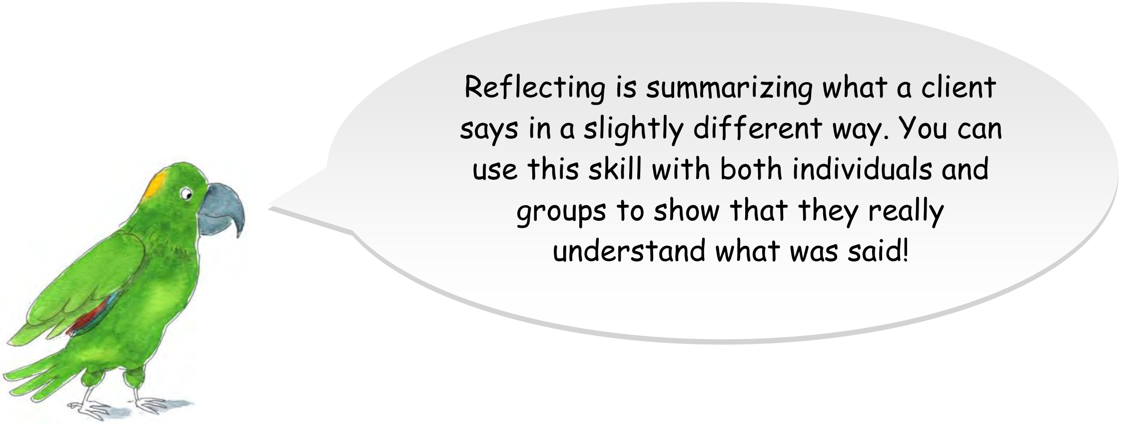
- Give feedback to the client and lets him or her know that he or she has been listened to, understood, and accepted
- Encourage the client to say more
- Show that you have understood the client's story
- Give a good alternative to always answering with another question

For example, you can use the following formulas for reflecting:

  – *"You seem to feel that* ___________ *because* __________*."*
  – *"So I sense that you feel* __________ *because* __________*."*
  – *"I'm hearing that when* ___________ *happened, you didn't know what to do."*

- When reflecting back, try to say it in a slightly different way. Do not just repeat what the client said. For example, if a client says, *"I can't tell my girlfriend that I have HIV,"* you could say, *"Talking to your partner about your HIV-status sounds like something that you are not comfortable doing."* Then say, *"Let's talk about that."*

Role play **Reflecting**	
Example 1	**Example 2**
Client: I really wanted to meet my friends yesterday, but I had too much housework to do so I couldn't go.	**Client:** I told my boyfriend to go to hell!
Peer Educator: It seems like you felt pretty sad because you could not meet your friends yesterday?	**Peer Educator:** You were mad at him?



Skill 5: Show empathy, not sympathy

- Empathy is trying to put yourself in another person's shoes.
- Empathy is different from sympathy. When you sympathize, you feel sorry for a person and look at him or her from your own point of view.
- For example, if the client says, *"Taking these medicines every day is so hard. I'm sick of it. I just want to feel normal and be like everyone else,"* you could reflect back by saying, *"You are feeling kind of stressed out and upset?"*
- However, if you respond by saying, *"You poor thing. I really know how you feel. When I first started taking ARVs, it was so hard for me as well. I felt really angry that I had to take these medicines for the rest of my life. It seemed impossible. I had no support from my family…,"* this is sympathizing because the attention is now on you and your experiences rather than on the client.

Role play **Showing empathy vs. sympathy**	
What NOT to do **Sympathizing**	**What to do** **Empathizing**
Peer Educator: What do you think about asking your partner to use condoms?	**Peer Educator:** What do you think about asking your partner to use condoms?
Client: I'd really be afraid that he might hit me, or even worse.	**Client:** I'd really be afraid that he might hit me, or even worse.
Peer Educator: Yes, I know what you mean, that happened to my sister. She actually did ask her boyfriend to use condoms and you know what? He hit her then he made her leave the house. He didn't let her come back for two full days.	**Peer Educator:** It sounds like you're afraid of how your boyfriend will respond.
Client: So did your sister go back?	**Client:** Yeah, I am. He's jealous and he has accused me of cheating in the past and has become really violent with me.

It's important for you to understand the client's point of view. Always remember—EMPATHIZE but don't SYMPATHIZE!

Skill 6: Avoid judging words

- Judging words are words like "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 he or she is wrong, or that there is something wrong with his or her actions or feelings.
- However, sometimes you may need to use the "good" judging words to build a client's confidence.

Never use judging words or make a client feel bad about something he or she has said. Remember—we need to work WITH our clients and not against them!

Role play **Avoiding judging words**	
What NOT to do **Using judging words**	**What to do** **Avoid words that sound judging**
Peer Educator: What do you think about asking your boyfriend to use condoms?	**Peer Educator:** What do you think about asking your boyfriend to use condoms?
Client: NO way.	**Client:** NO way.
Peer Educator: (Surprised) Really? That's the wrong way to feel! Have you had a good conversation about condoms?	**Peer Educator:** Mmm hmm.
Client: No, not really.	**Client:** I tried to get him to use condoms before, but he says sex doesn't feel as good when he uses them.
Peer Educator: He's stupid isn't he? I hope you get some sense and have a good conversation about condoms and how condoms prevent STIs and pregnancy.	**Peer Educator:** Yeah, I've heard other people say that as well. Have you ever had a talk with him about using condoms to protect his and your health?
Client: Yes, I will.	**Client:** That's a good idea, maybe I'll try that.

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

Summarizing:

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

Summarizing:

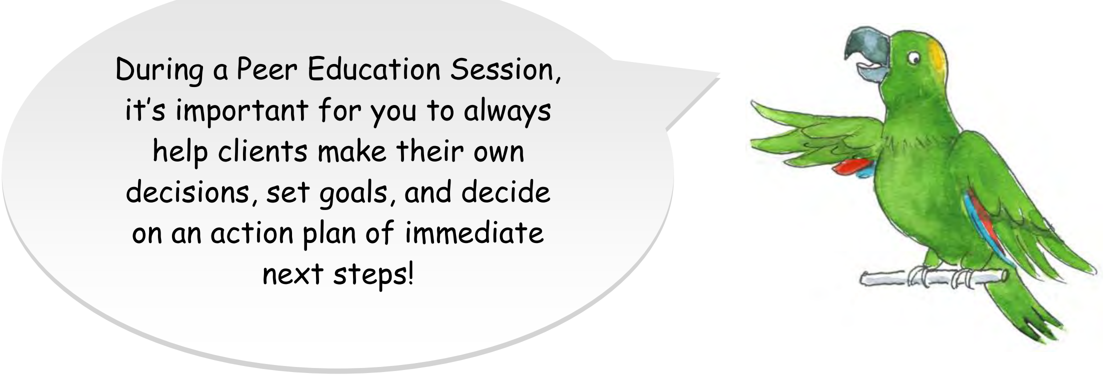
- Can be useful to make sure you have understood the main issues raised during a session
- Is best when both you and the client participate and agree with the summary
- You could say, *"I think we've talked about a lot of important things today.* (List main points.) *We agreed that the best next steps are to _________________. Does that sound right? Let's plan a time to talk again soon."*

Goal setting and deciding on "immediate next steps":

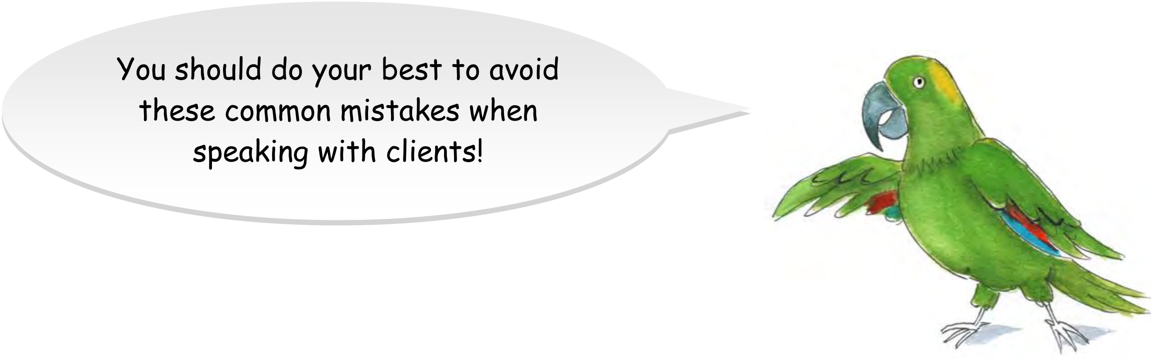
Towards the end of a Peer Education session, you work with the client to decide what he or she is going to do in the immediate future (e.g. in the next few days) and to come up with "next steps" to solve the client's issues in the short and long term.

Next steps and goals:

- Should be developed by you and the client together
- Try and help the client make realistic short- and long-term goals and actions
- Must be clear enough to help people measure their own progress (people feel good when they achieve something they have set out to do)
- To start, you could say, "*Okay, now let's think about some things you will do this week based on what we talked about.*"



Common Communication Mistakes to Avoid:



1. **Avoid exclamations of surprise.**

   Client: "I slept with my boyfriend last night and we did not use a condom."

   Wrong: "Oh, my goodness. Has your boyfriend been tested for HIV?"

   ***Correct**: "Tell me more about that."*

2. **Avoid preaching.**

   Client: "I feel really bad. I slept with 2 different people last weekend."

   Wrong: "You should feel bad. The Bible says that you are only to have sex with your husband."

   ***Correct**: "You said you feel really bad. Can you describe that a little more?"*

4. **Avoid being critical.**

   Client: "I did it again: I went to the bar last night and drank too much and then went home with someone I didn't know."

   Wrong: "I do not know if I can continue to counsel you if you do not start making good decisions."

   ***Correct**: "Tell me more about what happened and how you're feeling now."*

5. **Avoid making false promises.**

   Client: "I have had a really miserable week."

   Wrong: "Next week is bound to be better."

   ***Correct**: "What made this week so miserable?"*

6. **Avoid threats.**

   Client: "I had unprotected sex again this last week."

   Wrong: "If you do not stop having unprotected sex, you are going to give her HIV."

   ***Correct**: "How are you feeling about that?"*

7. Avoid burdening others with your own difficulties. Do not bring up your problems and concerns with a client.

Client: "I do not have enough money to pay the rent next month."

Wrong: "I hear you. I don't have enough to pay for electricity. I don't know what I'm going to do."

***Correct**: "Sounds like you have some real financial concerns. Let's talk more about that."*

8. Avoid appearing impatient—this could be impatience at the client's continued grief or depression. It could also be impatience caused by not having the time to talk to the client at that moment. Be direct and reschedule a time when you can talk to the client.

Client: (crying) "I miss my mother so much and cannot seem to stop crying."

Wrong: "It has been 6 months since your mother passed away. It is time you moved on."

***Correct**: "It's so painful to miss someone."*

9. Avoid sharing your personal beliefs or values.

Client: "The church I attend says it is wrong to have sex before marriage. What do you think?"

Wrong: "The church is absolutely right. That is why AIDS has spread so rapidly."

***Correct**: "Tell me more about what you think and feel about it."*

10. Avoid arguing.

Client: "I am so stupid. I cannot believe I failed the exam."

Wrong: "You are not stupid."

***Correct**: "How does failing the exam make you stupid?"*

My notes:

Tips for Communicating with Younger Adolescents:

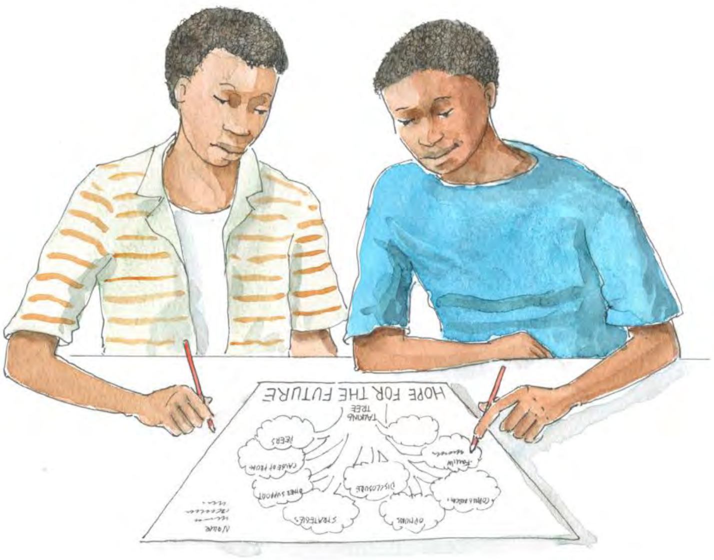
- They need time to feel safe and to trust. Maybe start the session by doing something together, like playing a game.
- They may feel scared and fear being judged.
- They may feel anxious or embarrassed when asking for help, especially when it's about contraception or other reproductive health issues.
- They need some time to observe you! Do not expect them to talk right away. Allow plenty of time and be patient.
- Explain things in simple terms.
- Just because he or she is not asking questions does not mean that he or she is not thinking about what is being said.
- Do not force him or her to share. Positively reinforce his or her effort to express him- or herself
- If a youth is rude or aggressive, remember that it may not be directed at you. He or she may be feeling angry with adults for treating him or her badly or letting him or her down. Be patient and don't take it personally.

Activities for Younger Adolescents:

- Reading a book or educational material together
- Drawing about their family, followed by some questions to encourage them to share their feelings:
  - *"Tell me about your drawing"*
  - *"What happened here?"*
  - *"How did you feel then?"*
  - *"How do you feel now?"*
- Talking while playing a board game
- Making a photo collage about their family
- An "All About Me" Box: use magazines, paper, and markers to decorate a shoe box so that it represents different aspects of their personality and life
- Helping them write a letter to a friend or family member about what is happening

My notes:

SESSION 4.4: Classroom Practicum on Communication



Case Studies for Classroom Practicum

Case Study 1:
M___ is an 18-year-old client you see regularly at the ART clinic and who you recognize from school. He tells you that he has a male partner that he sees on the weekends and that he has not disclosed to his status to him. He is very worried that his family and his friends at school will find out that he is HIV-positive and sometimes has sex with men. He is scared to open up and really talk to you about these issues.

How do proceed with M___?

Case Study 2:
N___ 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 that they were very healthy and not “bad girls.”

How do you proceed?

Case Study 3:
B___ is 15 years old and HIV-positive. Her father died of an AIDS-related illness. Her mother is also HIV positive, so B___ is the one mostly taking care of her 3 siblings. As a result, she is not always able to go to school. She comes to the clinic today and is very depressed. She is crying says that she feels hopeless.

How do you support B___?

Case Study 4:
T___ is 10 years old. He comes to the clinic and you sit down with him in a private room. He seems embarrassed to talk to you but it seems like he has something on his mind.

How do you proceed?

Case Study 5:
The nurse asks you to speak with a young woman named L___ about some adherence challenges she is having. When you come into the waiting area where L___ is sitting, you realize that she is someone you dated about a year ago.

How do you proceed?

Peer Educators are not counselors and should never work alone. Always remember to talk with your supervisor and other members of the multidisciplinary care team about any important issues!

Note: Some of the preceding information in this Module was borrowed and/or adapted from the following sources:

Colton, T., Costa, C., Twyman, P., Westra, L., & Abrams E. (2009). *Comprehensive peer educator training curriculum, Trainer manual, Version 1.0.* New York: ICAP.

Family Health International. (2006). *Community counselor training toolkit, Basic counseling skills, Module 2.*

Family Health International. (2006). *Community peer educator training toolkit, action with youth - HIV/AIDS and STD: A training manual for young people; Second edition.* International Federation of Red Cross and Red Crescent Societies.

REPSSI. (2007). *Mainstreaming psychosocial care and support: A manual for facilitators.*

Senderowitz, J., Solter, C., & Hainsworth G. (2004). *Comprehensive reproductive health and family planning training curriculum. 16: Reproductive health services for adolescents*. Watertown, MA: Pathfinder International.

World Health Organization. (2010). *IMAI one-day orientation on adolescents living with HIV, Facilitator guide.* Geneva, Switzerland: WHO Press.

SESSION 4.5: Module Summary

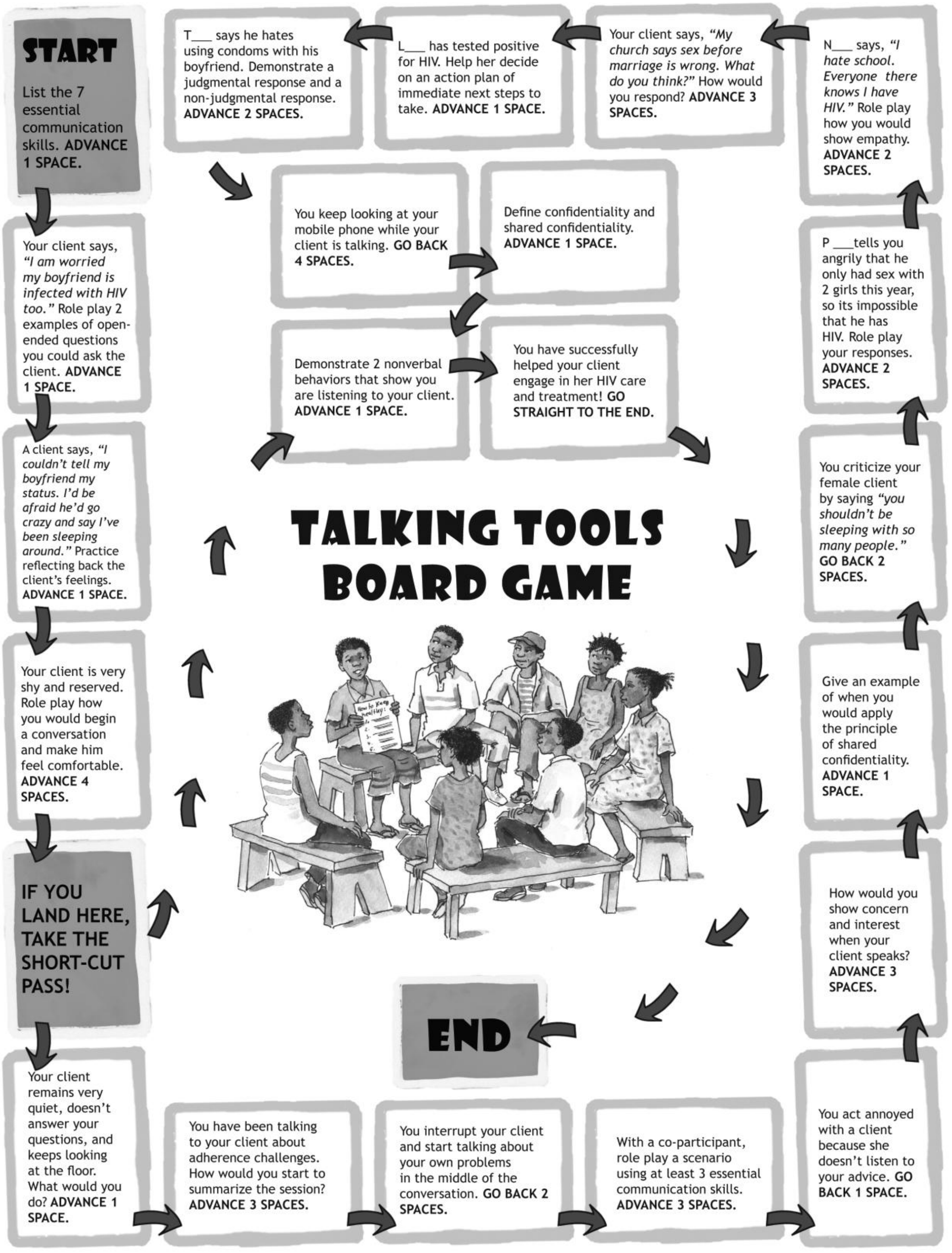
LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- Our own attitudes, values, and prejudices should not be a part of communication and counseling with clients and other community members.
- Peer Educators are not qualified counselors, but it is important to understand the basic principles of counseling and behavior change in order to be effective helpers.
- Counseling is a way of working with people to understand how they feel and of helping them decide what they think is best to do in their situation.
- Peer Educators are not responsible for solving all of the client's problems.
- Peer Educators' role is to support and assist the client's decision-making process.
- Behavior change happens gradually over time; it is a process. It does not happen overnight and setbacks are normal and part of changing behavior.
- It is important for clients to know that what they say will be kept private. Peer Educators should practice shared confidentiality.
- Peer Educators should make sure that there is privacy when speaking with a client and that they are not interrupted for any reason.
- There are 4 phases of a one-on-one Peer Education session: (1) Establishing the relationship; (2) Understanding the client's needs; (3) Creating an action plan; and (4) Ending the session.
- These are the 7 essential communication skills that Peer Educators should always use in their work—when they speak to individuals and when speaking in front of groups:
    1. Use helpful non-verbal communication.
    2. Actively listen and show interest in your client.
    3. Ask open-ended questions.
    4. Reflect back what your client is saying.
    5. Show empathy, not sympathy.
    6. Avoid judging words.
    7. Help your client set goals and summarize each counseling session.
- Younger adolescents sometimes need a different counseling approach. Allow plenty of time, be patient, and use an activity-based approach to encourage expression.
- The Talking Tree, Talking Tools Board Game, and Communication Skills Checklist are all helpful tools that can guide Peer Educators in their work with clients.

- Peer Educators should never work alone. They should always work closely and communicate regularly with a supervisor and/or a member of the multidisciplinary care team.

My notes:

APPENDIX 4A: Talking Tools Board Game



START

List the 7 essential communication skills. **ADVANCE 1 SPACE.**

Your client says, *"I am worried my boyfriend is infected with HIV too."* Role play 2 examples of open-ended questions you could ask the client. **ADVANCE 1 SPACE.**

A client says, *"I couldn't tell my boyfriend my status. I'd be afraid he'd go crazy and say I've been sleeping around."* Practice reflecting back the client's feelings. **ADVANCE 1 SPACE.**

Your client is very shy and reserved. Role play how you would begin a conversation and make him feel comfortable. **ADVANCE 4 SPACES.**

IF YOU LAND HERE, TAKE THE SHORT-CUT PASS!

Your client remains very quiet, doesn't answer your questions, and keeps looking at the floor. What would you do? **ADVANCE 1 SPACE.**

You have been talking to your client about adherence challenges. How would you start to summarize the session? **ADVANCE 3 SPACES.**

You interrupt your client and start talking about your own problems in the middle of the conversation. **GO BACK 2 SPACES.**

With a co-participant, role play a scenario using at least 3 essential communication skills. **ADVANCE 3 SPACES.**

You act annoyed with a client because she doesn't listen to your advice. **GO BACK 1 SPACE.**

How would you show concern and interest when your client speaks? **ADVANCE 3 SPACES.**

Give an example of when you would apply the principle of shared confidentiality. **ADVANCE 1 SPACE.**

You criticize your female client by saying *"you shouldn't be sleeping with so many people."* **GO BACK 2 SPACES.**

P ___tells you angrily that he only had sex with 2 girls this year, so its impossible that he has HIV. Role play your responses. **ADVANCE 2 SPACES.**

N___ says, *"I hate school. Everyone there knows I have HIV."* Role play how you would show empathy. **ADVANCE 2 SPACES.**

Your client says, *"My church says sex before marriage is wrong. What do you think?"* How would you respond? **ADVANCE 3 SPACES.**

L___ has tested positive for HIV. Help her decide on an action plan of immediate next steps to take. **ADVANCE 1 SPACE.**

T___ says he hates using condoms with his boyfriend. Demonstrate a judgmental response and a non-judgmental response. **ADVANCE 2 SPACES.**

You keep looking at your mobile phone while your client is talking. **GO BACK 4 SPACES.**

Define confidentiality and shared confidentiality. **ADVANCE 1 SPACE.**

Demonstrate 2 nonverbal behaviors that show you are listening to your client. **ADVANCE 1 SPACE.**

You have successfully helped your client engage in her HIV care and treatment! **GO STRAIGHT TO THE END.**

END

APPENDIX 4B: Talking Tree

Instructions for the Talking Tree: Each instruction below goes with a number on the Talking Tree. The Peer Educator should follow these instructions in order.

Begin by explaining that the African Baobab tree is one of the longest-living and largest trees on Earth. It symbolizes survival and life because it sometimes grows in harsh conditions. It also symbolizes protection and sharing because it can be used as shelter and a place for people to gather and meet. Talk about the various parts of the tree: the trunk, roots, branches, leaves, fruits, nuts, or birds living in the trees.

1. Allow some time for the client to describe what is currently happening in his or her life (i.e. why he or she came here today to talk with you). Ask the person to tell you about the main problem or issue he or she is having—when it started, how it developed, and how he or she feels about it. Let the person know you would like to work together in finding something that he or she can do to make the situation better. Write a brief description of what is happening under "What is the main issue for this client" on the left-hand side of the tree.
2. Ask the client what he or she thinks is causing the problem/issue and write this under "What is the cause of this issue?"
3. Ask the client to imagine him- or herself as a tree—the roots are "*where you come from, your home, your family, and your community.*" The roots are "*what supports and grounds you.*" Ask the client who provides him or her with the most support in life and who can help him or her resolve this issue. Write this information under "family, peers, and community" in the roots of the tree.
4. Next move to the trunk. The trunk is the client's "*hope for the future, a future goal, or dream.*" Write the goal on the trunk of the tree. Encourage the client to close his or her eyes and think about him- or herself in the future, achieving her goal. Ask: "*What are you doing in that picture?*"
5. The branches are the client's options, the ways he or she copes, and potential solutions (i.e. things he or she can do to achieve the hope or goal). Talk about the benefits and consequences of each option. Encourage the person to think about strategies that have worked in the past. Write these on the branches. Then talk about all the person's resources—the "*things you have going for you,*" like inner strengths, talents, skills, and spiritual resources to help in coping.
6. Then ask: *"What is the next step in achieving your goal or hope for the future?"* Help the client form an action plan of immediate next steps.
7. Lastly, summarize the main points that were discussed during the Peer Education session (example: disclosure to partner) and, if necessary, talk about any referrals or arrange another time to talk
8. Review and discuss the client's situation and "next steps" with the program supervisor or a member of the multidisciplinary care team.

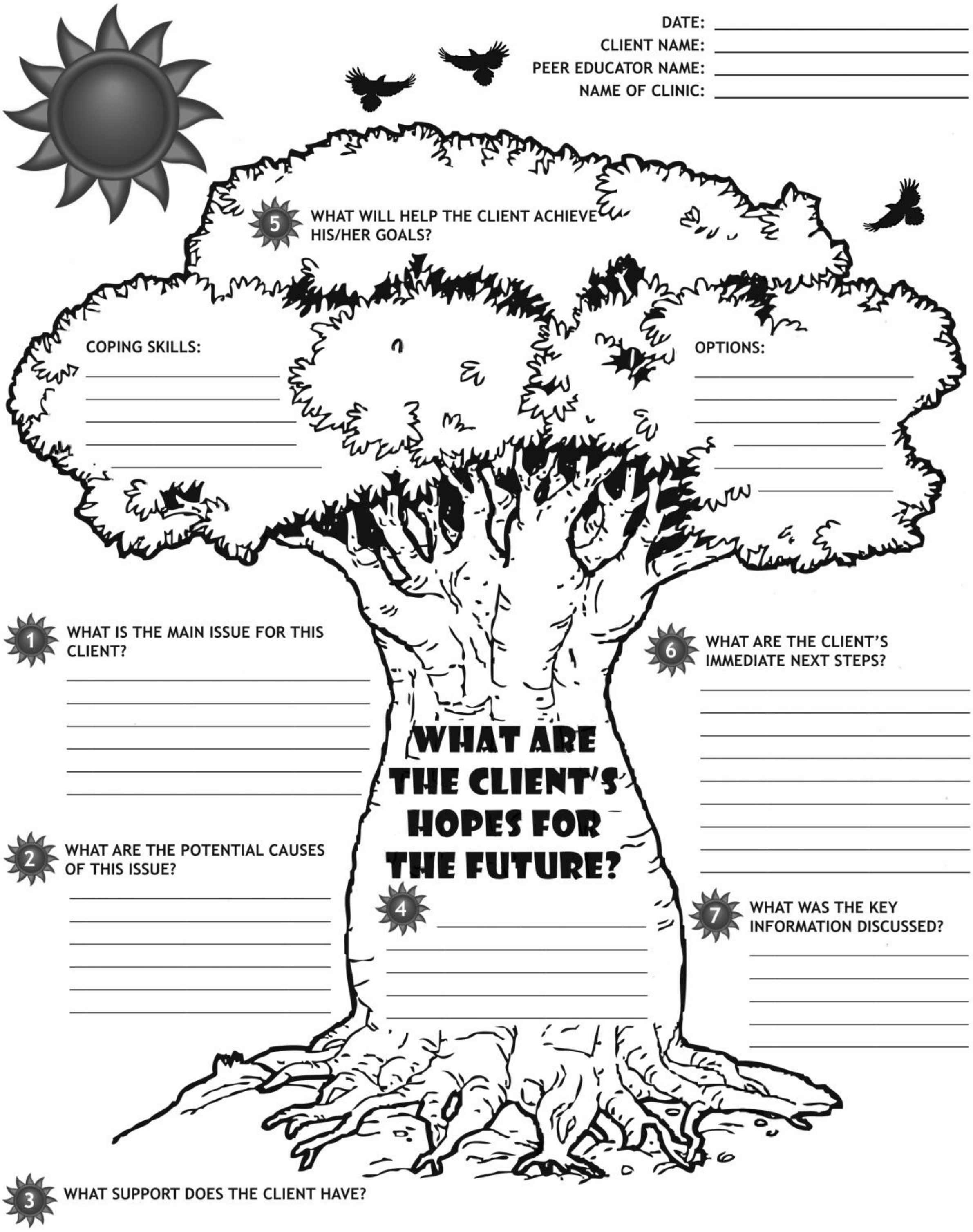
TALKING TREE

DATE: ____________________

CLIENT NAME: ____________________

PEER EDUCATOR NAME: ____________________

NAME OF CLINIC: ____________________



5 WHAT WILL HELP THE CLIENT ACHIEVE HIS/HER GOALS?

COPING SKILLS:

OPTIONS:

1 WHAT IS THE MAIN ISSUE FOR THIS CLIENT?

6 WHAT ARE THE CLIENT'S IMMEDIATE NEXT STEPS?

WHAT ARE THE CLIENT'S HOPES FOR THE FUTURE?

2 WHAT ARE THE POTENTIAL CAUSES OF THIS ISSUE?

4

7 WHAT WAS THE KEY INFORMATION DISCUSSED?

3 WHAT SUPPORT DOES THE CLIENT HAVE?

FAMILY:

PEERS:

COMMUNITY:

APPENDIX 4C: Communication Skills Checklist

	Counseling and Communication Skills		
	Skill	**Specific Strategies, Statements, Behaviors**	**(√)**
Establishing the Relationship	**Skill 1: Use helpful non-verbal commun-ication**	• 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)	
Understanding the Client's Needs	**Skill 2: 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.	
		• Allow the client to express emotions.	
		• Do not interrupt.	
		• Other (specify)	
	Skill 3: Ask open-ended questions	• Use open-ended questions to get more information.	
		• Ask questions that show interest, care, and concern.	
		• Ask questions to clearly understand the client's problems	
		• 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 person 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)	
Creating an Action Plan and Ending the Session	**Skill 7: Help your client set goals and summarize each session**	• Work with the client to come up with realistic "next steps"	
		• Summarize the main points of the Peer Education 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 AND ART

LEARNING OBJECTIVES:

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

- Define comprehensive HIV care for ALHIV
- Describe the key components of comprehensive HIV care for ALHIV and the importance of each
- Discuss some common medical problems for ALHIV, including opportunistic infections (OIs), and ways to prevent them
- Describe the goals and benefits of ART
- Explain who needs ART and when someone should start ART
- List some of the common ART regimens and side effects of ARVs
- Discuss internal and external referrals

CONTENT:

Session 5.1: Introduction: What is Comprehensive HIV Care?

Session 5.2: Prevention and Treatment of Illnesses Common Among ALHIV

Session 5.3: Understanding ART: Who, What, When, Why, and How?

Session 5.4: The Importance of Referrals in Comprehensive HIV Care

Session 5.5: Classroom Practicum on Comprehensive HIV Care and Treatment

Session 5.6: Module Summary

SESSION 5.1: What is Comprehensive HIV Care?

Comprehensive care for ALHIV includes:

- Provision of ART, including adherence monitoring and support
- Prevention, diagnosis, and treatment of opportunistic infections (OIs) and other illnesses, like tuberculosis
- Treatment for diarrhea and malaria
- PMTCT and antenatal care
- Sexual and reproductive health care
- Positive living and positive prevention counseling
- Psychosocial assessment, counseling, and support, including for disclosure
- Nutritional counseling and support
- Ongoing monitoring of health status through lab tests and physical exams
- Immunizations
- Informational materials on HIV, prevention, treatment, adherence, positive living, and legal rights
- Effective referral systems with follow-up, including linkages with family, community, NGO, and youth services (e.g. education, material support, food, income-generation activities), as well as legal services
- Services to support the transition to adult care
- Education, care, and support for family members/caregivers/parents (discussed throughout this curriculum, see pediatric guidelines for more information)

There is a lot people with HIV can do to stay healthy (care), even if they are not on ART (treatment). As part of their care, all ALHIV should come to the clinicfor regular checkups, tests, counseling, and medicines to help prevent medical problems, including OIs, and to stay healthy.

Also, if people come back to the clinic regularly for CD4 testing and checkups, they can start ART right away if they become eligible. In some places, people think that ART is only for very sick and dying people, but this is not true. **Starting ART as soon as possible once eligible lowers the chances that a person will become very sick and die.**

All ALHIV need care, and many (but not all) also need treatment with ART. Once a person tests positive for HIV, he or she should be enrolled in the care program at the hospital or clinic and should also be linked to needed community resources. Over time, the person will probably also need to be enrolled in treatment, which should begin as soon as possible once he or she is eligible.

My notes:

The goals of comprehensive HIV care are to:

- Reduce HIV-related illness and death among ALHIV
- Improve the health and quality of life of ALHIV
- Improve the lives of families and communities affected by HIV
- Prevent further spread of HIV

The Importance of One-Stop Shopping for ALHIV

- Offering all of the services ALHIV need together under one roof (sometimes called "one-stop shopping") and making sure that services are youth-friendly will increase adolescent clients' ability to access and get all the benefits from these services over time.

The Importance of Family-focused Care

Family-focused care means that all members of the multidisciplinary care team, including Peer Educators, think about the needs of all family members (not just those of the adolescent client). It also means thinking about the connections between the individual client, their family, and the community as a whole. You should make it a normal practice to ask clients about their family members, other household members, close ties or friends, and partners. They should also encourage clients to bring these people to the clinic for services if needed.

Clinical and Laboratory Monitoring Schedule for ALHIV (fill in as a group, according to your national guidelines)

	How often should these ALHIV come to the clinic?	**What will the nurse or doctor do at these visits?**	**What lab tests will ALHIV need at these visits?**	**What other services will ALHIV need?** (counseling, adherence support, medicine pick up, etc.)
ALHIV not eligible for ART				
ALHIV starting ART				
ALHIV - first 3 months on ART				
ALHIV stable on ART (more than 3 months)				

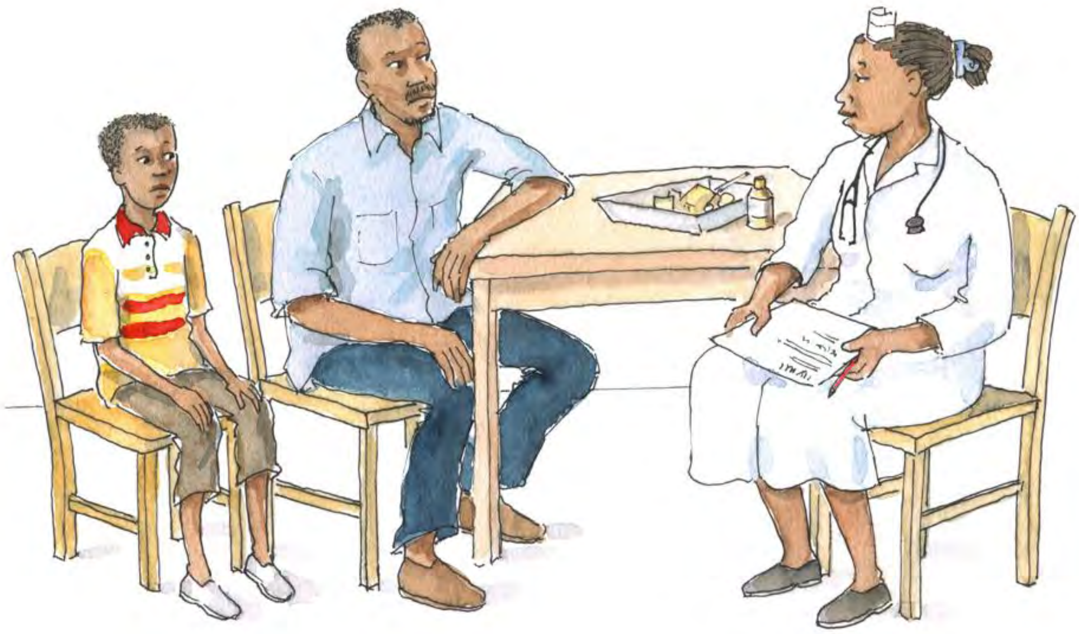
ALL ALHIV need lifelong HIV care! You play a big part in motivating youth to enroll in and STAY in HIV care services, even if they are feeling healthy and not on ART. Remember that comprehensive care includes families, partners, friends, and other community members, so it is important for you to ask about them at every visit!

SESSION 5.2: Prevention and Treatment of Illnesses Common Among ALHIV

ALHIV may experience a number of illnesses and problems, especially if they are not on ART or if they have adherence challenges. You can help ALHIV understand, prevent, and seek treatment for these illnesses.

Opportunistic infections:

- Opportunistic infections, or OIs, are the infections that make ALHIV sick because their body's immune systems are weakened and cannot fight back. ALHIV, especially people not on ART, can get many OIs.



Some illnesses, problems, complications, and symptoms common among ALHIV (You should always talk with the health providers if any of their peers have these kinds of problems):

LUNG PROBLEMS

Tuberculosis (TB) is the most common OI among PLHIV, usually affecting the lungs. Adolescents are very susceptible to TB because they are growing quickly.

Signs and symptoms:	Cough, fever, weight loss, night sweats
Prevention:	Cover mouth with a tissue or handkerchief when coughing or sneezing, keep windows open, and try to keep younger adolescents and children away from people with active TB. In some countries, doctors give preventative medicines to adults or young children who have been exposed to someone with active TB.
Treatment:	Usually 6-9 months of daily medicine

Pneumonia is a serious lung infection that often affects PLHIV. There are many kinds of pneumonia, but bacterial pneumonia and PCP (*Pneumocystis jiroveci* pneumonia) are the most common among PLHIV.

Signs and symptoms:	Coughing, weakness, and shortness of breath. PCP comes on slowly whereas bacterial pneumonia comes on suddenly. Bacterial pneumonia is usually not as serious or life-threatening as PCP.
Prevention:	Take cotrimoxazole (CTX) and wash hands with soap before eating and after using the toilet.
Treatment:	A doctor will prescribe antibiotics and sometimes oxygen.

MOUTH PROBLEMS

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. ART will usually prevent thrush and other mouth problems by keeping the immune system strong.

Treatment: Rinse the mouth with salt water, lemon juice, or gentian violet solution (dark blue crystals). Doctors may prescribe antifungals, antibiotics, or antivirals.

SKIN PROBLEMS

Skin problems may be due to thrush, warts, bacterial infections, shingles, allergies, pressure sores, Kaposi's sarcoma (a form of cancer), or many other causes.

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 soothe itching, use gentian violet solution to help clean the skin, use hydrogen peroxide to clean wounds and sores, use safe local remedies. Doctors may prescribe antibiotics or other medicine.

GENITAL PROBLEMS

Most genital problems are the result of sexually transmitted infections (STIs). Common STIs, including chlamydia and gonorrhea, will be discussed in more detail in *Module 10*.

Signs and symptoms:	Sores or rash in the genital or anal areas, unusual discharge from the penis or vagina, pain during urination. Sometimes there are no symptoms, especially in women.
Prevention:	Practice safer sex, use condoms, avoid sex if you or your partner have an STI
Treatment:	The doctor may prescribe antibiotics, depending on the type of STI. Do not have sex while treating an STI, take all medicines, and have all partners treated as well.

GASTRO-INTESTINAL PROBLEMS

PLHIV may have diarrhea frequently, which can lead to dehydration and weight loss.

Signs and symptoms:	Frequent loose, watery stools, stomach cramps, stomach pain, fever, bleeding, lightheadedness or dizziness from dehydration, poor growth, weight loss
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
Treatment:	Drink a lot of clear fluids, eat soft foods that are not spicy or greasy, increase food intake. Doctors may prescribe medicine if the diarrhea continues for a long time.

LIVER PROBLEMS

Hepatitis B virus infection is a serious liver infection that can lead to liver dysfunction, liver cancer, and death. It is spread through unsafe sex, through sharing contaminated needles, and from mothers to their babies.

Signs and symptoms:	Some people have no symptoms while others may feel tired; may 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 using contaminated needles; avoid body piercing and tattoos
Treatment:	Doctors may prescribe medicines to treat Hepatitis B infection (some of the same medicines used to treat HIV are also used to treat Hepatitis B).

Note: There are other types of Hepatitis, including Hepatitis A and Hepatitis C. Hepatitis C is often associated with intravenous drug use and can cause serious, chronic liver disease. Hepatitis A is usually less serious and resolves on its own.

BRAIN PROBLEMS

Encephalopathy and central nervous system disease – HIV can affect the brain, resulting in problems with brain function (memory, learning, understanding) as well as motor function (walking, moving, etc). Encephalopathy, a severe form of brain disease, is common in young children with perinatal HIV infection who do not get treatment.

Signs and symptoms: Depending on the type of brain disease, common symptoms are loss of memory; problems with learning, motor skills; and concentration; and depression.

Prevention: Taking ART

Treatment: Doctors will provide specific instructions for care, treatment, and rehabilitation, such as physical or occupational therapy.

My notes:

CANCERS

Lymphoma - Cancer of the lymphatic system can affect PLHIV. The lymphatic system helps defend the body against germs like viruses, bacteria, and fungi that can cause illnesses.

Kaposi sarcoma (KS)(see skin problems) – Cancerous lesions (sores, spots) on the skin and/or organs caused by blood vessels growing incorrectly.

Signs and symptoms: Kaposi sarcoma usually looks like pink or purple painless spots on the surface of the skin or in the mouth. It can also appear in the intestines, lymph nodes, and lungs, and it can attack the eyes. Lymphoma usually causes swollen glands and tumors in the chest or abdomen.

Prevention: Taking ART

Treatment: Doctors will provide specific instructions for care and treatment.

Cervical cancer is a common cancer in women, and especially females living with HIV. It usually develops very slowly. Almost all cervical cancers are caused by HPV (human papilloma virus). HPV is a common virus that is spread through sexual intercourse. It starts as a precancerous condition that can be detected by a Pap smear and is 100% treatable. This is why it is so important for young women to get regular Pap smears or other special tests that may be available.

Signs and symptoms: Most of the time, early cervical cancer has no symptoms. Symptoms that may occur include: abnormal vaginal bleeding between periods or after intercourse, unusual vaginal discharge, or heavier periods that last longer than usual.

Prevention: Routine screening for sexually active females can identify those with pre-cancerous cells so that they can be treated and monitored before more serious disease develops. A vaccine to prevent cervical cancer is now available in some places. Using condoms also reduces a person's risk of HPV and other sexually transmitted diseases.

Treatment: The doctor may prescribe treatment and may surgically remove the cancer. There is a vaccine to prevent HPV infection, but it is not yet widely available.

Cotrimoxazole (CTX)

Cotrimoxazole, sometimes shortened to CTX, is an antibiotic medicine (not an ARV) important in the care of ALHIV:

- If taken the right way, every day, CTX can help prevent many dangerous and life-threatening infections among ALHIV, including pneumonia and many others.
- When a person takes medicines to prevent infections from happening in the first place, we call this prophylaxis. Peer Educators may hear the phrase CTX prophylaxis in the clinic.
- Some adolescents who are not yet taking ART need to take CTX every day. Health care workers will decide based on the adolescent's CD4 count and the stage of his or her illness.
- ALL adolescents who are taking ART should also be taking CTX every day.
- It is very important that adolescents taking CTX adhere to this medicine because it will help prevent illnesses and infections and will help them stay healthy.
- You can remind clients about why it is so important to take CTX every day, can make sure clients know it is safe, and can help support clients' adherence to CTX over time.

There is a lot you can do to help ALHIV understand, prevent, and seek immediate care and treatment for illnesses and other problems. Remember: safer sex; good adherence to care, CTX, and ART; and getting vaccinations help prevent a lot of these illnesses from happening in the first place!

My notes:

SESSION 5.3: Understanding ART: Who, What, When, Why, and How?

When on ART, we take a combination of 3 or more ARVs from at least 2 different classes of drugs. This is because each medicine does something different in the body. There are different ARV medicines that:

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

How does ART work?

As we learned, HIV attacks the body's immune system and CD4 "guardian angel" cells. HIV goes into the CD4 cells and reproduces itself to make more of the virus.

When a person takes ART the right way, every day, for life, it helps CD4 cells fight against 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:

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

What is the difference between ARVs and ART?

Antiretrovirals (ARVs) are the drugs or medicines that people take to fight HIV. Antiretroviral therapy (ART) is the overall HIV treatment that is usually made up of a combination of 3 or more ARVs.

Who needs ART?

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

For ALHIV to start ART, they must have an HIV-positive test result and they must meet clinical and/or immunologic (CD4 cell) criteria. Check your national guidelines.

Client readiness for ART (check your national ART guidelines):

It is important that a client be ready to start taking ART. *Module 6* contains more on adherence preparation and support, but listed here are some of the key issues that should be addressed before a person starts ART. Remember, these are not all required for a person to start ART, but are highly recommended to help the person be ready. Sometimes, when a person is very sick or has a very low CD4 count, the most important thing is that he or she start treatment right away to prevent death.

It is important that a client:

- Wants ART and is committed to taking it correctly
- Has received pre-ART education and counseling (there is more on this in *Module 6*)
- Understands that ART is a lifelong commitment
- Understands possible side effects and how to manage them
- Has an adherence plan
- Has support to address any psychosocial barriers to adherence
- (*For younger adolescents)* Has a caregiver(s) who shows "readiness"—the caregiver(s) understands, accepts, and supports the child's HIV care and treatment
- Will accept a phone call or home visit from a Peer Educator, community health worker, or health care provider if he or she misses an appointment at the clinic

My notes:

Common ART regimens for adolescents (adapt to your national ART guidelines):

Common regimens	Drug name and dose		Timing	Possible side effects
AZT+3TC+NVP AZT+3TC+EFV TDF+3TC+NVP TDF+3TC+EFV TDF+FTC+NVP TDF+FTC+EFV d4T+3TC+NVP* d4T+3TC+EFV* *No longer recommended as first-line therapy, but still in use in many places	**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
	3TC	lamivudine 150 mg	Twice daily or every 12 hours	Stomach pain, nausea, numbness or tingling in hands and feet, vomiting
	FTC	emtricitabine 200 mg	Once daily	Diarrhea, headache, nausea, rash
	NVP	nevirapine 200 mg	Once daily for 14 days, then twice daily or every 12 hours	Nausea, headache, vomiting, fever, rash. **Rashes can be very serious—see a doctor right away.**
	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 during first trimester of pregnancy.	Rash, nausea, dizziness, diarrhea, headache, sleeplessness, bad dreams
	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. If person has numbness in hands or feet, should see a doctor.

Note: In the case of younger adolescents, dosing of ARVs depends on their weight and age.

Changing brands, shapes, sizes, and packaging

- Sometimes clients may have to switch brands of the same medicine, depending on what is available in the country.
- This can be hard for clients because the shape, size, packaging, and dosing of the medicine may change, even though they are still on the same regimen.
- Peer Educators should work with the pharmacist so they always know of any drug changes. This way they can help clients prepare for this change and make sure their adherence is kept up.

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

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

- 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 sometimes not right away.
- The body needs 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. During this time, clients still need to take their medicines the right way, every single day.
- There is a difference between minor side effects that will go away (where the client should keep taking the medicines) and more serious side effects that mean the person should see doctor or a nurse right away.
- Some minor side effects of ARVs can be nausea, vomiting, headaches, and diarrhea. These are usually not serious and will go away in a couple of weeks.
- A person should never make the decision alone to stop taking some or all of his or her medicines. He or she should only stop taking any medicines after speaking with health care workers at the ART clinic.
- If a client is having problems with taking ARVs, he or she should come to the clinic right away.
- A client should always be asked if he or she is having any side effects to the medicines and should always be ready to tell the doctor or nurse about them.

Some important ARV side effects 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; if the skin is peeling, looks infected (for example, has pus), is blistering, or has open sores; if the client has a fever; or if the rash is in the eyes or mouth
    - **If client is taking NVP and has any kind of rash, call or see the doctor or nurse right away**

Numbness or tingling feelings:

- Can be caused by taking d4T, ddI, other ARVs, TB medicines, or because of an infection. Can also be caused by diabetes or drinking too much.
- **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
    - Tell the doctor or nurse if numbness/tingling starts. There are some medicines that may be able to help.

My notes:

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, greasy, and fatty foods
  - Stay away from very spicy foods
  - Drink a lot of clean, boiled water, weak tea, or lemon water
  - Do not drink too much coffee or strong tea
  - Stop using traditional medicines that may be making things worse
  - **See the doctor or nurse if client has a fever, is vomiting excessively, cannot drink, has stomach pains, is dehydrated, or feels very confused**

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 client's headache does not go away with paracetamol or if he or she has a 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, and 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 client's diarrhea, if the client has 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 client 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 Peer Educators, friends, or family members
  - **See the doctor or nurse if client feels really depressed or wants to hurt him- or herself**

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 client has a drug or alcohol problem or feels 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 know about. These include:

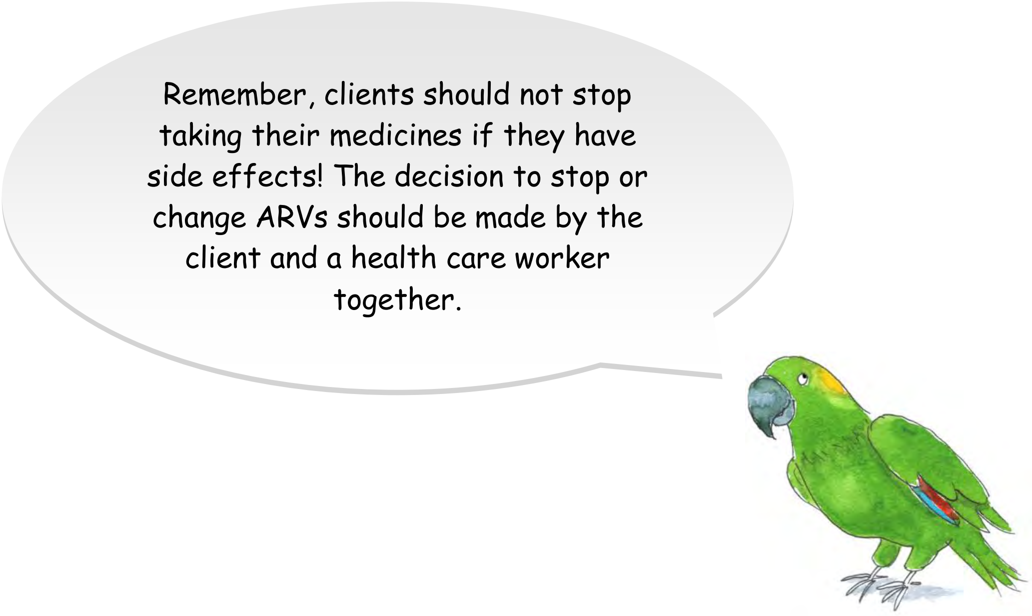
- Changes in body shape, which is a long-term side effect that can be caused by ART (especially regimens with d4T). Some PLHIV may develop more fat on their stomach, breasts, or other areas and they may lose fat in their face, arms, and legs.
- A build-up of lactic acid in the body, which can cause weakness, nausea, and other symptoms
- Increased fat and sugar levels in the blood
- Changes to different organs in the body, but this is rare
- **You can advise clients to:**
  - Eat well and exercise
  - Discuss any changes in their bodies with the doctor or nurse (there may be medicines that can be given to limit these changes)
  - Go to all of their clinic visits and get lab tests on schedule
  - Continue taking the ARVs

My notes:

Serious Side Effects that Require Immediate Care at a Health Facility

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

- A red rash that is getting worse
- A rash in the eyes or mouth
- A severe headache with a stiff neck
- A 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 diarrhea with blood in it
- Problems breathing
- Severe abdominal pain
- Dehydration or cannot drink
- Blurry vision
- Depression or thoughts of suicide
- A lot of confusion
- Seizures or convulsions



SESSION 5.4: The Importance of Referrals in Comprehensive HIV Care

Referring:

- No one person or organization can provide a person and his or her family with all of the needed comprehensive care and support services. That is why it is important to have a strong referral system in place.
- Making a referral means that you formally send a person and/or family members to another place in the hospital, another health facility, or another organization for services. There are two basic kinds of referrals:
    - **Internal referrals** are from one part of the health facility to another part of the same health facility (for example, from the VCT to the ART clinic or from the PMTCT unit to the ART clinic).
    - **External referrals** are from the facility to a community organization or from a community organization to the health facility (for example, a Peer Educator refers a person to a ALHIV support group or a home-based care worker refers a client to the hospital to get a CD4 test).
- Peer Educators play an important role in both internal and external referrals.
- The **"referral network"** should include organizations and people in a defined geographical area that provide services and support needed by ALHIV, their caregivers, and their families.

Helping people get from place to place in the health facility:

ALHIV often need different services at the hospital or health facility on the same visit. This can be very overwhelming for people who do not know 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. A key role of yours is to help adolescent clients get from one place to another within the health facility 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. Depending on the health facility's referral policy, certain groups of clients will be "priority referrals," like pregnant adolescents, adolescents initiating ART, etc.
- Make sure you know which days and which hours during the day different services are offered; where each service is at the hospital or clinic; and the fastest way to get there. It is helpful to walk around the facility alone first and then you will be able to better help clients.
- Make sure you know where people are being referred and why. What services do they need when they get there? For example, if someone is being referred to the lab, what tests does he/she need?
- It is best if there is a referral form where the doctor or nurse writes exactly why someone is being referred. You should be familiar with any referral forms used at the health facility.
- Tell health care workers when you think a client needs to be referred. You may have knowledge about clients' social support needs that other members of the multidisciplinary team are not aware of.
- You should help people understand why they are being referred and why it is important to get these services. People often do not understand why they have been referred and sometimes just leave. This is common with referrals from PMTCT services to ART services.
- If possible, walk with the person to the other part of the hospital or health center and make sure that he/she has a comfortable place to wait.
- You should wait with the person at the referral point. This is a good time to provide education and support.
- To decrease waiting time, you should tell staff that the client is waiting and talk with the doctor or nurse to try and get the person seen as soon as possible. This is especially important if the client is pregnant. One of the biggest reasons why people do not get care is because they do not want to wait a long time.
- If people need other services or need to get more referrals, stay with them until they leave the health facility. Continue to explain why each service is important and walk them from place to place.

My notes:

SESSION 5.5: Classroom Practicum on Comprehensive HIV Care and Treatment

Phases of a Peer Education Session (review from *Module 4)*
There are 4 main stages or phases in the process of a counseling session:

1. Establishing the Relationship
2. Understanding the Client's Needs
4. Creating an Action Plan
5. Ending the Session

There are 7 essential communication skills that Peer Educators should practice and use in their work (review from *Module 4*):

Skill 1: Use helpful non-verbal communication.
Skill 2: Actively listen and show interest in your client.
Skill 3: Ask open-ended questions.
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 Peer Education session.

Remember, when helping clients to set goals and to decide on "immediate next steps":

- You help the client by making sure that he or she is able to make care and treatment decisions based on options, information, and understanding.
- It is the client's responsibility to act on the information once he or she clearly understands it.

Case Studies for discussion:

Case Study 1

L___ is an 18-year-old female who recently started ART. She complains that she is feeling very tired, has frequent headaches, and often feels nauseous. She thinks that her ARVs are making her sick and wants to stop taking them. She has come to you and the nurse for advice.

What would you say to L___?

Case Study 2

N___ is a 14-year-old who was diagnosed with HIV last year and who is eligible to start ART. N___ often misses her appointments at the clinic and when she does come, her aunt (who cares for her) does not usually come with her. N___ sometimes gets annoyed with you for asking so many questions and says she doesn't like to share her business with everyone. She also says that she doesn't like coming to the clinic because she is afraid that she will see someone she knows. And anyway, she says, she feels good and doesn't need treatment.

What would you say to N___?

Case Study 3

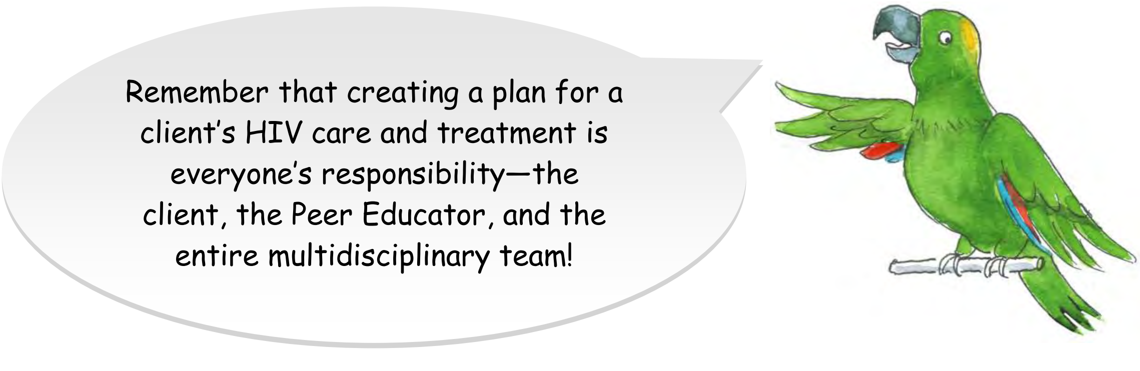
D___ is an 11 year old on ART who lives with a family member with TB. His mom brings him to the clinic because he has been coughing and has a fever. She tells you and the nurse that she is worried that he will catch TB.

What would you say to D___ and his mom?

Case Study 4

S___ is an 18 year old who is not yet eligible for ART. She tells you that she sees no point in coming back to the clinic because this is an ART clinic and she doesn't need ART.

What would you say to S___?



My notes:

Note: Some of the preceding information in this Module was borrowed and/or adapted from the following sources:

Colton, T., Costa, C., Twyman, P., Westra, L., & Abrams E. (2009). *Comprehensive peer educator training curriculum, Trainer manual, Version 1.0*. New York: ICAP.

Community Media Trust. *Siyayinqoba Beat It! - HIV Prevention and Treatment Literacy Manual*. Retrieved from http://www.beatit.co.za/treatment-information-download-workbooks/index

WHO/UNICEF. (2008). *Global consultation on strengthening the health sector response to care, support, treatment and prevention for young people living with HIV*. Geneva, Switzerland: WHO/UNICEF.

SESSION 5.6: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- All ALHIV should be enrolled in care!
- Peer Educators should counsel all ALHIV 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 ALHIV include: checkups by health care workers, preventing and treating OIs (especially by taking CTX), regular CD4 tests, 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 means clients can be identified and started on treatment as soon as they are eligible, instead of waiting until they are very sick.
- OIs attack the body when the immune system is weak.
- One of the best things ALHIV can do to stay healthy is to prevent OIs and other complications by living positively, by 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 illnesses among PLHIV.
- ARVs are antiretroviral medicines used to fight HIV.
- ART means antiretroviral treatment, which is the overall HIV treatment and is usually made up of a combination of 3 or more ARVs.
- 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.
- Some people on ART have side effects that make them feel badly. 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.
- Peer Educators play a key role in referring clients for services, in helping them understand why they are being referred, and in taking them to the referral point when possible.

APPENDIX 5A: Talking Tree

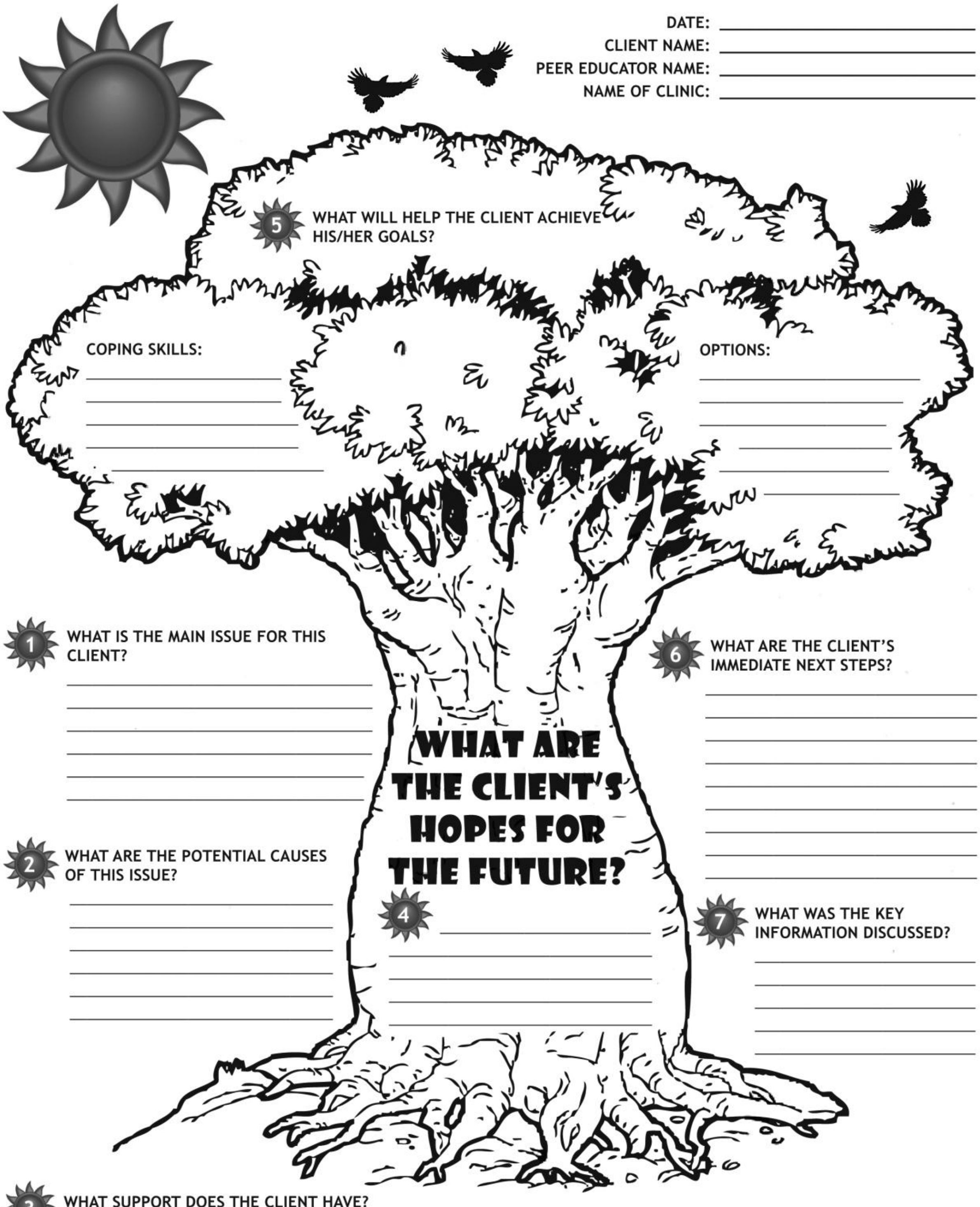
Instructions for the Talking Tree: Each instruction below goes with a number on the Talking Tree. The Peer Educator should follow these instructions in order.

Begin by explaining that the African Baobab tree is one of the longest-living and largest trees on Earth. It symbolizes survival and life because it sometimes grows in harsh conditions. It also symbolizes protection and sharing because it can be used as shelter and a place for people to gather and meet. Talk about the various parts of the tree: the trunk, roots, branches, leaves, fruits, nuts, or birds living in the trees.

1. Allow some time for the client to describe what is currently happening in his or her life (i.e. why he or she came here today to talk with you). Ask the person to tell you about the main problem or issue he or she is having—when it started, how it developed, and how he or she feels about it. Let the person know you would like to work together in finding something that he or she can do to make the situation better. Write a brief description of what is happening under "What is the main issue for this client" on the left-hand side of the tree.
2. Ask the client what he or she thinks is causing the problem/issue and write this under "What is the cause of this issue?"
3. Ask the client to imagine him- or herself as a tree—the roots are "*where you come from, your home, your family, and your community.*" The roots are "*what supports and grounds you.*" Ask the client who provides him or her with the most support in life and who can help him or her resolve this issue. Write this information under "family, peers, and community" in the roots of the tree.
4. Next move to the trunk. The trunk is the client's "*hope for the future, a future goal, or dream.*" Write the goal on the trunk of the tree. Encourage the client to close his or her eyes and think about him- or herself in the future, achieving her goal. Ask: " *What are you doing in that picture*?"
5. The branches are the client's options, the ways he or she copes, and potential solutions (i.e. things he or she can do to achieve the hope or goal). Talk about the benefits and consequences of each option. Encourage the person to think about strategies that have worked in the past. Write these on the branches. Then talk about all the person's resources—the "*things you have going for you,*" like inner strengths, talents, skills, and spiritual resources to help in coping.
6. Then ask: *"What is the next step in achieving your goal or hope for the future?"* Help the client form an action plan of immediate next steps.
7. Lastly, summarize the main points that were discussed during the Peer Education session (example: disclosure to partner) and, if necessary, talk about any referrals or arrange another time to talk
8. Review and discuss the client's situation and " next steps" with the program supervisor or a member of the multidisciplinary care team.

TALKING TREE

DATE: ______________________
CLIENT NAME: ______________________
PEER EDUCATOR NAME: ______________________
NAME OF CLINIC: ______________________



5 WHAT WILL HELP THE CLIENT ACHIEVE HIS/HER GOALS?

COPING SKILLS:
____
____
____
____
____

OPTIONS:
____
____
____
____
____
____

1 WHAT IS THE MAIN ISSUE FOR THIS CLIENT?
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____
____
____
____
____

6 WHAT ARE THE CLIENT'S IMMEDIATE NEXT STEPS?
____
____
____
____
____
____
____
____
____

WHAT ARE THE CLIENT'S HOPES FOR THE FUTURE?

2 WHAT ARE THE POTENTIAL CAUSES OF THIS ISSUE?
____
____
____
____
____
____

4 ______________________
____
____
____
____

7 WHAT WAS THE KEY INFORMATION DISCUSSED?
____
____
____
____
____

3 WHAT SUPPORT DOES THE CLIENT HAVE?

FAMILY:	PEERS:	COMMUNITY:
______________	______________	______________
______________	______________	______________
______________	______________	______________
______________	______________	______________

MODULE 6: SUPPORTING ADHERENCE TO HIV CARE AND TREATMENT

LEARNING OBJECTIVES:

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

- Define retention, adherence to care, and adherence to medicines
- Discuss the importance of adherence in HIV prevention, care, and treatment programs for ALHIV
- Describe common factors affecting retention and adherence to care and medicines among ALHIV of different ages and developmental stages
- Provide basic adherence preparation support and education to ALHIV and caregivers
- Help ALHIV and caregivers come up with practical adherence strategies and solutions
- Provide ongoing follow-up adherence support to ALHIV and their caregivers

CONTENT:

Session 6.1: Introduction: What Do We Mean by Adherence and Why is it Important for ALHIV?
Session 6.2: Common Challenges to Retention and Adherence for ALHIV
Session 6.3: Helping ALHIV and Caregivers Prepare for and Adhere to ART
Session 6.4: Providing Ongoing Adherence Support to ALHIV
Session 6.5: Classroom Practicum on Adherence Support
Session 6.6: Module Summary

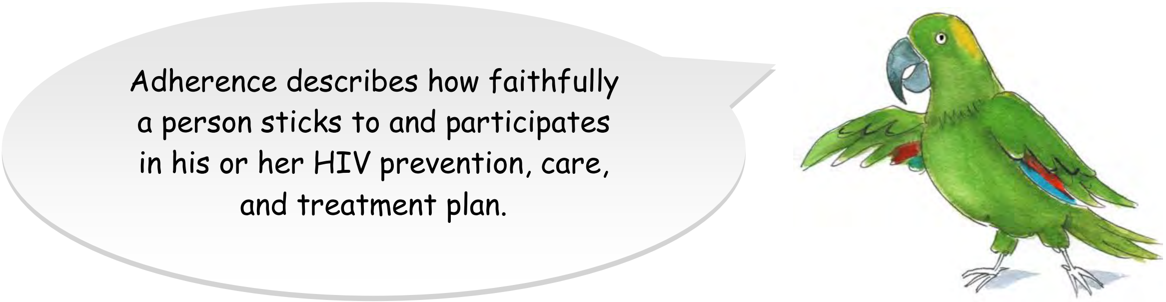
SESSION 6.1: Introduction: What Do We Mean by Adherence and Why is it Important for ALHIV?

Retention:

- Retention refers to keeping (or "retaining") clients in the care program. In this case, that means that all ALHIV continue with lifelong HIV care and treatment services. A goal of all HIV care and treatment programs is to retain clients in the full program of care.
- Retaining clients in care is the responsibility of the health care team. We need to do all that we can and set up services and systems that help retain young clients in care.

Definition of adherence:

The standard clinical definition of adherence has been when a person takes more than 95% of his or her medicines the right way, at the right time. Over time, this definition has been broadened to include more factors related to continuous care, like following a care plan, going to scheduled clinic appointments, picking up medicines on time, and getting regular CD4 tests.



Adherence:

- Includes active client (and caregiver) participation in the client's care plan
- Includes adherence to both medicines and care
- Depends on a shared decision-making process between the client (and caregivers) and health care providers
- Determines the success of HIV prevention, care, and treatment programs
- Is not static—in other words, it changes over time, as ALHIV age and as they go through different developmental stages and life changes

Adherence to care includes:

- Starting and continuing on a lifelong care and treatment plan
- Going to appointments and tests as scheduled, like regular CD4 tests
- Taking (or giving) medicines to prevent and treat opportunistic infection (OIs)
- Participating in ongoing education and counseling
- Picking up medicines 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
- Living a healthy lifestyle and trying to avoid risky behaviors

Adherence to treatment includes:

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

My notes:

Non-adherence includes:

- Missing one or many appointments at the hospital or health center, lab, or pharmacy
- Not following the care plan
- Missing a dose or doses of medicine
- Sharing medicines with other people
- Stopping medicine for a day or many days, or taking a "treatment break" or "holiday"
- Taking medicines at the wrong times
- Taking medicines without following instructions about food or diet

Remember, no one is perfect. It is important not to judge clients (and caregivers) if they are non-adherent. Instead, we should try to understand why people do not adhere and help clients and caregivers find ways to start having good adherence again as soon as possible.

Why is near-perfect adherence to HIV care and treatment important?

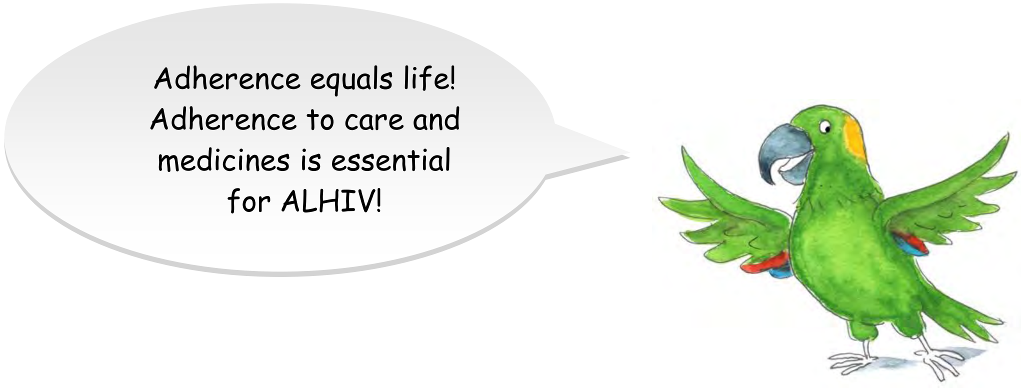
- To make sure that ART and other medicines do their job
- To increase the CD4 cell count and decrease the amount of HIV in the body
- To make sure the virus does not become resistant to certain medicines
- To make sure people get all the benefits that medicines and ARVs have to offer, like feeling better, not getting as sick, and not getting sick as often
- To prevent mother-to-child transmission of HIV
- To reduce the risk of spreading the virus to others
- To monitor people's health and also to help them find community support resources
- To keep people looking and feeling good so they can get back to "normal" life, including going to school, working, socializing, and being an active family and community member
- To prevent sickness and death
- To keep children and adolescents growing and developing
- To keep families and communities healthy and productive

What happens when a person does not adhere to their medicines?

- The levels of drugs in the body go down and HIV keeps multiplying (making more of itself).
- The CD4 cell count will go down and the person will start getting more OIs.
- The person is more likely to pass HIV to an uninfected person.
- Children in particular will become ill very quickly. Many children living with HIV will die without ART.
- Children and adolescents may not grow or develop well.
- A mother is more likely to pass HIV to her child during pregnancy, delivery, or breastfeeding.
- The viruscan 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 the person may have to start taking a new regimen or second-line ARVs. But, there might not be many kinds of these ARVs available so poor adherence can decrease future treatment options.

DRUG RESISTANCE

- When the virus develops **drug resistance** to one or all of the ARVs he or she is taking, it means that the drugs have stopped working and will not work anymore, even if they the person takes them correctly again.
- Drug resistance is one of the main reasons why ART fails!
- HIV is a very "intelligent" virus—it only takes a couple of missed doses for it to become resistant and to learn how to be stronger than the ARVs, to multiply, and take over the body again.
- **NEVER STOP TAKING YOUR ARVS, UNLESS YOUR DOCTOR TELLS YOU TO!**



My notes:

SESSION 6.2: Common Challenges to Retention and Adherence for ALHIV

Some of the common factors affecting retention and adherence for adolescents

Things about individual people than can affect adherence:

- Some adolescents are going through a rebellious stage and want to define who they are. They may take more risks and probably have a desire to "fit in" with peers and to appear "normal." All of these factors can have a negative effect on their adherence to care and medicines.
- Older adolescents may feel self-conscious about taking medicine.
- The level of stigma and discrimination from peers, family, and/or others in the community
- People naturally forget.
- A person may forget when drinking alcohol or using drugs.
- If a person has side effects (feels sick from the medicine)
- If a person runs out of tablets or forgets to go to the pharmacy at end of the month
- If a person has a hard time accepting his or her HIV-status
- How far along a person is in the disclosure process
- The level of family or social support (i.e. they may not have a treatment "buddy" or supporter)
- How sick or well a person feels
- If a person has to travel or migrate
- The amount of time spent away from home (like at school or at work)
- If a person has a mental illness (like depression)

Things about our <u>families, communities, and culture</u> that can affect adherence:

- Poverty
- If there is a lack of food
- The level of stigma and discrimination around HIV
- Younger adolescents may not have enough family support
- Caregivers' availability, health, and understanding of adherence
- Societal discomfort with youth and issues related to HIV (like sexuality)
- The level of disclosure and social support at home, at school, and in the community
- The level of peer support and disclosure to peers
- If there is no child care when a person has an appointment at the clinic (especially for youth-headed households)
- If a person can take time off from school or work to go to an appointment at the clinic
- Gender inequality: In some countries, women are less likely to have access to adequate nutrition to support their treatment, they may depend on men economically, they may sometimes be forced to share their treatment with their husbands, and it may be harder for them to travel to clinics to access treatment.
- 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 <u>health services</u> that can affect adherence and a client's long-term retention in care:

- Youth-friendliness of services/availability of youth-friendly services
- The level of confidentiality
- If there are drug stock-outs
- The distance to the clinic/transportation costs
- The convenience of clinic hours
- If there are patient record and tracking systems (and how well they work)
- The number and type of health care workers at the clinic or hospital
- The language(s) spoken by the health care workers
- The attitudes of the health care workers
- Waiting times
- The availability of space for private counseling
- The existence of linkages between different services
- The existence of referral systems
- The existence of linkages to social and material support in the community
- The existence of linkages to home-based care services
- The availability of support groups
- PLHIV involvement at the clinic or hospital, including ALHIV
- The cost of health services or medicines

Things about <u>ARV medicines</u> that can affect adherence:

- Side effects
- The number of pills in the regimen
- The timing of the doses
- Changing pediatric doses as the child grows and ages
- The availability of reminder tools, like pill boxes, calendars, alarms, etc.
- The taste of the medicines
- Changes in drug supplier (the labeling, pill size, color, or formulation may change)

We often blame clients for not adhering to care and treatment, but not having access to quality, youth-friendly health services is often one of the biggest barriers to adherence. Also, you must remember to be nonjudgmental and always be supportive when clients share their adherence challenges!

My notes:

SESSION 6.3: Helping ALHIV and Caregivers Prepare for and Adhere to ART

The importance of adherence preparation and support for clients and caregivers:

- Group education sessions are useful for giving many people key information at one time.
- However, ALHIV initiating care and treatment should also be given time to speak to a counselor, nurse, and/or Peer Educator alone and in private.
- At least one individual counseling session (more is better) should be provided to all clients (and caregivers) before they begin taking ART. You can help the nurse or counselor during these sessions.
- This is a good time to see what the client (and caregiver) has understood from any group education sessions they have attended, and in which areas they need extra support.
- The Peer Education session should include working with the client (and caregiver or treatment buddy) to talk about any adherence challenges he or she may have and to make an adherence plan.

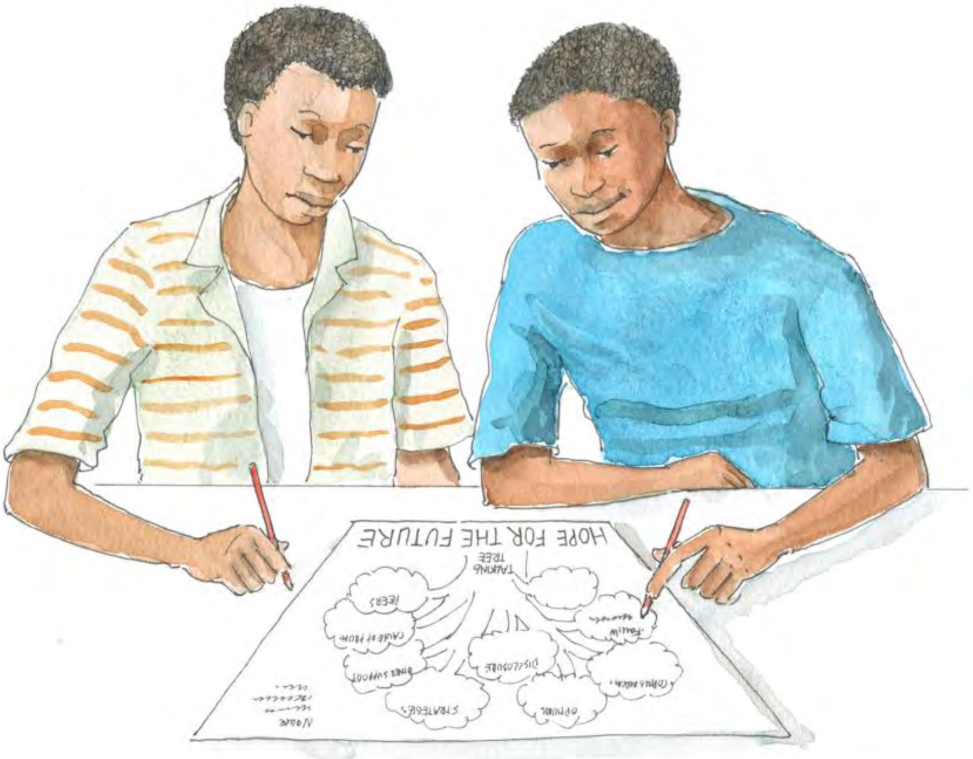
What is a treatment buddy?

A client about to start ART sometimes chooses a **treatment buddy** or **treatment supporter** to give him or her ongoing support for adherence to care and treatment.

A treatment buddy is usually a client's friend, family member, or another PLHIV who is also enrolled in care and is a trusted person to whom a client can disclose his or her status. Generally, a treatment buddy gets some basic education on HIV, adherence, and positive living, and can then give psychosocial and adherence support to the client throughout the course of his or her care. Having a treatment buddy provides a client with another key aspect of comprehensive care.

When helping adolescents and their caregivers prepare for adherence, always address the WHO, WHAT, WHEN, and HOW of the medicines:

- ✓ ***WHO*** *will help you remember to take your medicine every day at the same time? Is there someone who can help you come to the clinic for appointments?*
- ✓ ***WHAT*** *medicines are you taking? What is the dose and how often will you take it? What will you do when you are about to run out of your medicines? What will you do if you miss a dose of your medicine?*
- ✓ ***WHEN*** *will you take your medicines? Establish a routine.*
- ✓ ***WHERE*** *will you take your doses of ARVs (e.g. at school, at home, at work, etc.)? Where will you store your ARVs?*
- ✓ ***HOW*** *will you remember to take your medicines every day and at the same time? When you are at school or work? When you are away from home? When you are with your family? When you are with your friends?*



Strategies that you can use with younger adolescents and their caregivers to promote adherence to medicines:

- Work closely with the nurse, counselor, your supervisor, or another member of multidisciplinary care team to support adherence and help the nurse or counselor to prepare and educate younger adolescents and their caregivers.
- Be a good role model and give practical suggestions based on your own personal experience with overcoming adherence challenges.
- Help the nurse or counselor explain to the caregivers and their children what is meant by adherence, using easy-to-understand language.
- Reinforce the importance of good adherence to the child's health.
- Tell the caregivers that, with good adherence, children and younger adolescents with HIV can live long, healthy, and productive lives.
- Talk about the need for open, honest communication with the child and the health care team.
- If the adolescent hasn't been disclosed to, talk about the need for him or her to know about his or her HIV-status and how this will help with adherence (see *Module 9*).
- Help the client and caregivers think of a treatment buddy.
- Use the Adherence Support Tree to help the client and caregivers form an adherence plan.

It is important for you to help the multidisciplinary care team provide adherence education. But most of all, it is important that you give ongoing adherence support to ALHIV and their caregivers **at every clinic visit and over time**.

Adherence preparation case studies:

Case Study 1:

M___ is 11 years old and is going to begin taking ART. Her auntie is her primary caregiver and will be responsible for giving M___ her medicines every day. M___ understands that she has HIV and needs to take medicines every day, but her auntie is worried about how she will manage. The nurse asks you to join a session to talk with them about adherence and about making an adherence plan.

How do you help M___ prepare for adherence?

Case Study 2:

P___ is 16 years old and lives on his own. He needs to start taking ART and the nurse asks you to help prepare him for adherence. P___ works during the day as a taxi assistant and you sense that it might be challenging for him to take his medicines the right way because he hasn't disclosed to anyone and he works long hours.

How do you help P___?

Case Study 3:

D___ is 17 years old and lives with her mother and father. She is going to start taking ART and you and one of the counselors are asked to help prepare her and to help her make an adherence plan. D___ is at the clinic alone and says she doesn't talk much about HIV with her mother and father.

How do you proceed with D___?

Case Study 4:

V___ is a 14-year-old girl who has been on ART for 7 years. Recently, she moved to the capital city to live with her uncle and his family. She is new at the ART clinic. When V___'s aunt brings her to the clinic, you sense that her aunt does not know much about V's care and treatment. The doctor invites you into the session to help talk with V___ and her aunt about adherence.

How do you help V___ and her aunt prepare for adherence?

You can use the Adherence Support Tree as a guide for adherence support and preparation with clients and caregivers. Providing good adherence education and support is a very important job and it is too much for one person to do alone! Helping clients and caregivers with adherence is the responsibility of the entire multidisciplinary care team!

My notes:

SESSION 6.4: Providing Ongoing Adherence Support to ALHIV

There are many factors that affect a client's long-term retention in care. You can improve ALHIV's retention by:

- Helping the multidisciplinary care team make sure that HIV services are youth-friendly and that adolescent clients are treated respectfully and non-judgmentally
- Making sure adolescents feel welcomed, comfortable, and safe at the clinic and that they can "hang out" there and meet other young people
- Building a relationship of trust and respect with clients
- Referring or linking clients to support groups and other services for ALHIV
- If the client joins a support group, giving information and suggesting activities to that group that correspond to the client's age
- Making time for private one-on-one sessions if necessary, and ensuring privacy and confidentiality
- Making sure that all clients are given reminders of upcoming appointments and of what was discussed during one-on-one sessions (e.g. by giving them a copy of their Adherence Support Tree with the date and time of their next appointment)
- Helping the multidisciplinary care team support clients and caregivers with adherence, disclosure, sexual and reproductive issues, etc.

You can provide ongoing adherence support around HIV treatment:

Assessing adherence is very difficult and there is no perfect way to do it. Only by talking with the client regularly and by looking at the person's response to ART over time can we really learn about his or her adherence. It is very important that you help the nurse or counselor assess the client's adherence at each visit.

- The purpose of ongoing adherence monitoring and support is to encourage the client (or caregivers) to express challenges and to be open about any problems they may be facing so that you can give them ongoing support.
- Make adherence a normal part of every clinic visit. Remember, clients' adherence and psychosocial support needs change over time and especially as ALHIV go through different stages and experience changes.
- Do not judge clients. Make them feel comfortable instead of fearful that they will be punished or judged if they talk about their adherence challenges.
- Explain to clients that everyone has problems taking medicines the right way all the time.
- Build a trusting relationship and encourage clients to be completely honest with you about adherence. Remember: our job as Peer Educators is to work WITH our clients, not against them!
- Talk about clients' adherence issues at multidisciplinary team meetings so that clinical staff know about them (including common challenges faced by ALHIV).

Anticipate "Adherence Fatigue":

- With time, children and adolescents may get tired of taking medicines.
- With time, caregivers may get tired of giving medicines.
- Do not assume that just because a client has been adherent in the past, that this client will always be adherent.
- This is especially true for ALHIV because they will likely have different adherence challenges at different developmental stages.

How to ask clients (and caregivers) about their adherence:

- *I would like you to think about the last 7 days. How many pills did you take late in the last 7 days? What were the main reasons you took them late?*
- *How many pills did you miss in the last 7 days? What were the main reasons you missed them?*
- *How did the medicines make you feel?*
- *Can you tell me about any changes you have noticed lately (like changes in your health)?*
- *Can you tell me about any challenges you have had lately with your medicines?*
- *What support or reminders do you have to take your medicines at the same time, every day?*
- *What questions do you have about your care or your medicines?*

If, after talking with a client about adherence, you feel that he or she is adhering well:

- Praise the client for good adherence.
- Encourage the client to come back and talk to you if there are any problems.
- Talk about how important it is for the client to be open with health care workers and Peer Educators and to solve challenges together.

If you feel that a client (or caregiver) has had some problems with adherence or if the clinical team thinks there may be adherence problems:

- **Always report back to the multidisciplinary care team and get direction from a nurse, counselor, or supervisor on how to manage these problems!**
- Work with a counselor or nurse to plan an individual Peer Education session.
- Give some practical suggestions and tips to the client about adherence, based on your personal experiences.
- Try to identify the specific challenges that the client or caregiver is having. You may want to use the Adherence Support Tree to guide your sessions with the client so that you can think about possible solutions together.
- Be supportive! Remind clients and caregivers that we all have adherence challenges, especially ALHIV, who are going through changes in their lives and different stages of adolescence.
- Discuss the importance of adherence.
- Be a good role model and share your own experiences with adherence challenges!
- Give referrals to support groups or other organizations.
- Work with a nurse or counselor to plan next steps, including setting up the client's next appointment.
- Praise the client for sharing his or her challenges.
- Record the session on the client's Adherence Support Tree.
- Follow up at the client's next visit.

My notes:

Practical Adherence Strategies, Tools, and Reminders for ALHIV

- Clients can use pill boxes to store their medicines. These boxes are divided into different sections for each day of the week. They are used to help remind people when to take their medicines and can also be helpful when people need to take their medicines while away from home. If a person has forgotten whether or not he or she has taken a dose, he or she can check if there are still pills in the section for that day or not.
- Using a calendar (a paper calendar or a calendar on a mobile phone) to track appointments and to give themselves written reminders
- Setting a beeping alarm on their mobile phone to remind them to take their medicines
- Keeping a diary
- Planning ahead for weekends or when they are away from home
- Identifying a treatment buddy (someone to help them remember to take their medicines)
- Incorporating their medicines into their daily routine (e.g. always taking their medicines with meals)
- Calling ahead of time to order refills of their medicines
- Going to a support group to expand their network of people who can support them with adherence

It is important for you and ALL members of the multidisciplinary care team to support clients' adherence to care at each clinic visit and over time.

SESSION 6.5: Classroom Practicum on Adherence Support

Case studies for role play

Case Study 1:

A 14-year-old youth named V___ has been on ART for 8 years. Usually his adherence is almost perfect and he has been feeling fine when he comes for refills, but this time he says things are not going well. You ask him about what is going on and he tells you that his father was fired from his job and is now staying at home. There is no money to pay the bills, his father is drinking a lot, and his parents are often fighting. He says that he does not feel like going to school because he is not doing well in his classes and has few friends. Within the last few weeks, V___ forgot to take his pills 3 different times. The nurse asks you to speak with V___.

How would you support V___?

Case Study 2:

A 16-year-old young woman named B___ tested positive for HIV 6 months ago and enrolled at the clinic. She is caring for her sick mother. She is so busy that she has missed a couple of appointments at the ART clinic, but she feels fine and says she's not eligible to start ART anyway. Her boyfriend is the only one who knows she is HIV-positive, but he has not been tested.

How would you support B___?

Case Study 3:

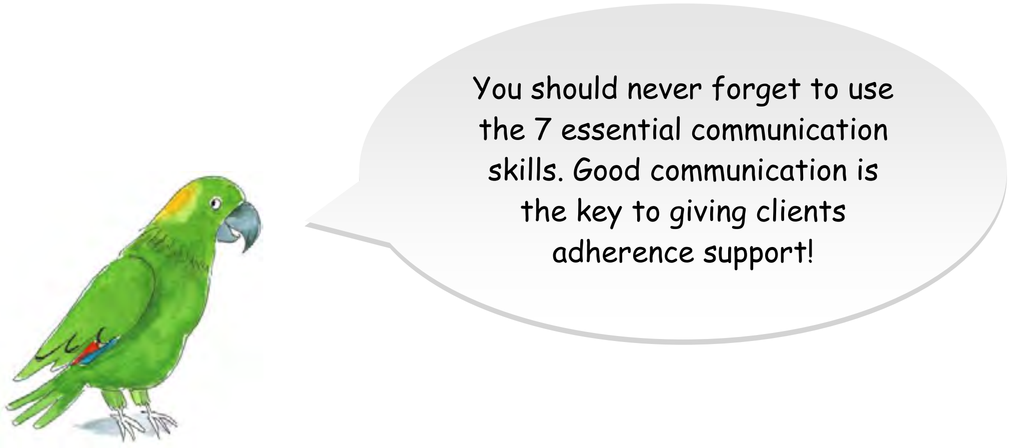
A 13-year-old young woman named D___ comes to you because she "is feeling bad" and wants to stop taking ART. She tells you that she has missed 3 doses in the last month but thinks that taking her medicines most of the time is good enough She says that she thinks the pills are making her look fat and that she feels self-conscious about her body. She also tells you that she really likes this boy in her class but that she is afraid he thinks she is ugly. She says her classmates tease her when she goes to school and that she does not have many friends.

How would you talk with D___?

Case Study 4:

You meet with a young 12-year-old boy named T___ who has been on ART for the last 6 years. His mother complains that T___ always used to cooperate and take his medicines with no problem. But now he is fighting her with every dose by running away and spitting out his ARVs. The nurse is very busy today and asks you to help her speak with T___ and his mother.

How would you talk to T___ and his mother?



My notes:

Note: Some of the preceding information in this Module was borrowed and/or adapted from the following sources:

Colton, T., Costa, C., Twyman, P., Westra, L., & Abrams E. (2009). *Comprehensive peer educator training curriculum, Trainer manual, Version 1.0.* New York: ICAP.

ICAP. (2008). *Adherence and psychosocial support implementation workshop for multidisciplinary HIV care teams, Facilitator manual.* New York: ICAP.

SESSION 6.6: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- Retention refers to keeping (or "retaining") clients in the care program. In this case, it means continuing with lifelong HIV care and treatment services. A goal of all HIV care and treatment programs is to retain clients in the full program of care.
- Adherence means how faithfully people stick to their care and treatment plan.
- Adherence support is most successful when it is provided by a number of people on the multidisciplinary care team, including Peer Educators, and when it is in partnership with clients and their family.
- Adherence to care is important to make sure people stay healthy, live positively, know when to start ART, and get psychosocial support.
- Adherence to treatment is important to lower the amount of HIV in people's bodies 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, which prevents the ART from working and makes people sick. Non-adherence can make ALHIV very sick and can also cause problems with their growth and development.
- There are many barriers and challenges to good adherence, including things related to people's lives, to medicines, and to health services.
- There are many challenges to adherence that are unique to adolescents: they engage in more risk taking behaviors and they have a desire to "fit in" with peers and appear "normal." They may not take their medicines because they are feeling rebellious and want to be their own person.
- Adherence barriers and challenges change over time, especially for ALHIV as they go through different developmental stages and life changes. It is important to ask clients about adherence at all follow-up visits.
- It is important that Peer Educators build a trusting relationship with clients so that they feel comfortable being completely honest about their adherence support needs.
- Peer Educators play an important role in helping clients and their families/caregivers prepare to start taking ART. The use of tools—such as a pill box, an alarm, or an adherence calendar or diary—can help support adherence.
- Adherence and a client's adherence plan should be discussed at every counseling session!
- It is important not to judge clients (and caregivers) if they are non-adherent. Instead, we should try to find the root causes of non-adherence.

- It is important to remember to use good communication skills whenever speaking to a client about adherence issues.
- The Adherence Support Tree is a useful tool that can help Peer Educators provide adherence preparation as well as ongoing support.

APPENDIX 6A: Adherence Support Tree

Instructions for the Adherence Support Tree:
Each instruction below goes with a number on the Adherence Support Tree. The Peer Educator should follow these instructions in order.

1. Start on the trunk. Begin by explaining what we mean by adherence to treatment and why near-perfect adherence is important.
2. Continue by helping the client make an ART adherence plan: address the WHO, WHAT, WHEN, WHERE, and HOW of the medicines. The lines around left-hand side of the tree are spaces for writing down important information related to the client's adherence plan. This is a chance for the Peer Educator to reinforce what the nurse or counselor has told the client about the right ways to take ARVs!
    - ✓ ***WHO*** *will help you remember to take your medicine every day at the same time? Is there someone who can help you come to the clinic for appointments?*
    - ✓ ***WHAT*** *medicines are you taking? What is the dose and how often will you take it? What will you do when you are about to run out of your medicines? What will you do if you miss a dose of your medicine?*
    - ✓ ***WHEN*** *will you take your medicines? Establish a routine.*
    - ✓ ***WHERE*** *will you take your doses of ARVs (e.g. at school, at home, at work, etc.)? Where will you store your ARVs?*
    - ✓ ***HOW*** *will you remember to take your medicines every day and at the same time? When you are at school or work? When you are away from home? When you are with your family? When you are with your friends?*
3. Ask the client to imagine him- or herself as a tree. The roots are "*where you come from, your home, your family, and your community,*" they are "*what support and ground you.*" Ask the client who will support him or her with their adherence plan and write this under "peers, family, and community" in the roots of the tree. Note if the client has a treatment buddy.
4. Discuss the possible challenges to adherence in the client's (and caregiver's) life. Write these under "What are the Anticipated Adherence Challenges?"
5. The branches are the client's adherence strategies. These are things she or he can do to have perfect adherence, like using reminders, routines, using a treatment buddy, etc. Give the client practical suggestions and help him or her plan ways of remembering to take medicines and to come to the clinic for appointments.

6. Always plan a follow-up session and record any action points under "Immediate Next Steps." Tell the client that you will always be available to talk more with him or her. Adherence and follow up to the adherence plan should be discussed during every Peer Education session!
7. Lastly, summarize the main points that were discussed during the adherence support session, talk about any necessary referrals, and arrange another time to talk (if necessary).
8. Review and discuss the client's situation and "next steps" with the program supervisor or a member of the multidisciplinary care team.

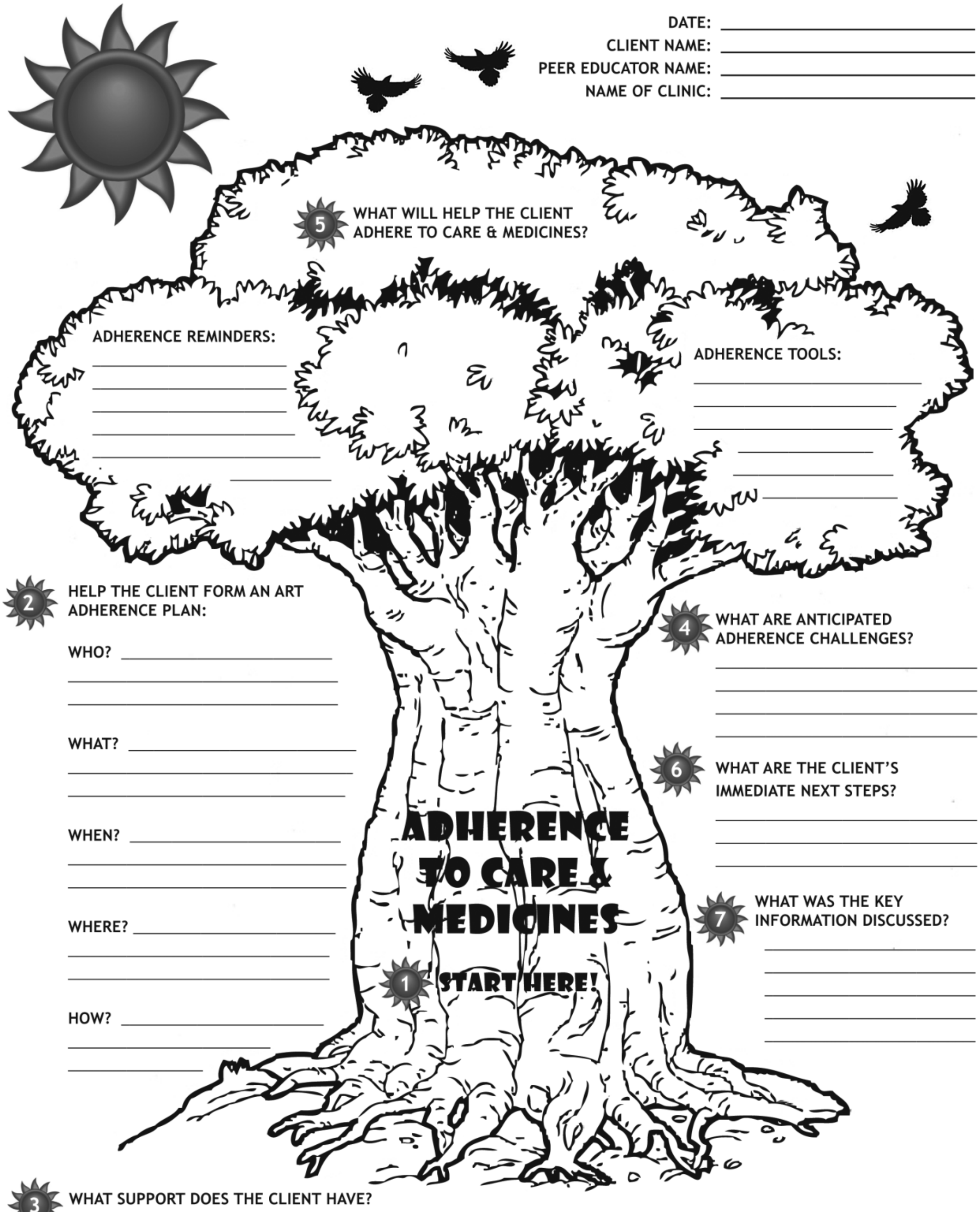
ADHERENCE SUPPORT TREE

DATE: ______________________________

CLIENT NAME: ______________________________

PEER EDUCATOR NAME: ______________________________

NAME OF CLINIC: ______________________________



5 WHAT WILL HELP THE CLIENT ADHERE TO CARE & MEDICINES?

ADHERENCE REMINDERS:

____

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____

ADHERENCE TOOLS:

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____

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____

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2 HELP THE CLIENT FORM AN ART ADHERENCE PLAN:

WHO? ______________________

____

____

WHAT? ______________________

____

____

WHEN? ______________________

____

____

WHERE? ______________________

____

____

HOW? ______________________

____

____

4 WHAT ARE ANTICIPATED ADHERENCE CHALLENGES?

____

____

____

____

6 WHAT ARE THE CLIENT'S IMMEDIATE NEXT STEPS?

____

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____

7 WHAT WAS THE KEY INFORMATION DISCUSSED?

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____

____

____

____

ADHERENCE TO CARE & MEDICINES

1 START HERE!

3 WHAT SUPPORT DOES THE CLIENT HAVE?

FAMILY:

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____

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PEERS:

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____

____

COMMUNITY:

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____

APPENDIX 6B: Communication Skills Checklist

	Counseling and Communication Skills		
	Skill	**Specific Strategies, Statements, Behaviors**	**(√)**
Establishing the Relationship	**Skill 1: Use helpful non-verbal commun-ication**	• 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)	
Understanding the Client's Needs	**Skill 2: 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.	
		• Allow the client to express emotions.	
		• Do not interrupt.	
		• Other (specify)	
	Skill 3: Ask open-ended questions	• Use open-ended questions to get more information.	
		• Ask questions that show interest, care, and concern.	
		• Ask questions to clearly understand the client's problems	
		• 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 person 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)	
Creating an Action Plan and Ending the Session	**Skill 7: Help your client set goals and summarize each session**	• Work with the client to come up with realistic "next steps"	
		• Summarize the main points of the Peer Education 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 7: PROVIDING PSYCHOSOCIAL SUPPORT

LEARNING OBJECTIVES:

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

- Define psychosocial support
- Describe the common psychosocial needs of younger and older ALHIV
- Discuss different types of stigma and discrimination ALHIV may face and strategies to deal them
- Describe ways that stigma and discrimination negatively affect ALHIV's access and adherence to HIV prevention, care, and treatment services
- Work as part of the multidisciplinary care team to help address the psychosocial support needs of ALHIV and to help with coping, using the Talking Tree
- Give support and referrals to ALHIV who are experiencing crisis

CONTENT:

Session 7.1: Introduction: What Do We Mean by Psychosocial Support?

Session 7.2: Addressing the Psychosocial Support Needs of ALHIV

Session 7.3: Dealing with Stigma and Discrimination

Session 7.4: Identifying and Helping with Crisis

Session 7.5: Classroom Practicum on Psychosocial Support

Session 7.6: Module Summary

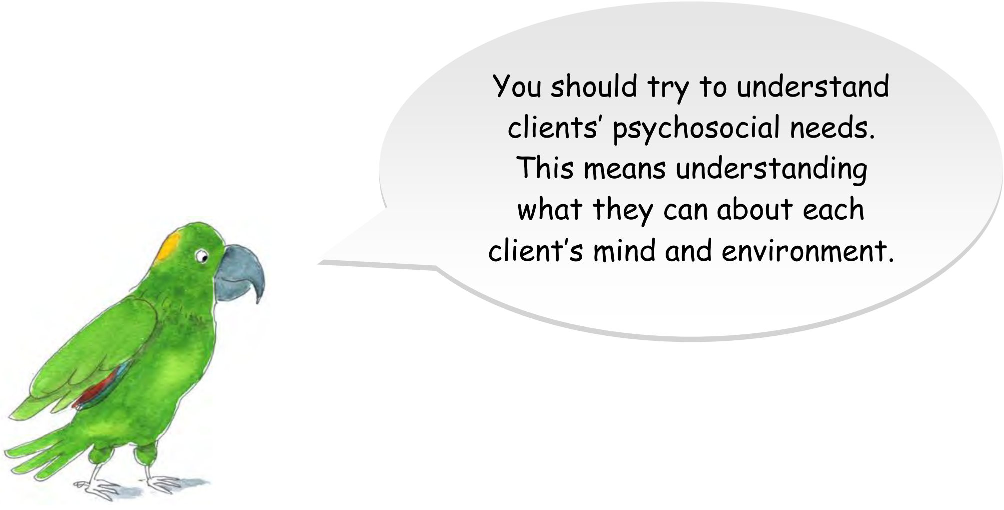
SESSION 7.1: Introduction: What Do We Mean by Psychosocial Support?

Definition of psychosocial support:

- **Psycho** refers to the mind and soul of a person. This means a person's feelings, thoughts, beliefs, attitudes, and values.
- **Social** refers to a person's relationships and environment. This includes interactions and relationships with family, peers, at school, and in the community.
- **Psychosocial support** addresses the ongoing emotional, social, and spiritual concerns and needs of people living with HIV, their partners, their family, and their caretakers (in the case of children living with HIV).
- **Psychosocial well-being** is when a person's internal and external needs are met and the person is physically, mentally, and socially well.

Providing psychosocial support to ALHIV is important because:

- HIV affects all parts of a person's life: physical, mental, social, and spiritual.
- ALHIV have normal developmental issues like feeling that they want to be normal and fit in.
- Adolescents' relationships with their parents and caregivers can be difficult as they test limits and move towards independence.
- Psychosocial support can help clients and caretakers get confidence in themselves and their skills (dealing with long-term illness, dealing with stigma or discrimination, dealing with taking medicines every day, caring for an HIV-exposed or HIV-infected child, etc.).
- Psychosocial well-being is related to better adherence to HIV care and treatment.
- Good mental health is closely linked to physical health.
- Psychosocial support can provide or link people with needed social, economic, educational, housing, and legal services.
- Psychosocial support can help people mentally and practically prepare for difficult things like bad health, having an HIV-infected baby, or death.


You should try to understand clients' psychosocial needs. This means understanding what they can about each client's mind and environment.

My notes:

SESSION 7.2: Addressing the Psychosocial Support Needs of ALHIV

Common psychosocial support needs of younger ALHIV (ages 10-14):

MATERIAL	SOCIAL	PSYCHOLOGICAL
• Food • Shelter • Clothing • Medical Care • Possessions • Education	• Family • Friends • Play/expression	• Parental love and emotional care • Guidance • Security • Protection • Recognition

Common psychosocial support needs of older ALHIV (ages 15-19):

MATERIAL	SOCIAL	PSYCHOLOGICAL
• Food • Shelter • Clothing • Medical Care • Possessions • Money/income • Access to secondary or higher education	• Culture • Community • Religion/spiritual support • Family • Friends/peers	• Sense of belonging or fitting in • Self-esteem • Respect • Recognition • Independence • Love/companionship from partner • Awareness and expression of sexuality

Common psychosocial needs of ALHIV:

- Support in understanding and coming to terms with their HIV-status and the effect their status has on their own and their family's lives
- Talking about their opinions about taking medicines when they may not be feeling sick and they just want to fit in and be normal
- Acceptance from caregivers and family members
- Peer support from other people whom they look up to
- Strategies to disclose their HIV-status to their peers, family, and community members
- Talking about ways to encourage their partners and family members to test and, if appropriate, to enroll into care and treatment programs
- Access to education, training, and work opportunities once they have completed school/training
- Access to higher education
- Access to social welfare services
- Access to community-based organizations that support income-generating activities
- Spiritual support and referrals to spiritual counseling
- Getting information about their legal issues and rights
- Mental health support, including for anxiety and depression
- Substance abuse management

My notes:

Remember that Peer Educators are not counselors but they can offer ALHIV much-needed emotional support and education. They can also link ALHIV to

Some ways that you can help address clients' psychosocial support needs:

- Use good communication skills, actively listen, and provide clients with emotional support.
- Ask how the client is doing (using open-ended questions) at each visit.
- Follow up on psychosocial issues and needs discussed during previous visits.
- Figure out if a client needs a referral for more support (e.g. for school, food, etc.) and tell the multidisciplinary care team.
- Give clients referrals to support groups, youth groups, etc.
- Use the Talking Tree as a tool to guide the conversation during individual Peer Education sessions and to help clients solve their own problems.
- Identify clients in distress who need attention from a trained counselor, mental health provider, or a member of the multidisciplinary care team.
- Act as a role model for adolescent clients and share practical suggestions based on personal experience.
- Report any serious problems to the supervisor and/or multidisciplinary care team.

SESSION 7.3: Dealing with Stigma and Discrimination

Key Definitions

Stigma: When we have a negative attitude toward people that we think are not "normal" or "right." For example, stigma can mean not valuing PLHIV or people associated with PLHIV.

To stigmatize someone: Labeling a person and seeing him or her as inferior (less than or below others) because of something about this person (e.g. because of his or her job, because he or she is poor, because he or she has a disease, etc.). A lot of times people stigmatize others because they do not have the right information and knowledge. People also stigmatize others because they are afraid.

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

Key points about stigma and discrimination

- All over the world, stigma and discrimination are some of the biggest challenges of living with HIV or being affected by HIV. Stigma and discrimination make it hard for people to access HIV prevention, care, and treatment services. Stigma and discrimination can also prevent PLHIV from accessing community-based services (like food support).
- We have all felt rejected or isolated at some point in our lives. We have also all probably rejected or isolated another person because we thought of them as different.
- Peer Educators need to help clients understand and deal with stigma and discrimination. They can work with the multidisciplinary care team and the community to fight stigma and to make sure that people have access to the services they need, without discrimination.

There are different kinds of stigma:

- **Stigma toward others:** Rejecting or isolating other people because they are different or because they are seen as different (e.g. being isolated by peers at school or being abandoned by friends)
- **Self-stigma:** When a person adopts the cruel and hurtful views that others may have of him or her. In other words, when a person begins to see him- or herself in a negative way because others see him or her in a negative way. Often, self-stigma can lead people to isolate themselves from their families and communities (e.g. N___ is HIV-positive and is afraid of "giving the disease" to her family, so she keeps to herself and eats her meals alone.)
- **Secondary stigma:** When people are stigmatized by their association with PLHIV. This may include community health workers; doctors and nurses at HIV clinics; and the family members or caregivers of PLHIV. An example of secondary stigma is when, in some countries, police harass HIV activists.

There are different forms of discrimination:

- Facing violence at home or in the community
- Not being able to go to school
- Being kicked out of school
- Not being able to get a job
- Being isolated or shunned from the family or community
- Not having access to quality health care or other services
- Being rejected from a church, mosque, or temple
- Police harassment
- Verbal discrimination: gossiping, taunting, scolding
- Physical discrimination: insisting that a person use separate eating utensils or sleep in a separate living space

Stigma and discrimination prevent good access to HIV prevention, care, and treatment services for many people. They can also prevent PLHIV and their families from living healthy and productive lives.

My notes:

Stigma and discrimination around HIV impacts everyone. Stigma and discrimination can:

- Keep people from getting an HIV test
- Make it hard for people to tell their partner(s) their HIV test result
- Make it hard for people to suggest safer sex practices to their partner(s)
- Cause a lot of anxiety, stress, and depression
- Make it hard for parents to disclose to their children
- Make it hard for pregnant women to take ARVs or access other PMTCT services
- Prevent people from caring for PLHIV in their family, in the community, and in clinics
- Make people afraid of knowing their HIV-status, enrolling in care, or getting a CD4 test. This results in fewer people being able to access ART.
- Prevent or delay disclosure, forcing people to keep their status and their ART a secret. This affects the amount of support these people receive.
- Cause people to be isolated from friends and family, which means that they will not be supported to take ART and to adhere to care and treatment
- Result in low quality services at clinics and hospitals, making it less likely that people will access the care they need

Stigma and discrimination has specific effects on ALHIV. Stigma and discrimination can:

- Keep ALHIV from accessing care, treatment, counseling, and community support services because they want to hide their status
- Increase ALHIV's resistance to getting help and contribute to their existing discomfort and fear
- Make adolescents feel isolated and like they don't fit in with their peers
- Make it difficult for adolescents to do well in school
- Can affect caregivers of ALHIV, making it less likely that people will want to care for ALHIV or seek services themselves
- Impact some adolescents more than others. For example, orphans who are HIV-positive may be rejected by their extended families and community, they may be denied access to schooling and health care, and they may be left to take care of themselves.

Some common individual strategies for dealing with stigma (in any place):

- Stand up for yourself and speak up.
- Educate people.
- Be strong and prove yourself.
- Talk to people whom you feel comfortable with.
- Try to explain the facts.
- Ignore people who stigmatize you.
- Avoid people who you know will stigmatize you.
- Join a support group.
- Taking and adhering to medicines and ART reduces stigma around HIV, helps normalize HIV, and allows the community to see HIV as a chronic disease. People who openly take ART can reduce stigma around the disease.

Some strategies for dealing with different forms of stigma at a clinic or hospital:

- Make sure young people and ALHIV, such as Peer Educators, are part of the care team. This means they should attend regular staff meetings, trainings, and other events.
- Make sure young people help evaluate the clinical services that are being offered and that feedback is formally reviewed by managers and health care workers.
- Link the clinic with youth groups and ALHIV support groups in the area.
- Talk openly about your own attitudes, feelings, fears, and behaviors with other Peer Educators and health care workers. Support each other to address fears and avoid burnout.
- Share your own experiences as a client with health care workers.
- Encourage health care workers and other Peer Educators to be open about their status. Encourage them to support one another.
- Report any discrimination you see at the clinic toward PLHIV or their families to a manager.
- Listen to clients about their feelings and concerns about stigma and discrimination, and report these back to other health care workers.

You and the multidisciplinary care team can work together to identify stigma and discrimination within the clinic. Then they can then work together to make changes!

My notes:

SESSION 7.4: Identifying and Helping with Crisis

What is a crisis?

- A crisis is an event that causes emotional, mental, physical, and behavioral distress or problems.
- A crisis can be any situation in which a person suddenly feels unable to solve or cope with his or her problems.
- Many different events or circumstances can cause a crisis: life-threatening events like natural disasters (e.g. an earthquake), sexual assault or other crimes; physical or mental illness; thoughts of killing yourself or someone else; or big changes in relationships or your life (for example, if a friend or family member dies, if your parents get divorced, if you become homelessness, if someone who was supporting you stops giving you money, if you lose your job, or if you are kicked out of school).

Coping skills are specific ways that individuals and communities help themselves deal with difficult situations. Each individual has his or her own coping skills—what is useful for one person may or may not work for another.

Examples of good coping skills that Peer Educators can use themselves and also discuss as options with clients:

- Talk about the problem with someone you trust, like with a friend, family member, counselor, or Peer Educator.
- Join a support group.
- Exercise.
- Change your environment, take a walk, or listen to music.
- Get spiritual help.
- Go to a cultural event, like traditional dancing or singing.
- Join in recreational activities, like sports or youth clubs.
- Return to your daily routine, like household chores (e.g. cooking) or going to school.
- Do something to make yourself feel useful, like helping a sibling with homework.

Because all people are unique, each person reacts differently to crisis. Some reactions and effects of crisis include:

- Shock
- Sadness/crying
- Fear
- Anxiety
- Confusion
- Sleep problems/nightmares
- Loss of appetite
- Withdrawal/isolation
- Anger

Listening breaks people's isolation and encourages them to share their thoughts, feelings, and beliefs.

Expression helps people to:

- Feel relief
- Think more clearly about what has happened
- Feel accepted, cared for, and valued by the person listening
- Develop confidence
- Build self-esteem
- Explore options or solutions to make better decisions
- Prevent bad feelings from coming out as aggressive behavior

Listening and reflecting back a client's feelings are some of the most important communication skills when you provide psychosocial support!

My notes:

SESSION 7.5: Classroom Practicum on Psychosocial Support

Case studies to discuss in small groups:

Case Study 1:

N___ is 15 years old and just tested positive for HIV. During adherence counseling, she told the health worker that if the treatment is for life, it will be difficult for her to take because she does not want to disclose her status to anyone. She said she is afraid that her parents would throw her out of the house and not support her. The health care worker told her this was a silly response and that she needs to do what is right. N___ comes to you for help.

What kind of psychosocial support would you give N___?

Case Study 2:

A 10-year-old boy named V___ has been feeling "down." He comes to you because "he wants to talk to someone" but seems very quiet and embarrassed to say what he wants. He barely speaks in your session. You ask V to draw a picture and in the picture you see a woman drinking from a bottle. V___ tells you it is a picture of his mother.

How do you proceed?

Case Study 3:

A 17-year-old woman named B___ tested positive for HIV 6 months ago. She is caring for her 3 younger sisters. She is so busy that she has missed a couple of appointments at the ART clinic. Her partner 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. She feels a lot of anger.

How would you talk with B___?

Case Study 4:
A 16-year –old boy named D___ has been on ART for many years. Because his mom and dad died he is living with his brother, his brother’s wife, and their children. D___ tells you that his brother is worried that D___ will pass HIV to the children when he plays with them or when he eats with them. D___ asks you to talk to his brother, who is at the clinic today.

How do you proceed?

Case Study 5:

You meet with a young 13-year-old girl named T___ whose mother has just died from a HIV-related infection. T___ is enrolled in the ART program and usually comes to all of her appointments and adheres to her medicines. T___ says that she is feeling very sad today and that she has lost hope. She used to be ranked first in her class and now she is ranked last. She feels lonely, confused, and never feels like hanging out with her friends anymore.

How would you support T___?

You can use the Talking Tree
to help clients problem-solve
and cope during times of crisis!

Note: Some of the preceding information in this Module was borrowed and/or adapted from the following sources:

Chiiya, C., Chonta, M., Clay, S., Kidd, R. & Röhr-Rouendaal, P. (2010). *We are all in the same boat: using art and creative approaches to tackle HIV-related stigma.* UNESCO.

Colton, T., Costa, C., Twyman, P., Westra, L., & Abrams E. (2009). *Comprehensive peer educator training curriculum, Trainer manual, Version 1.0.* New York: ICAP.

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

REPSSI. (2007). *Mainstreaming psychosocial care and support: A manual for facilitators.*

Annan, J., Castelli, L., Devreux, A. & Locatelli E. (2003). *Handbook for teachers.* Uganda: AVSI.

SESSION 7.6: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- Psychosocial support addresses the ongoing emotional, social, and spiritual concerns and needs of people living with HIV, their partners, their family, and their caretakers (in the case of children).
- Younger ALHIV may have many material and psychosocial needs including food, shelter, medical care, parental love, and protection.
- Older ALHIV may have many psychosocial needs as well, including acceptance from peers, a sense of purpose, self-esteem, autonomy, and independence.
- Peer Educators play a key role in helping to address clients' psychosocial needs over time.
- **Stigma** means having a negative attitude toward people that we think are not "normal" or "right." For example, stigma can mean not valuing PLHIV or people associated with PLHIV.
- A **crisis** is an event that causes emotional, mental, physical, and behavioral distress or problems.
- **Coping skills** are specific ways that individuals and communities help themselves deal with difficult situations. Each individual has different coping skills.
- Peer Educators can use the Talking Tree to help figure out a client's psychosocial needs and to support them to come up with their own solutions.
- Helping to manage a client's crisis is the responsibility of the entire multidisciplinary care team. A Peer Educator should never act alone.

APPENDIX 7A: Feeling Chart

Note: This Emotions Vocabulary Chart was borrowed from http://www.ami-tx.com/Portals/3/EmotionsFlyer.pdf

APPENDIX 7B: Talking Tree

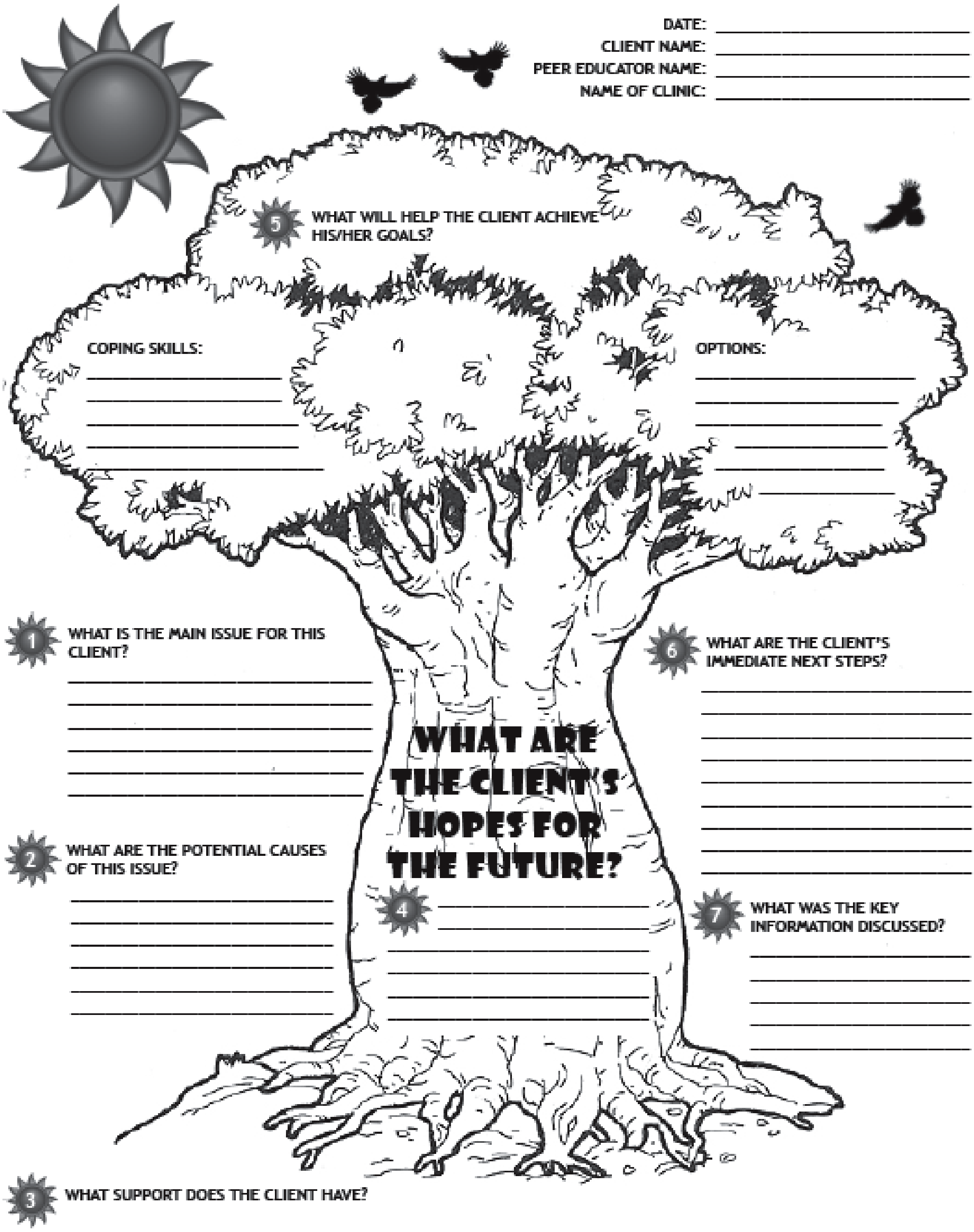
Instructions for the Talking Tree: Each instruction below goes with a number on the Talking Tree. The Peer Educator should follow these instructions in order.

Begin by explaining that the African Baobab tree is one of the longest-living and largest trees on Earth. It symbolizes survival and life because it sometimes grows in harsh conditions. It also symbolizes protection and sharing because it can be used as shelter and a place for people to gather and meet. Talk about the various parts of the tree: the trunk, roots, branches, leaves, fruits, nuts, or birds living in the trees.

1. Allow some time for the client to describe what is currently happening in his or her life (i.e. why he or she came here today to talk with you). Ask the person to tell you about the main problem or issue he or she is having—when it started, how it developed, and how he or she feels about it. Let the person know you would like to work together in finding something that he or she can do to make the situation better. Write a brief description of what is happening under "What is the main issue for this client" on the left-hand side of the tree.
2. Ask the client what he or she thinks is causing the problem/issue and write this under "What is the cause of this issue?"
3. Ask the client to imagine him- or herself as a tree—the roots are "*where you come from, your home, your family, and your community.*" The roots are "*what supports and grounds you.*" Ask the client who provides him or her with the most support in life and who can help him or her resolve this issue. Write this information under "family, peers, and community" in the roots of the tree.
4. Next move to the trunk. The trunk is the client's "*hope for the future, a future goal, or dream.*" Write the goal on the trunk of the tree. Encourage the client to close his or her eyes and think about him- or herself in the future, achieving her goal. Ask: " *What are you doing in that picture*?"
5. The branches are the client's options, the ways he or she copes, and potential solutions (i.e. things he or she can do to achieve the hope or goal). Talk about the benefits and consequences of each option. Encourage the person to think about strategies that have worked in the past. Write these on the branches. Then talk about all the person's resources—the "*things you have going for you,*" like inner strengths, talents, skills, and spiritual resources to help in coping.
6. Then ask: *"What is the next step in achieving your goal or hope for the future?"* Help the client form an action plan of immediate next steps.
7. Lastly, summarize the main points that were discussed during the Peer Education session (example: disclosure to partner) and, if necessary, talk about any referrals or arrange another time to talk
8. Review and discuss the client's situation and " next steps" with the program supervisor or a member of the multidisciplinary care team.

TALKING TREE

DATE: ____________________
CLIENT NAME: ____________________
PEER EDUCATOR NAME: ____________________
NAME OF CLINIC: ____________________



5 WHAT WILL HELP THE CLIENT ACHIEVE HIS/HER GOALS?

COPING SKILLS:
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____
____
____
____

OPTIONS:
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____
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1 WHAT IS THE MAIN ISSUE FOR THIS CLIENT?
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6 WHAT ARE THE CLIENT'S IMMEDIATE NEXT STEPS?
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WHAT ARE THE CLIENT'S HOPES FOR THE FUTURE?

4 ____________________
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2 WHAT ARE THE POTENTIAL CAUSES OF THIS ISSUE?
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7 WHAT WAS THE KEY INFORMATION DISCUSSED?
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____

3 WHAT SUPPORT DOES THE CLIENT HAVE?

FAMILY:
____
____
____
____

PEERS:
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____
____
____

COMMUNITY:
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____
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____

APPENDIX 7C: Communication Skills Checklist

	Counseling and Communication Skills		
	Skill	**Specific Strategies, Statements, Behaviors**	**(√)**
Establishing the Relationship	**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)	
Understanding the Client's Needs	**Skill 2: 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.	
		• Allow the client to express emotions.	
		• Do not interrupt.	
		• Other (specify)	
	Skill 3: Ask open-ended questions	• Use open-ended questions to get more information.	
		• Ask questions that show interest, care, and concern.	
		• Ask questions to clearly understand the client's problems	
		• 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 person 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)	
Creating an Action Plan and Ending the Session	**Skill 7: Help your client set goals and summarize each session**	• Work with the client to come up with realistic "next steps"	
		• Summarize the main points of the Peer Education 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 8: PLANNING AND CO-FACILITATING SUPPORT GROUPS FOR ALHIV

LEARNING OBJECTIVES:

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

- Discuss the overall goals and objectives of peer support groups
- List the different types of support groups that may be helpful for ALHIV and their families
- Discuss how to help plan a ALHIV support group meeting
- Discuss how to co-facilitate or help lead a ALHIV support group meeting
- Conduct participatory group activities as part of ALHIV support group meetings

CONTENT:

Session 8.1: Introduction: What Are Support Groups and Why Do We Need Them?
Session 8.2: Practical Tips on Planning and Facilitating Support Group Meetings
Session 8.3: Suggested Activities for ALHIV Support Groups
Session 8.4: Classroom Practicum on Planning and Facilitating a Support Group Meeting
Session 8.5: Module Summary

SESSION 8.1: What Are Support Groups and Why Do We Need Them?

What are support groups?

- Peer support groups are groups of people who come together because they share a common situation.
- In peer support groups, members help each other to better manage their situations, to share challenges, and to discuss solutions.
- Members support each other to do the things each has decided will improve his or her psychological, social, physical, and medical well-being.

Some of the common characteristics of support groups include:

- They are made up of peers—people who are all directly affected by the same issue, illness, or circumstance (for example, a support group might be for ALHIV, caregivers of children living with HIV, young pregnant women living with HIV, etc.).
- They usually have a discussion leader or facilitator. Peer Educators may be leaders or co-facilitators of support groups.
- They tend to be fairly small in size so that everyone can have a chance to talk.
- Attendance is voluntary—no one should ever be forced to join a support group.
- Information shared within the group is private and confidential. Peer Educators should create a “safe space” for group members and should help make sure that all group members respect and maintain confidentiality. Peer Educators can be role models for confidentiality and make confidentiality the “norm” in the clinic and in support groups.

Support groups come in many shapes and sizes:

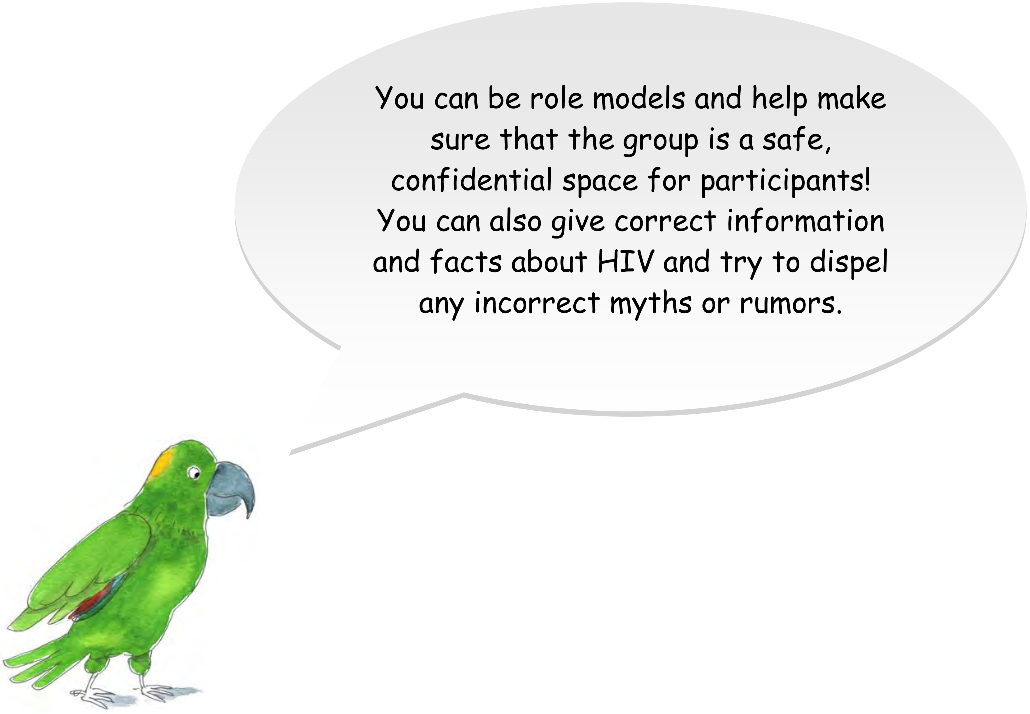
- Some support groups may be designed to be ongoing, with members coming and going in and out of the group over time.
- Other support groups may have a specific number of topics to cover, after which members are "graduated" out of the support group.
- Some support groups may be held at health facilities and others may be held in the community (for example, at schools, youth centers, community centers, or even in a person's home).
- Support groups are most successful when they bring together groups of people who share common circumstances or issues (see below).

Here are some of the different types of support groups that may exist or be needed:

- **Adolescent support groups**: ALHIV face special challenges and may want to form their own support groups. These groups may involve recreational activities (sports, crafts, drama, etc.), as well as time for education, discussion, and mutual support. Also, adolescents who are all starting ART or who are at a similar stage in their treatment (either preparing to begin ART, starting ART, or having been on ART for a long time) may find it helpful to meet each other for mutual support. It is best that they are co-facilitated by a member of the multidisciplinary care team AND a ALHIV, like a trained Peer Educator.
- **Play groups for younger adolescents:** Younger adolescents or children living with HIV and their caregivers may benefit from groups where children of similar ages can play together and where they all have a chance to share and talk. These groups often involve child-friendly activities, like drawing, art, and music.
- **Groups for caregivers of ALHIV:** Family members of ALHIV may benefit from talking with each other or with a health care worker in a support group setting. Often family members need emotional support as well as ongoing educational and practical information to help support children's and adolescent's care and treatment.
- **Young mothers support groups:** Young mothers living with HIV and those caring for HIV-exposed or HIV-infected children may want to have their own support group. Young mothers support groups can provide needed psychosocial and emotional support to members and also help mothers understand and access key HIV and PMTCT services. These groups can also address concerns specific to mothers, like safer infant feeding, care of HIV-exposed babies, and the importance of adherence to PMTCT and ART services.
- **Adolescent bereavement group:** The death of a loved one is an extremely painful experience, especially if it is the loss of a parent. One way that adolescents can cope with the death of a loved one is to join a bereavement group.
- **Couples support groups:** Young couples may wish to form support groups. This includes couples where both people are living with HIV and couples where only one is (i.e. discordant couples). Couples can share common concerns and challenges and support each other to live positively with HIV and to prevent new HIV infections.
- **Groups for other populations:** Other groups of people with common characteristics may wish to form their own support groups. This could include support groups for sex workers, men who have sex with men, street youth, orphans, or other vulnerable groups. In areas with a diverse population, groups of people that have the same ethnicity or speak the same language may wish to form their own support groups.

What role can you play in support groups?

- Depending on the specific program, you can work with health care workers and/or youth leaders to start support groups in health facilities or in the community.
- You can help organize support group meetings (like by helping the leader to decide on the location and to work out logistics, etc.)
- You can help recruit support group members from the clinic or the community.
- You can suggest youth-friendly activities or appropriate topics for the group to discuss.
- You can be a role model for the group members and help make sure that the group provides a safe, confidential space for participants.
- You can give correct information and facts about HIV and try to dispel any incorrect myths or rumors (refer to *Module 3*).
- You can facilitate or co-facilitate support group meetings, for example with counselors, nurses, or youth group leaders.
- Whatever your exact role, you should always work closely with members of the multidisciplinary care team and group leaders to plan, coordinate, and conduct support groups for ALHIV.



What are the benefits of support groups to the members?

- When a person does not know many (or any) other people who are going through what he or she is coping with, that person can feel isolated and stigmatized. Support groups help people who have a problem or illness feel less alone and more understood.
- Participants in a group can be role models for one another.
- A support group can be a safe place for someone who needs to talk about personal issues, experiences, struggles, and thoughts.
- Adolescents benefit from support groups because they trust information that they get from their peers more than information they get from adults. In a support group, members are equals. This can make people feel much more comfortable talking openly about their problems.
- Support groups can help members understand clinic- and community-based services better, can give members support to seek and adhere to different services, and can engage members' families and peers as supporters.
- Support groups also offer a way to link health facility services and community-based services for their members. For example, health care workers can speak about HIV services as part of community-based support group meetings. Or, leaders of community-based organizations, such as youth groups, can speak about the services they offer at health facility-based support group meetings.
- Support groups may also give income-generating, vocational, or educational assistance, or have savings and loan programs, which can benefit its members.

The main goal of support groups is to offer psychosocial and emotional support to members. While some support groups may decide to do other activities, like income generation projects, there should always still be a focus on psychosocial support.

SESSION 8.2: Practical Tips on Planning and Facilitating Support Group Meetings

Things to Think About When Starting a Support Group

First, learn what support groups already exist in the community and at health facilities and then try to understand more about what support groups are needed:

- Ask adolescents who go to the clinic what kinds of support groups they are interested in, when they could come to a meeting, where they would like the meeting to be held, and what kinds of things they would like to talk about (e.g. adherence, stigma, relationships, disclosure, etc.).

Decide, mutually with the group facilitator/multidisciplinary care team member, who the support group is for:

- Who will be invited to attend?
- What is the ideal number and type of participants? It is recommended that support groups not have more than 10-15 people in the same meeting so that everyone can participate.
- How will you let people know about the support group?

Work with the group facilitator/multidisciplinary care team member and define the overall goals of the support group:

- What is the purpose of the support group?
- Is the support group meant to go on indefinitely or will it cover a certain number of topics and then come to an end?

Assist the group facilitator/multidisciplinary care team member to decide how often the group will meet and to select a convenient location, days, and times for the meetings:

- Where will the support group be held?
- What time and how often will the groups be held? Do most participants go to school or work during the day or do they have household chores that they need to do at certain times of the day? Is 1 hour enough or is 2 hours better?
- Will the group meet once each month? More often? Less often?

Decide with the group facilitator/multidisciplinary care team member who will lead the support group meetings and who will be invited to speak:

- Who will run the support group and what topics will be discussed? Will there be guest speakers?
- If the Peer Educator helps to facilitate the group, what are his or her exact roles and responsibilities going to be?

Planning and leading support groups are difficult tasks that require a lot of practice and experience. Working together with other multidisciplinary care team members is necessary to make sure that the group meetings are productive and well-organized!

Key Steps to Planning a Successful Support Group Meeting

Work in partnership with the group facilitator/member of the multidisciplinary care team to plan the logistics of the meeting:

- Is it a private space with enough places for people to sit?
- Can the room be arranged so participants are in a semi-circle (instead of in rows)?
- Will someone arrange tea or snacks for the meeting?
- Who will keep attendance and other records related to the support group?

Help plan an agenda and stick to it!

- Most support groups should last between 1-2 hours.

Suggested agenda items for support group meetings:

- Registration/sign-in
- Refreshments (tea, coffee, snacks, etc.)
- Welcome/opening (song, prayer, dance)
- Introductions
- Overview of the agenda
- Reminder about confidentiality and other ground rules
- Main group learning activity (game, health talk, etc.)
- Question and answer session
- Plan for the next meeting
- Closing (song, prayer, dance, etc.)

Make sure to suggest and help plan new learning opportunities and fun activities for support group members:

- Help keep everyone busy and having fun! Decide with the group facilitator which games and participatory activities will be conducted during the meeting (refer to suggestions in *Session 8.3*).
- Consider including a health talk as a part of each support group meeting. Health talks should be kept short and simple (about 15-20 minutes) so that support group members have time to discuss their feelings, questions, and concerns. Ask a nurse or other “expert” to lead the health talk.
- Get feedback from support group members on topics they would like to discuss during the meetings (including topics for the health talks) and incorporate these into the agenda. This can be done through an anonymous questions box.

Make sure the facilitator or co-facilitator reminds the participants about confidentiality and helps establish "ground rules":

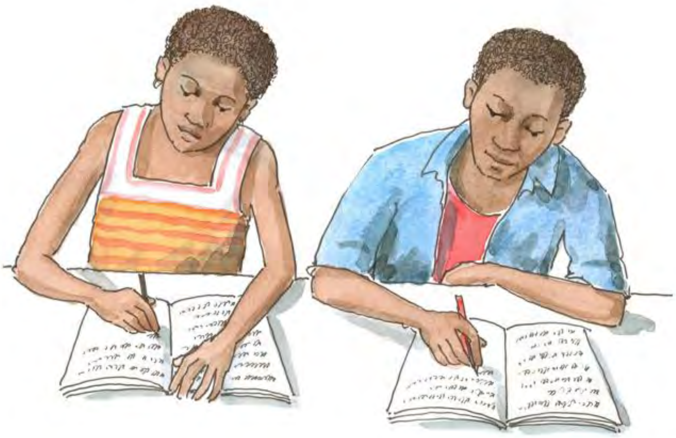
- It is always a good idea to remind support group members at the start of each meeting that what is said during the meeting will not be repeated to anyone. You can say, *"what is said in this room stays in this room."*
- During the first group meeting, ask the participants to brainstorm possible grounds rules. Examples include: not arriving late, what is said in the room stays in the room, not interrupting when another person is talking, respecting the opinions of others, allowing everyone a chance to speak, etc.

Offer ongoing support to participants:

- Encourage participants to speak in private with you or another facilitator (ideally, a member of the multidisciplinary care team) after the meeting if they have concerns they do not want to share with the group.
- Work with the group leader and make sure group members are given any needed referrals to other types of support and services.
- There may be situations where support group members urgently need assistance (for example, if they are mentally distressed, suicidal, violent, or a victim of violence). In these cases, Peer Educators should practice shared confidentiality and tell members of the multidisciplinary care team about these issues right away!
- Participants may also want to keep in touch with one another between support group meetings (e.g. through smaller informal meetings, text messaging, phone calls, etc.).

Keep basic records of the meeting:

- Always keep an attendance record. Remember that this record should be kept confidential.
- Ask someone to take simple notes at the meeting (or you can do this yourself after the meeting has finished). Write down what topics were discussed, key concerns of members, and any next steps.
- Write down the date, time, and location of the next meeting. Remember to remind participants about the time and date of group meetings and follow up with those who miss meetings using text messaging, email, or telephone (make sure to get their consent first).



Key Tips for Facilitators/Co-Facilitators of Support Group Meetings

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 feel less like a classroom and more comfortable to talk. The person leading the session 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 not so loud that you are shouting.
- Always remind participants about confidentiality and be sure that you also practice confidentiality.
- Lead an introductory activity (have people introduce themselves or say something about their families) so participants feel more comfortable with one another.
- Interact with participants and get them involved by moving around the room, asking questions, and asking people to share personal stories/concerns, etc.
- Tell participants that they all likely know something about the topic being discussed. Encourage them to share what they know and to use this as an opportunity to identify and correct any misconceptions.
- 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 participants who seem shy or quiet and emphasize that everyone’s personal experiences, questions, and concerns are important.
- Use visual aids and avoid lecturing.
- Only say what you know are the facts. If you are not sure about something, check with a nurse or counselor. Never make up information.
- Encourage participants to speak with you in private after the meeting if they have concerns they do not want to share with the group.
- At the end of the meeting, ask participants to summarize what they have learned and the actions they plan to take.
- Always leave time for questions and re-explain anything that participants did not understand completely.

My notes:

SESSION 8.3: Suggested Activities for ALHIV Support Groups

Key Points on Facilitating Activity-Based Support Groups

- Activity-based support groups help group members improve their social and problem-solving skills as well as their ability to work together.
- Learning to facilitate support groups takes time and practice. Using an activity as a focus for the group is a good way to create structure for meetings. Activities help get group members talking, especially in the beginning when they may feel shy or scared.
- The success of activity-based group sessions depends mostly on the preparation of group leaders. Always plan ahead and come to the session prepared!
- After welcoming the group members, making introductions, and deciding on ground rules, the group leaders should introduce the activity and explain that it relates to a particular theme in the lives of ALHIV (e.g. adherence, school, partners, living positively with HIV, stigma, etc.).
- Next, the group leader should carefully explain the rules of the activity. Explain instructions step-by-step and be sure to ask if anyone has questions or is unclear about the instructions. It is also helpful to write out any instructions on a flip chart.
- The role of the group leaders is to help participants have meaningful discussion during the activity. Ask members to share what they observe, think, and feel during the activity, and how they think the activity relates to their life.
- At the end of the activity, always ask group members about the feelings and opinions they had during the activity, what they learned, how this applies to their own lives, and what they liked/disliked about the activity. The trainer can summarize these statements as a way to close the session.

Ideas for support group activities with ALHIV:

Arts and Crafts Games

These games help adolescents think about themes in their lives in new ways. They can be very useful for younger adolescents, who enjoy doing activities that are hands-on, participatory, and creative.

Examples: Painting or drawing a picture of a scene where participants were discriminated against and discussing their feelings; making puppets out of locally-available materials and doing a performance; creating team murals (each team makes a wall drawing showing how they would fight stigma in the community and get everyone to support ALHIV)

Question Box

Make a box at the health clinic or hospital for anonymous questions. Tell group members that whenever they think of a question, they can write it on a piece of paper and put it in the box. These questions can then be picked out of the box at random during the support group meeting and discussed by everyone.

Songs/rap/poetry

Ask participants to work in small groups to create a song, rap, or poem about a health topic (e.g. about adherence, positive living, disclosure, negotiating safer sex, reducing stigma, etc.).

Plays/drama/mime/role play

Ask participants to work in small groups to create a play about a specific issue, such as negotiating safer sex, disclosing to a friend, living positively with HIV, or fighting stigma in schools or the community.

Journaling

Ask participants to create an "All About Me" box or journal using magazines, markers, and any other decorative items they can think of. Ask participants to think about the special things (hobbies, traits, talents, strengths, etc.) that make up their identity. Also, ask them to think about their future goals and dreams, including in the box or journal images that show who they want to be as an adult (e.g. having a family, going to university, having a career).

Sculpturing

Ask participants to put their whole bodies into a position that communicates an image of an issue or relationship. The resulting "sculpture" is then discussed.

Example: Ask young people to get into groups of 2 and ask each pair to make a sculpture showing how people treat ALHIV. Ask them to decide on roles—one person should be a ALHIV and the other should be a person stigmatizing him or her (i.e. someone in the community, school, or clinic). After all groups have come up with their sculptures, ask some of the pairs to go into the center of the circle and show their sculpture to the others. After each demonstration, ask:

> *What do you think this person is saying?*
> *How do you think these people are feeling?*

Ask the people in the sculpture:

> *What are you thinking?*
> *Why are you doing that?*
> *How are you feeling?*

Charades

Players try to act out terms or concepts without speaking.

Materials: A watch or clock; slips of paper (blank or with phrases written on them, like "*good adherence to care and medicines*," "*poor adherence to care and medicines*," or phrases about good coping and positive living, like "*eating well*" and "*exercising*"); two baskets, hats, or other containers for the slips; and a piece of paper and pencil to keep score.

Play: Divide the participants into 2 teams and give each team half of the slips of paper. If the slips of paper are blank, give the teams time to come up with an idea to write on each (a term, phrase, or concept related to the material they are learning). Choose a neutral timekeeper/scorekeeper or have the teams take turns keeping score. Review the gestures and hand signals that will be used during the game (e.g. holding up 1 finger will mean first word in the phrase, pointing to your ear will mean "sounds like…").

To play, teams take turns having 1 player choose a slip from the other team's basket. Then the player has 3 minutes to, without speaking, use gestures and actions to help his or her team members guess what is written on the slip.

Normally the game continues until every player has had a chance to "act out" a phrase. Scoring may be based on 1 point for every slip correctly guessed. Another scoring option is based on the total time that each team needed for all of the rounds; with this system, the team with the lowest score wins the game.

My notes:

SESSION 8.4: Classroom Practicum on Planning and Facilitating a Support Group Meeting

Case studies for small group work

Case Study 1:

You and another Peer Educator are starting a ALHIV support group at your health facility with the help of one of the health care workers. By talking to ALHIV at the clinic, you have learned that most of the younger ALHIV do not belong to a support group and that they would be interested in joining one. The group will meet twice per month.

1. *What is the general goal of the group?*
2. *Make a simple agenda for the first support group meeting, choosing at least one group activity.*
3. *Practice how you would start the support group meeting.*

Case Study 2:

One of the nurses at your health facility notices that many of her older adolescent clients are not coming back to the clinic on time for their appointments and are not taking their ARVs consistently. She is having trouble getting through to her clients about the importance of adherence to care and treatment and is worried that some of her clients are not practicing safer sex with their partners. The nurse comes to you because she wants you to help organize an adherence and positive living support group for older adolescents at the clinic. She says that she will co-facilitate the support group meetings with you.

1. *What is the general goal of the group?*
2. *Make a simple agenda for the first support group meeting, choosing at least one group activity.*
3. *Practice how you would start the support group meeting.*

Case Study 3:

A nurse asks you to help her with a support group for younger adolescents and their caregivers. Most of these clients have not been fully disclosed to by their caregivers—in other words, they may know something about HIV, but they have not yet been told that they are living with HIV for life. About 8 caregivers and the young adolescents they care for are expected to come to the meeting.

1. *What is the general goal of the group?*
2. *Make a simple agenda for the first support group meeting, choosing at least one group activity.*
3. *Practice how you would start the support group meeting.*

Case Study 4:

You, a counselor at your clinic, and another Peer Educator try to learn more about support groups in the community so you can refer your clients to them. You learn that there was a strong support group for ALHIV run by a local church and that this group was mostly for youth who were HIV-infected at birth. 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 care 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. You will work with your colleagues and the local church to plan the next ALHIV support group meeting in 2 weeks.

1. *What is the general goal of the group?*
2. *Make a simple agenda for the support group meeting, choosing at least one group activity.*
3. *Practice how you would facilitate the support group meeting, starting from the beginning.*

Note: Some of the preceding information in this Module was borrowed and/or adapted from the following sources:

The International HIV/AIDS Alliance. (2010). *We are all in the same boat. Using art and creative approaches with young people to tackle HIV-related stigma.* UNESCO.

Morgan, J. (2009). *Hero book manual.* REPSSI.

Program for Appropriate Technology in Health (PATH). (2006). *Games for adolescent reproductive health: An international handbook,* Washington, DC: PATH.

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 8.5: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- Peer Educators play an important role working with multidisciplinary care team members to start support groups in the health facility or in the community, co-facilitating support group meetings, and helping others organize and recruit members for support groups.
- While there are many different types of support groups, they should all aim to provide psychosocial and emotional support to their members.
- In peer support groups, members help each other to improve, to better manage their situation, to share challenges, and to discuss solutions.
- A support group should be a safe place for people who need to talk about personal issues, experiences, struggles, and thoughts.
- Careful planning is one of the keys to a successful support group. This includes having clear goals and objectives for the groups and an agenda for each meeting. It is important to ask potential support group members questions like what they want to get out of the support group and when/where is convenient for them (this is especially important for youth who are often busy at school or work).
- Including short health talks as part of support group meetings is one way to share information with members and to encourage them to seek health services. This is also a way to get other multidisciplinary care team members involved in the support group.
- Support group meetings should always be participatory and everything that is said during the meetings should be kept confidential.
- Good facilitation skills are important for running successful support group meetings.
- All adolescents can benefit from activity-based support groups, which can incorporate games, music, acting, journaling, and play.

MODULE 9: UNDERSTANDING AND SUPPORTING THE DISCLOSURE PROCESS

LEARNING OBJECTIVES:

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

- Reflect on your own values around disclosure
- Discuss why and how disclosure is a process
- Discuss the advantages and disadvantages of disclosure in your life and the lives of other ALHIV
- Discuss why it is important for Peer Educators to be open with their own status
- Work with other members of the multidisciplinary care team to provide practical support to adolescents throughout their disclosure process
- Discuss why it is important for younger adolescents and children living with HIV to know their HIV-status
- Work with other members of the multidisciplinary care team to support caregivers in the disclosure process with children and younger adolescents

CONTENT:

Session 9.1: Introduction to Disclosure

Session 9.2: Supporting ALHIV in Their Disclosure Process

Session 9.3: Working with ALHIV Who Have Not Been Fully Disclosed to and Supporting Caregivers in the Disclosure Process

Session 9.4: Classroom Practicum on Disclosure Support

Session 9.5: Module Summary

SESSION 9.1: Introduction to Disclosure

Disclosure Basics

The word **disclose** means:

- To reveal
- To make known
- To make public
- To share

What is disclosure?

- Disclosure is when someone tells one or more people about his or her HIV-status.
- **Disclosure is an ongoing process**, it is not a one-time event (see below).
- ALHIV need ongoing support and need to talk regularly about disclosure with their family, friends, and the entire multidisciplinary care team (including Peer Educators).

What exactly do we mean by "disclosure is an ongoing process?"

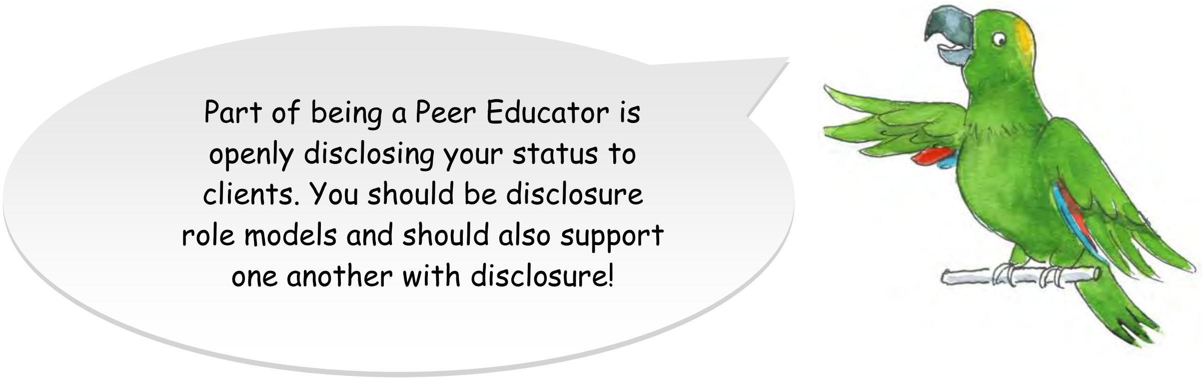
- For children and young adolescents, caregivers should start the disclosure process early. First they may want to "partially disclose" to the child, which means just telling him or her some things about having a sickness and needing to go to the clinic. Over time, caregivers should move to "full disclosure," which means the child or adolescent knows that he or she is living with HIV and knows exactly what this means.
- Once older children and adolescents know their HIV-status, it takes some time for them to fully understand what this means and to come to terms with their status.
- For adolescents who know their HIV-status, disclosure to others is also a process. At first, young people will likely want to tell only one or a few people they are close with about their HIV-status (like family members, sexual partners, close friends, etc.). Over time, and as they feels more comfortable, adolescents will likely tell more people about their HIV-status.
- All of these processes require ongoing communication and counseling with young people and caregivers. Peer Educators can play an important role in this ongoing process.

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 from peers or family members
- The ability to talk about symptoms and concerns
- Easier access to health care
- Improved adherence to care and medicines
- The ability to discuss safer sex and family planning choices with one's partner(s)
- The ability to refer one's partner(s) for HIV counseling and testing, and to care and treatment if needed
- For pregnant women, the ability to get support for PMTCT from family members and friends (like giving the baby ARVs and feeding the baby safely)
- The freedom to ask a friend or relative to be a treatment buddy
- Access to patient support groups and community organizations
- Serving as a disclosure role model for other people

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
- Discrimination at school
- Discrimination in the community
- Discrimination at work, including the possible loss of one's job
- Others making assumptions about one's sexuality, promiscuity, or lifestyle choices
- Rejection in the community
- Partner not wanting to have children
- Physical violence
- Self-stigma
- Loss of economic support from family members or partners.


Part of being a Peer Educator is openly disclosing your status to clients. You should be disclosure role models and should also support one another with disclosure!

My notes:

SESSION 9.2: Supporting ALHIV in Their Disclosure Process

How can Peer Educators help ALHIV during the disclosure process?

- Adolescents should make their own decisions about disclosure but Peer Educators can support them by answering their questions in an accurate and detailed way.
- Give realistic information and practical suggestions based on your own experience with the disclosure process.
- Remember to give clients ongoing and regular reassurance and emotional support during the disclosure process. Most ALHIV will disclose to one person at first and then more people over time.
- Talk about disclosure in ALHIV support groups.
- Use good communication skills (e.g., use good body language, ask open-ended questions, summarize and reflect, etc.) to talk about the client's fears and feelings around disclosure.
- Discuss the advantages and disadvantages of disclosure specific to each client's life.
- Help people weigh the advantages and disadvantages of disclosing their HIV-status to different people in their lives.
- Identify who supports them (e.g. peers, family, community members, etc.).
- Help clients decide whom to disclose to, when, and where, using the Talking Tree as a tool to guide the conversation.
- Encourage clients to take the time they need to think things through.
- Work with clients to think about a person's possible responses.
- Practice disclosure with clients through role plays, including giving suggestions about how they could start the conversation. For example, you can suggest the following "conversation starters" to clients who are unsure about what to say to family or friends:
    - *"I wanted to talk to you about something because I know you can help and support me."*
    - *"I went to the clinic today for a checkup and they talked to me about how it is important for everyone to get an HIV test because you can't tell if someone has HIV just by looking at them."*
    - *"I want to talk with you about something very important right now. I am talking to you about it because I love you and I trust you."*
    - *"I need to talk to you about something difficult right now. It is important that I be able tell you even the hard things. We need to support each other."*

- **Never work alone! ALWAYS work together with other members of the multidisciplinary care team—like nurses, counselors, or social workers—to support clients with disclosure.**

My notes:

Case Studies for large group discussion:

Case Study 1:

J___ is 16 years old and found out that she is HIV-positive at a VCT clinic 2 months ago. She came back to the ART clinic today for a second visit and says that she has not yet told anyone about her HIV-status because she is too ashamed and scared.

How would you help J___ explore the advantages and disadvantages of disclosure?

Case Study 2:

V___ is a 12-year-old boy who was perinatally infected with HIV. He tells you that he is really worried and stressed out about telling his best friend at school that he has HIV. His family knows his status but none of his friends know.

How would you talk to V___?

Disclosure can be scary for adolescents! Some ALHIV fear rejection and violence from family, friends, and partners. Some adolescents may also be scared to disclose their HIV-status because they are afraid to reveal information about their drug use, sexual behaviors, or sexual orientation.

SESSION 9.3: Working with ALHIV Who Have Not Been Fully Disclosed to and Supporting Caregivers in the Disclosure Process

What are some of the reasons adults (including health care workers) do not want to tell children or younger adolescents about their HIV-status?

- Sometimes they do not know where to start.
- If there are other children who are not HIV-infected in the home, there may be concerns about how the other children will react or how the HIV-infected child will feel.
- They fear that disclosing will cause psychological harm to the child.
    - They fear that disclosing will reduce the child's will to live.
    - They fear that disclosing will make the child think he or she is not normal.
    - They have the belief that children are supposed to be happy, and that knowing they have HIV will make them no longer enjoy their childhood.
- They are afraid that the child's or family member's HIV-status will be revealed by accident.
    - Children are not always good at keeping secrets.
    - Children may not understand the stigma attached to HIV.
- They want to protect the child from social stigma, discrimination, and rejection.
- They feel guilty that the child is HIV-infected.
- They are not comfortable talking about taboo subjects (like sex) with children.
- They believe that children are too young to understand complicated health issues.

Why might parents or caregivers find disclosing to their child difficult?

- They may have a hard time coping with their own illness or the illness of other loved ones.
- Families have different ways of coping. Some use silence, have limited communication, or deny that the child has HIV.
- Some caregivers believe that the child will not understand.

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

- All youth have a right to know about their own health.
- Youth who have not been disclosed to may:
  - Have frightening or incorrect ideas about their illness
  - Feel isolated and alone
  - Learn their HIV-status by mistake
  - Have poor adherence
- Youth often want and ask to know what is wrong. Youth are observant, smart, and curious. They often know much more than adults think they do.
  - Younger adolescents may already suspect their HIV-status but are keeping it a secret or waiting for an adult to talk to them about it.
  - Younger adolescents may have fears about their HIV-status, especially if one or both of their parents has died.
- The later a young person is told about their status, the more difficult it will be for the young person to accept.
- When youth learn about their status directly from their caregivers, it can provide comfort and reassurance. Too often, younger adolescents overhear health care workers and caregivers talking about their health as if they were not in the room.
- Younger adolescents who know their HIV-status can take an active role in their own care and treatment plan and, when old enough, can take steps to live positively and prevent new infections.
- Orphaned or other vulnerable adolescents may wonder why they have lost a parent or been rejected by the family. They need to know the truth. This will also help adolescents get the services they need, especially those who do not have regular caregivers.

Partial and full disclosure

Partial disclosure:

- Means giving a child information about his or her illness without using the actual words "HIV" or "AIDS"
- Should start at an early age (and definitely by age 5)
- Helps move the disclosure process forward and prepares the child for full disclosure later on
- Is an effective strategy to help caregivers who do not yet feel ready for full disclosure
- Is part of a process in which caregivers move little by little toward full disclosure

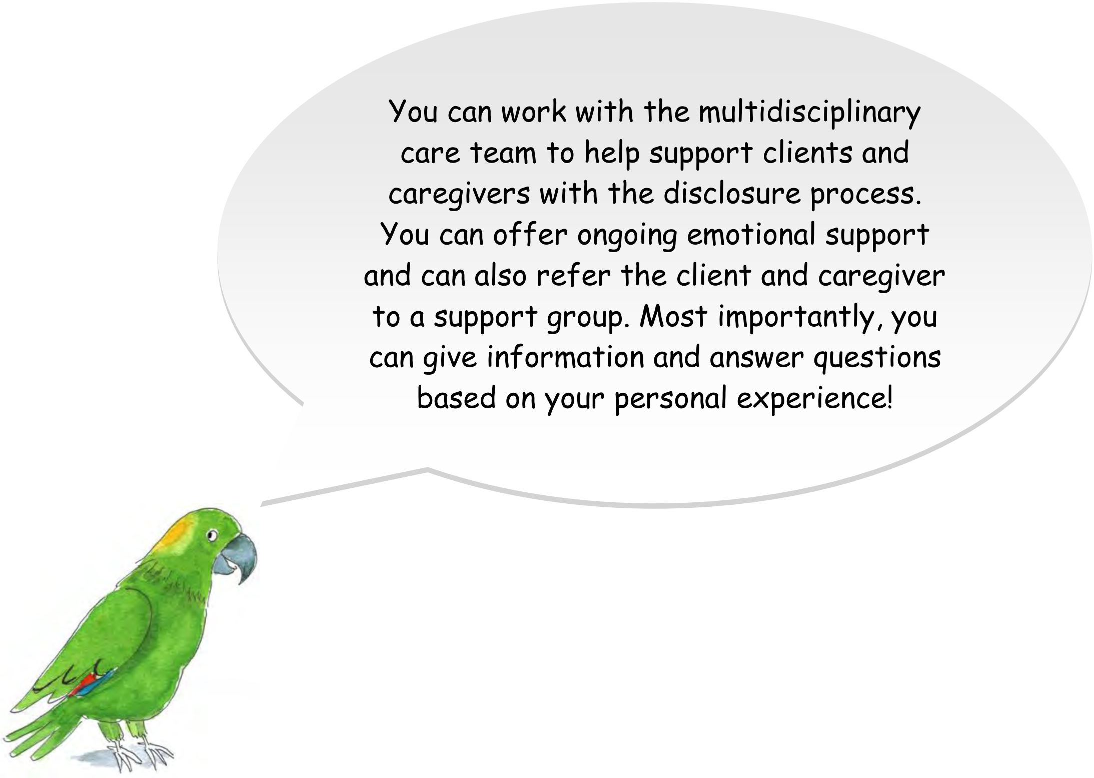
Full disclosure:

- Means telling a child specifically that he or she is HIV-infected and giving him or her information about what this means (including that the child will need lifelong HIV care and treatment)
- Is easier for the child if they have been partially disclosed to over time, understand some basics about their health and their care and medicines, and have been supported throughout the disclosure process
- It often takes time for young people to understand and come to terms with their HIV diagnosis, so the disclosure process requires ongoing communication (at the clinic and at home) even after the young person knows his or her status.
- Remember that disclosure is an ongoing process and not a one-time event. Clients and caregivers both need ongoing and regular disclosure support from the entire multidisciplinary team, including Peer Educators.

My notes:

You can help adolescents and their caregivers with the disclosure process by:

- Helping provide an environment where children can keep asking questions and talk about their experiences coming to terms with their HIV-status
- Being an ongoing source of information and support throughout the disclosure process, both for caregivers and adolescents
- Working with members of the multidisciplinary care team to encourage caregivers to talk regularly with their child about his or her status and to encourage open communication at home
- Helping a nurse, counselor, or social worker talk with the parents or caregiver at follow-up appointments to see how the child is handling knowing his or her status
- Talking about your personal experiences with disclosure
- Offering support and understanding to the family to cope with their emotions and feelings during the disclosure process
- Suggesting (and leading) a ALHIV support group



SESSION 9.4: Classroom Practicum on Disclosure Support

Case studies for role play:

Case Study 1:

H___ is 16 years old and tested positive for HIV about 2 years ago. H___ got tested because his girlfriend at that time found out she was HIV-positive. He now has a different girlfriend and he has not told her about his HIV-status. He takes good care of himself and feels fine. Today, he has come to the clinic for his regular appointment and wants to talk with you about how to tell his girlfriend that he is living with HIV. He does not like using condoms and is afraid that if he starts using them with her, she will know he has HIV.

What would you say to H___ in order to support him in the disclosure process?

Case Study 2:

S___ is a 14-year-old girl who was perinatally infected with HIV. S___ really wants to disclose to one of her male friends at school. S___ likes her friend very much and she knows that he likes her, but S___ is nervous about her friend's reaction. They have been arguing recently because S___ has been avoiding him. S___ has come today to ask your help to decide what to do.

What would you say to S___ to support her in the disclosure process?

Case Study 3:

D___ is a 10-year-old girl who has been living with HIV since she was a baby. Her mother died 5 years ago and since then she has lived with her grandmother. D___ and her grandmother have come to the clinic today for D___'s monthly visit. When the nurse asks her about missed doses, D___'s grandmother says that D___ does not want to take her medicines anymore. She says that D___ was a "good" girl in the past and took them without complaining but now she keeps asking why she has to take these pills. She says D___ wants to know when she will finally be done taking them. When the nurse asks the grandmother what D___ knows about her health she becomes quiet. The nurse decides to speak with D___'s grandmother and asks you to help her with the counseling session.

Is there any support you can offer to D___'s caregiver to help with the disclosure process?

Case Study 4:

L___ is a 12-year-old boy living with HIV who is taking ART. He lives with his mother, his uncle, and 5 older half-siblings and cousins. Each time L___ comes to the clinic he becomes upset when he gets blood drawn and he has recently been asking, *"why do I need to take medicines"* and *"why am I always sick"?* Today, L___ seems mad that he had to come to the doctor instead of playing with his cousins. When you ask his mother, she says she has not told L___ anything about his HIV-status or the reasons he has to come to the clinic so much. She asks your advice about what to do. The nurse decides to have a conversation with L___'s mother about disclosure and asks that you help her with the conversation.

Is there any support you can offer to L___'s mother to help with the disclosure process?

Helping clients during the disclosure process does NOT mean putting pressure on them to disclose. Instead, it means helping the multidisciplinary care team support clients to work through issues related to disclosure, allowing them to talk about their concerns and, if they have decided they want to disclose their status to others, working with them to make a plan.

My notes:

Note: Some of the preceding information in this Module was borrowed and/or 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.

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.

The International HIV/AIDS Alliance. (2008). *'Building Blocks: Africa-wide briefing note on 'Young Children and HIV.'* International HIV/AIDS Alliance.

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.

Adherence Networking Group. (2006). *Kids count: Children's ART adherence resource pack.* Centre for the Study of AIDS, University of Pretoria and the Perinatal HIV Research Unit, South Africa.

SESSION 9.5: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- When Peer Educators are very open about their own HIV-status, it helps to reduce stigma and discrimination.
- Peer Educators can work with ALHIV to help them understand why disclosure is important.

- Disclosure can:
  - Help a person access prevention, care, treatment, and support
  - Improve adherence
  - Help reduce stigma and discrimination by bringing HIV out into the open
  - Slow the spread of HIV by helping people protect themselves and their partners
- Peer Educators can help adolescents weigh the advantages and disadvantages of disclosure and they can be supportive counselors throughout the disclosure process. They 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 all adolescents to know about their HIV-status.
- ALHIV who have not been disclosed to may:
  - Have frightening or incorrect ideas about their illness
  - Feel isolated and alone
  - Find out about their HIV-status by mistake
  - Have poor adherence
- **Partial disclosure** means giving a child information about his or her illness without using the actual words "HIV" or "AIDS."
- **Full disclosure** means telling a child that he or she is HIV-infected and giving him or her information about what this means. This includes telling the child that he or she will need lifelong HIV care and treatment.
- When to say "HIV" varies with the child and the family, but most children should know they have HIV as soon as they have developed the emotional maturity to understand what this means.
- Many children who are told their HIV-status want to continue to talk about it, so it is important that they are given ongoing support and opportunities both at home and at the clinic to talk and ask questions.
- Peer Educators can use the Talking Tree and role playing to help prepare ALHIV for the disclosure process.

APPENDIX 9A: Talking Tree

Instructions for the Talking Tree: Each instruction below goes with a number on the Talking Tree. The Peer Educator should follow these instructions in order.

Begin by explaining that the African Baobab tree is one of the longest-living and largest trees on Earth. It symbolizes survival and life because it sometimes grows in harsh conditions. It also symbolizes protection and sharing because it can be used as shelter and a place for people to gather and meet. Talk about the various parts of the tree: the trunk, roots, branches, leaves, fruits, nuts, or birds living in the trees.

1. Allow some time for the client to describe what is currently happening in his or her life (i.e. why he or she came here today to talk with you). Ask the person to tell you about the main problem or issue he or she is having—when it started, how it developed, and how he or she feels about it. Let the person know you would like to work together in finding something that he or she can do to make the situation better. Write a brief description of what is happening under "What is the main issue for this client" on the left-hand side of the tree.
2. Ask the client what he or she thinks is causing the problem/issue and write this under "What is the cause of this issue?"
3. Ask the client to imagine him- or herself as a tree—the roots are "*where you come from, your home, your family, and your community.*" The roots are "*what supports and grounds you.*" Ask the client who provides him or her with the most support in life and who can help him or her resolve this issue. Write this information under "family, peers, and community" in the roots of the tree.
4. Next move to the trunk. The trunk is the client's "*hope for the future, a future goal, or dream.*" Write the goal on the trunk of the tree. Encourage the client to close his or her eyes and think about him- or herself in the future, achieving her goal. Ask: " *What are you doing in that picture*?"
5. The branches are the client's options, the ways he or she copes, and potential solutions (i.e. things he or she can do to achieve the hope or goal). Talk about the benefits and consequences of each option. Encourage the person to think about strategies that have worked in the past. Write these on the branches. Then talk about all the person's resources—the "*things you have going for you,*" like inner strengths, talents, skills, and spiritual resources to help in coping.
6. Then ask: *"What is the next step in achieving your goal or hope for the future?"* Help the client form an action plan of immediate next steps.
7. Lastly, summarize the main points that were discussed during the Peer Education session (example: disclosure to partner) and, if necessary, talk about any referrals or arrange another time to talk
8. Review and discuss the client's situation and "next steps" with the program supervisor or a member of the multidisciplinary care team.

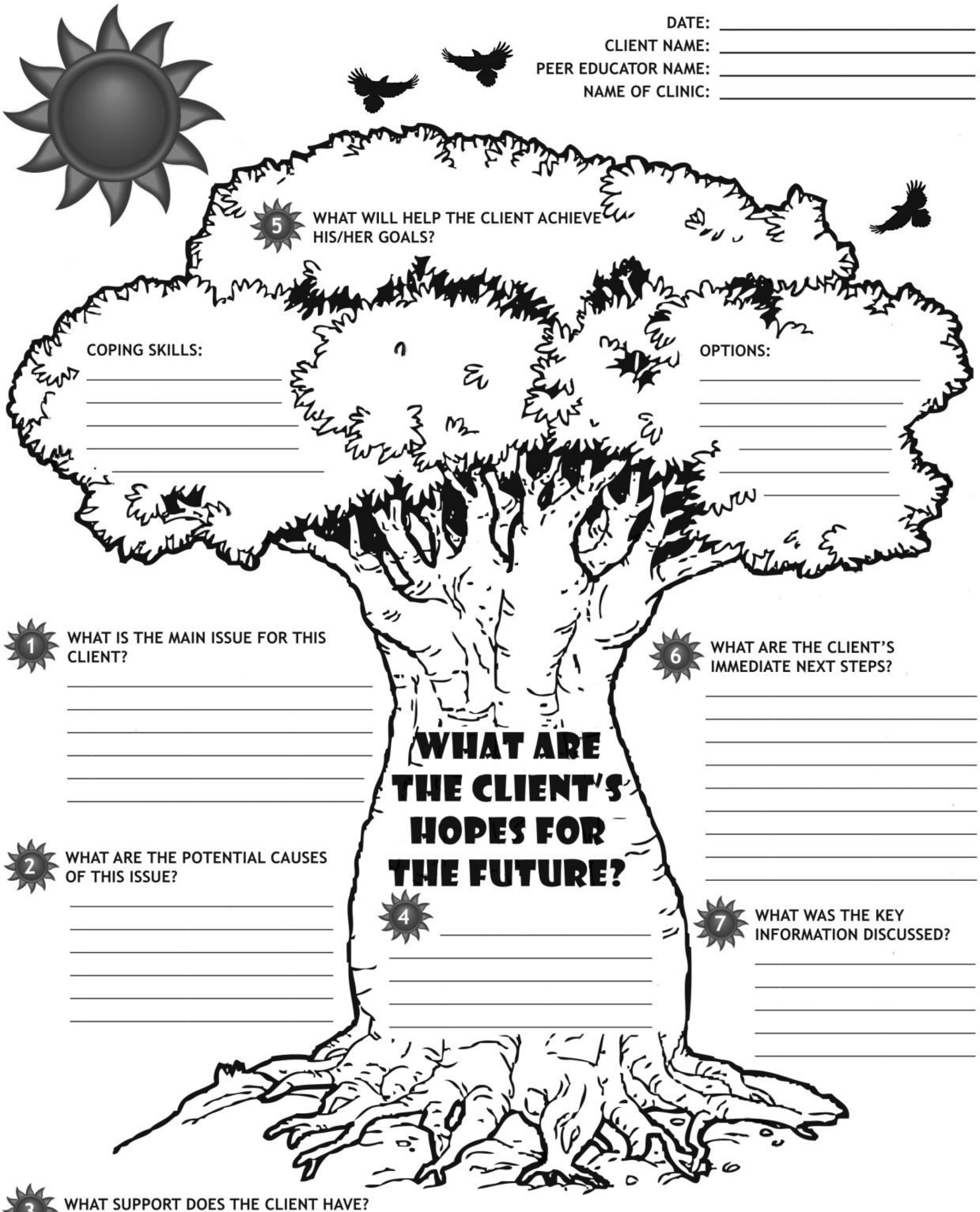
TALKING TREE

DATE: ____________________

CLIENT NAME: ____________________

PEER EDUCATOR NAME: ____________________

NAME OF CLINIC: ____________________



5 WHAT WILL HELP THE CLIENT ACHIEVE HIS/HER GOALS?

COPING SKILLS:

OPTIONS:

1 WHAT IS THE MAIN ISSUE FOR THIS CLIENT?

6 WHAT ARE THE CLIENT'S IMMEDIATE NEXT STEPS?

WHAT ARE THE CLIENT'S HOPES FOR THE FUTURE?

2 WHAT ARE THE POTENTIAL CAUSES OF THIS ISSUE?

4

7 WHAT WAS THE KEY INFORMATION DISCUSSED?

3 WHAT SUPPORT DOES THE CLIENT HAVE?

FAMILY:

PEERS:

COMMUNITY:

MODULE 10: SEXUAL AND REPRODUCTIVE HEALTH

LEARNING OBJECTIVES:

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

- Define the terms sex and sexuality
- Discuss different forms of sexual behavior and expression
- Reflect on your attitudes and values about different sexual behaviors
- Understand the importance of being non-judgmental when talking with adolescents about sexual and reproductive health
- Describe the basic functions of sexual and reproductive body parts in men and women
- Provide basic information about ways to practice safer sex, contraception, and dual protection
- Demonstrate male and female condom use
- Review basic information about the prevention and treatment of common STIs
- Provide basic information on PMTCT to adolescent clients
- Discuss the needs of adolescent clients who have experienced sexual abuse and gender-based violence

CONTENT:

Session 10.1: Introduction: Let's Talk About Sex

Session 10.2: Parts of the Body Involved in Sex and Reproduction

Session 10.3: Safer Sex and Contraception

Session 10.4: Preventing and Treating Sexually Transmitted Infections (STIs)

Session 10.5: Preventing Mother-to-Child Transmission of HIV (PMTCT)

Session 10.6: Sexual Abuse and Gender-Based Violence

Session 10.7: Module Summary

SESSION 10.1: Introduction: Let's Talk About Sex

Sex:

- Sex is a normal part of life for some older adolescents and adults.
- Sex means different things to different people and there are many different types of sexual behaviors.
- It is very important for Peer Educators to be comfortable talking about sex and reproduction with their clients.
- HIV is mainly spread to adolescents and adults through unsafe sex.
- Unsafe sex is any kind of sex that puts people or their sexual partners at risk of getting a sexually transmitted infection, including HIV, or of unwanted pregnancy.
- In order to help people protect themselves and their families, we must make sure people know the facts about sex.

Sex means different things to different people. People have different sexual behaviors, including:

- Vaginal sex (when the penis or fingers go into the vagina)
- Anal sex (when the penis or fingers go into the anus)
- Oral sex (when a person kisses or licks their partner's penis, vagina, or anus)
- Inserting fingers or objects into the vagina or anus
- Masturbation (alone or with a partner)
- Having sex with men, women, or both men and women

Note: we will learn more about the parts of the body mentioned here in the next Session

Sexuality:

- Is more than sex and sexual feelings
- Includes all the feelings, thoughts, and behaviors of being a girl, boy, woman, or man, including feeling attractive, being in love, and being in relationships that include sexual intimacy and physical sexual activity
- Is an experience involving the whole mind and body
- Is constantly evolving as we grow and develop
- Is a part of us from birth until death

The following are some aspects of sexuality. Each of these aspects is connected to the others and makes a person who he or she is.

- Body image: How we look and feel about ourselves, and how we appear to others
- Gender roles: The way we express being either male or female, and the expectations people have for us based on whether we are male or female
- Relationships: The ways we interact with others and express our feelings for others
- Intimacy: Sharing thoughts or feelings in a close relationship, with or without physical closeness
- Love: Feelings of affection and how we express those feelings for others
- Sexual arousal: The different things that excite us sexually
- Social roles: How we contribute to and fit into society
- Genitals: The parts of our bodies that define our sex (male or female). They are part of sexual pleasure and reproduction.
- Ways we can express sexuality: dancing, flirting, wearing attractive clothes, having wet dreams, masturbation, daydreams, and others.

Remember:

- In many places, "sex" is usually thought to mean only penis-vagina sex between a man and a woman. However, sexual behaviors actually include much more than penis-vagina sex.
- If you do not talk about sex and sexual behaviors with clients, clients may not get the information, skills, and supplies they need to protect themselves and their partners and to reduce their risk of HIV, STIs, sexual violence, discrimination, and unwanted pregnancy.
- While you can have their own opinions about different sexual behaviors, they should not put their values on clients. Clients should feel comfortable talking about their sexual behaviors with Peer Educators no matter what.

Adolescence is an important stage of sexual development:

- Adolescence is a time of change, sexual experimentation, and risk taking.
- Adolescents are defining their sexual identity and exploring their sexuality.
- Adolescents may fear that they will be judged or that their sexual orientation will be disclosed to others, so listen and support them in a nonjudgmental way.

Different types of sexual behaviors (adapt to the local context as needed):

Hugging	Kissing	Giving oral sex	Receiving oral sex
Group sex	Penis-vagina sex	Anal sex	Oral-anal sex
Two women having sex	Two men having sex	Getting paid for sex	Sex in a public place
Being faithful to one partner	Having many sex partners	Sex with a person who is much younger	Sex with a person who is much older
Masturbation	Masturbating your partner with your hand	Watching pornographic movies	Sex with people you do not know well
Sex with your spouse	Sex between a teacher and a student	Having "dry sex"	Hurting someone during sex
Sex between relatives	Sex with children	Sex before marriage	Sex with someone other than a boyfriend or girlfriend
Rape	Paying for sex	Sex with animals	Having sex without feeling pleasure
Swallowing cum (semen)	Telling someone a lie just to have sex	Sex with someone of a different race	Sex with someone of a different ethnic group
Forcing your partner to have sex	Sex with someone who is married	Sex with a disabled person	Sex after drinking alcohol
Sex after using drugs	Watching other people have sex	Having sexual desires about other people	Being celibate (not having sex), even if you are older
Having sex because it is your duty	Placing objects in the rectum/anus	Placing objects in the vagina	Using toys or vibrators for sexual pleasure

SESSION 10.2: Parts of the Body Involved in Sex and Reproduction

Because HIV is most often spread through unsafe sex, it is very important that Peer Educators understand the parts of the body involved in sex and reproduction. By making sure that young people have the facts, we can help them protect themselves!

Adolescents go through many physical, emotional, and sexual changes before becoming adult men and women:

Changes in women	Changes in men	Changes in both sexes
• Menstruation • Development of breasts • Widening of hips • Appearance of body hair (pubic hair, leg, and underarm hair) • Development of vulva and pelvis	• Growth of penis, scrotum, and testicles • Morning erections • Development of muscles • Appearance of body hair (pubic area, underarms, chest, and facial hair)	• Growth • Acne • Change in tone of voice • Interest in physical changes, sex, and sexuality • Sexual experimentation • Hormonal changes

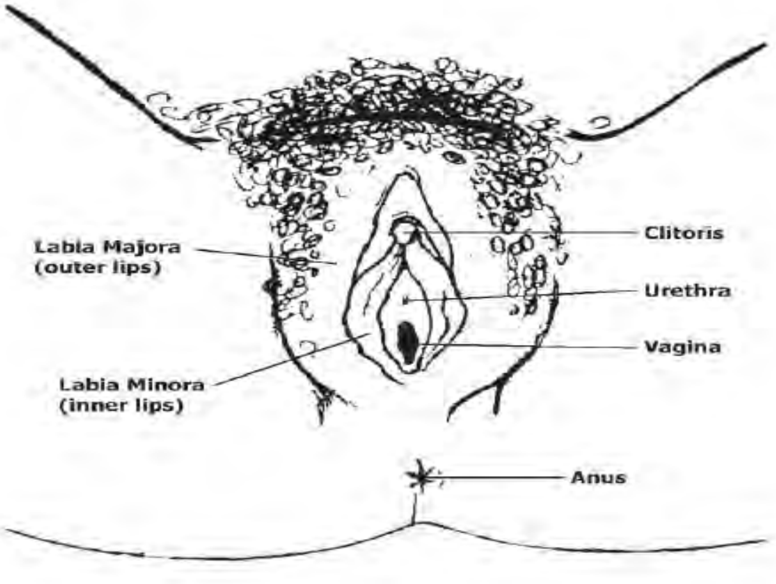
My notes:

Female sexual and reproductive body parts:

External female body parts (parts you can see):

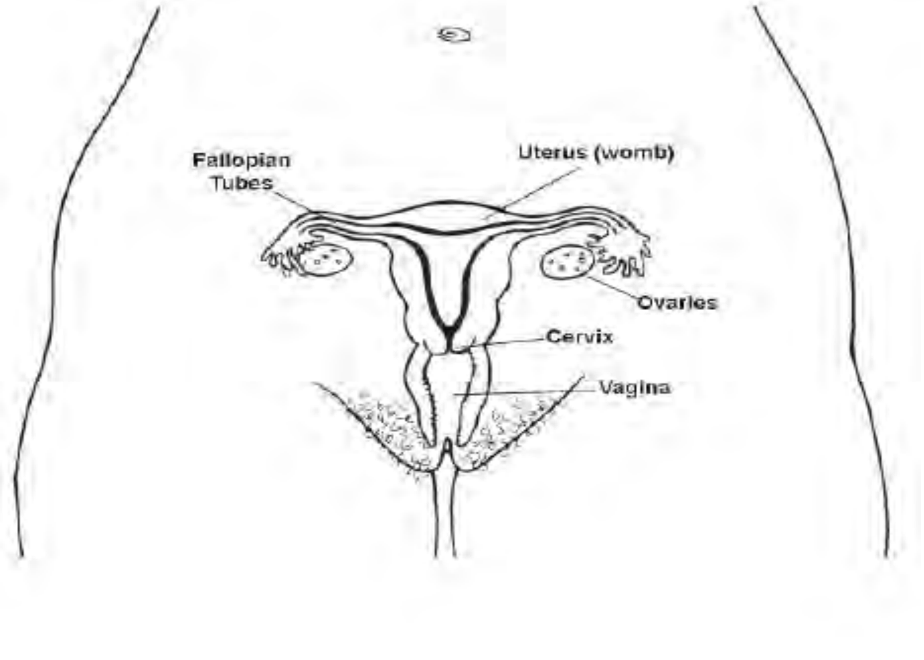
- **Urethra:** where urine (pee) comes out of the body
- **Vagina:** where the penis or fingers enter during sex and also where a baby comes out. The vagina is the opening to the cervix and the uterus, which is where babies grow.
- **Anus:** where stool (poop) comes out of the body and where the penis 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 leading to orgasm

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



Internal female body parts (parts you cannot see):

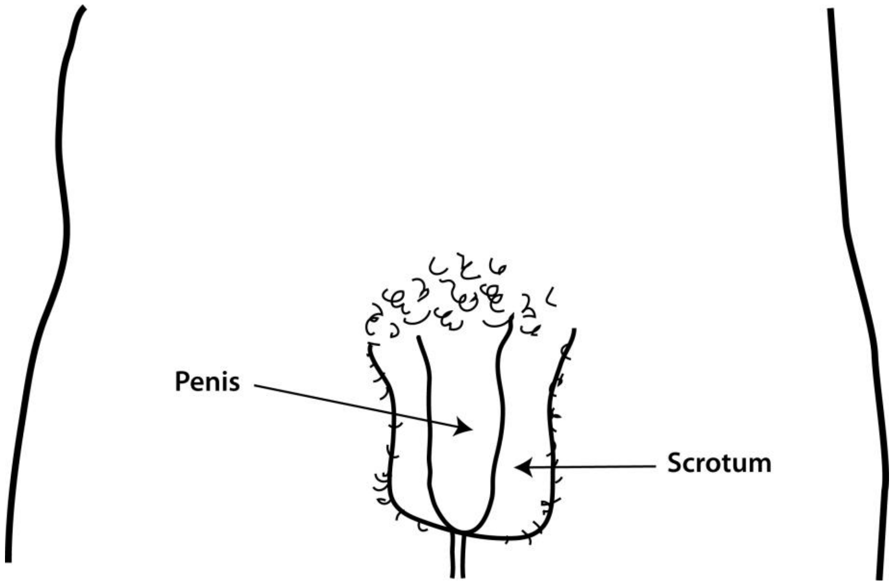
- **Uterus** or **womb:** where a baby grows and where monthly bleeding comes from
- **Ovaries:** where the eggs are stored
- **Fallopian tubes:** attached to the uterus. The eggs travel through the fallopian tubes to get from the ovaries to the uterus.
- **Cervix:** "mouth" of the uterus. Sperm enters 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, which is where babies grow.



Male sexual and reproductive body parts

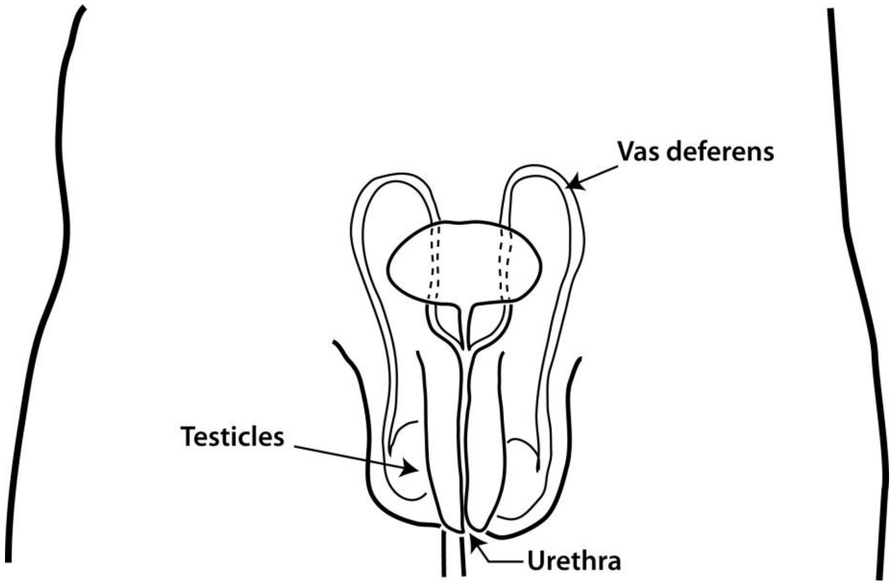
External male body parts (parts you can see):

- **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 females.



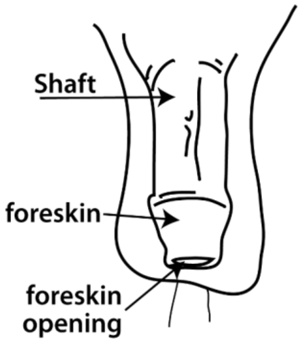
Internal male body parts (parts you cannot see):

- **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.

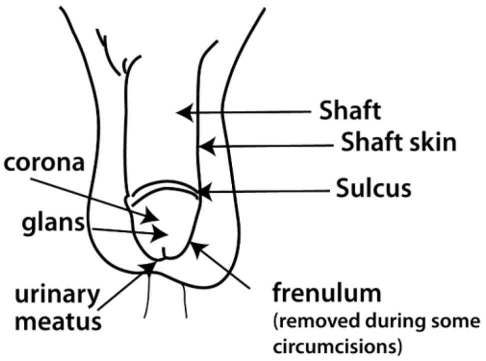


My notes:

Uncircumcised Penis



Circumcised Penis



Note: A **circumcised penis** is one that has had the foreskin cut off.
An **uncircumcised penis** is one with foreskin. This is how all boys are born.

My notes:

SESSION 10.3: Safer Sex and Contraception

What do we mean by safer sex?:

Safer sex is anything that sexual partners do to lower their HIV, other STI, and pregnancy risk. Safer sex involves choosing sexual practices and protection methods that do not allow body fluids to pass from one person to the other.

Some ways to have safer sex are:

- Using a condom for all types of sexual intercourse (oral sex, anal sex, vaginal sex)
- Masturbating one's partner, as long as males do not ejaculate near any opening or broken skin on their partner
- Mutual masturbation
- Rubbing against each other with clothes on
- Sharing fantasies
- Massaging
- Hugging
- Kissing

Reasons why adolescents may not practice safer sex:

- They think they are not vulnerable to pregnancy or HIV. They think: *"It can't happen to me"* or *"I don't have sex often enough to get pregnant or contract a STI/HIV."*

- They do not have access to youth-friendly reproductive health services.
- They do not have access to accurate information at home, in school, in the community, or from media sources (television, radio, etc.).
- Contraceptive methods are not available or they are too expensive.
- Denial: *"My partner would never expose me to any risk."*
- They feel pressure from their boyfriend or family to get pregnant.
- They are scared their partner will reject them.
- They are scared of side effects.
- They feel embarrassed.
- The doctor or nurse at the clinic has a judgmental attitude.
- They do not know how to negotiate condom use with their partner.
- They have inaccurate information, like thinking that a girl cannot get pregnant if she is menstruating or that a girl cannot get pregnant if when she has sex for the first time.

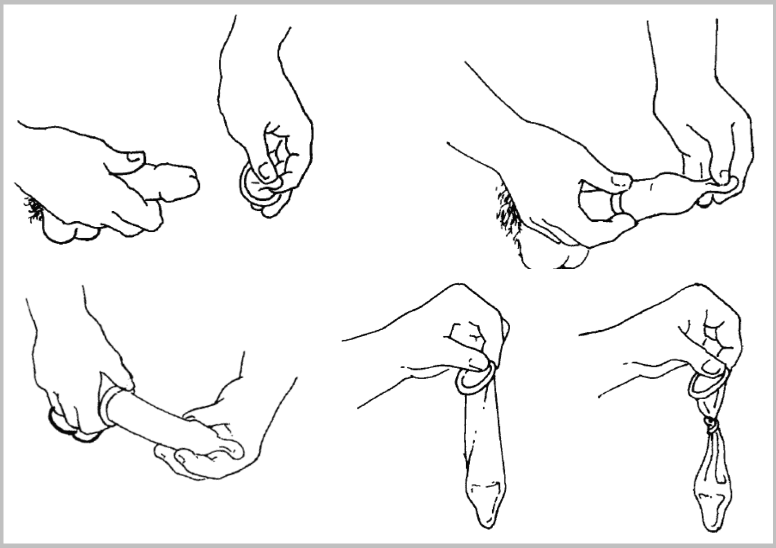
Condoms:

- 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 to prevent transmission of HIV to your partner. Condoms also prevent other STIs and unwanted pregnancy.
- There are a lot of myths about condoms, like that they are only for sex workers or that married people do not use them. You should spread the truth about condoms, promoting them as a way for young people to protect themselves and their partners from HIV and other STIs.
- Some people feel that condoms make sex less enjoyable. We should respect everyone’s personal experiences with condoms, but remember that even if it does change the way sex feels, it is still worth it to protect ourselves and our partner(s).
- Some people think that if both partners are living with HIV, then they do not need to use condoms. It is important for you to explain that even if both partners are living with HIV, using condoms is still a good idea. This is because there may be some chance of passing different types of HIV from one partner to the other, which may lead to drug resistance. Condoms can also prevent the spread of other STIs between partners. Peer Educators can help explain the facts so people and couples can then make up their mind about using condoms with their partners.

Part of your job is to spread the truth about condoms, to give out condoms, and to help ALHIV learn how to use them. This is so they can protect themselves and their partners from HIV, STIs, and unwanted pregnancy.

How to use a Male Condom

These are the basic steps you should know for using, and showing others 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:

- 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.
- Open the packet on one side and take the condom out. Do not use your teeth to open the package.
- 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.
- Hold the condom so that the tip is facing up and it can be rolled down the penis.
- 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.
- 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.
- Remove the condom and tie it in a knot to avoid spilling. Throw it away in a latrine or bury it.
- Use a new condom every time!

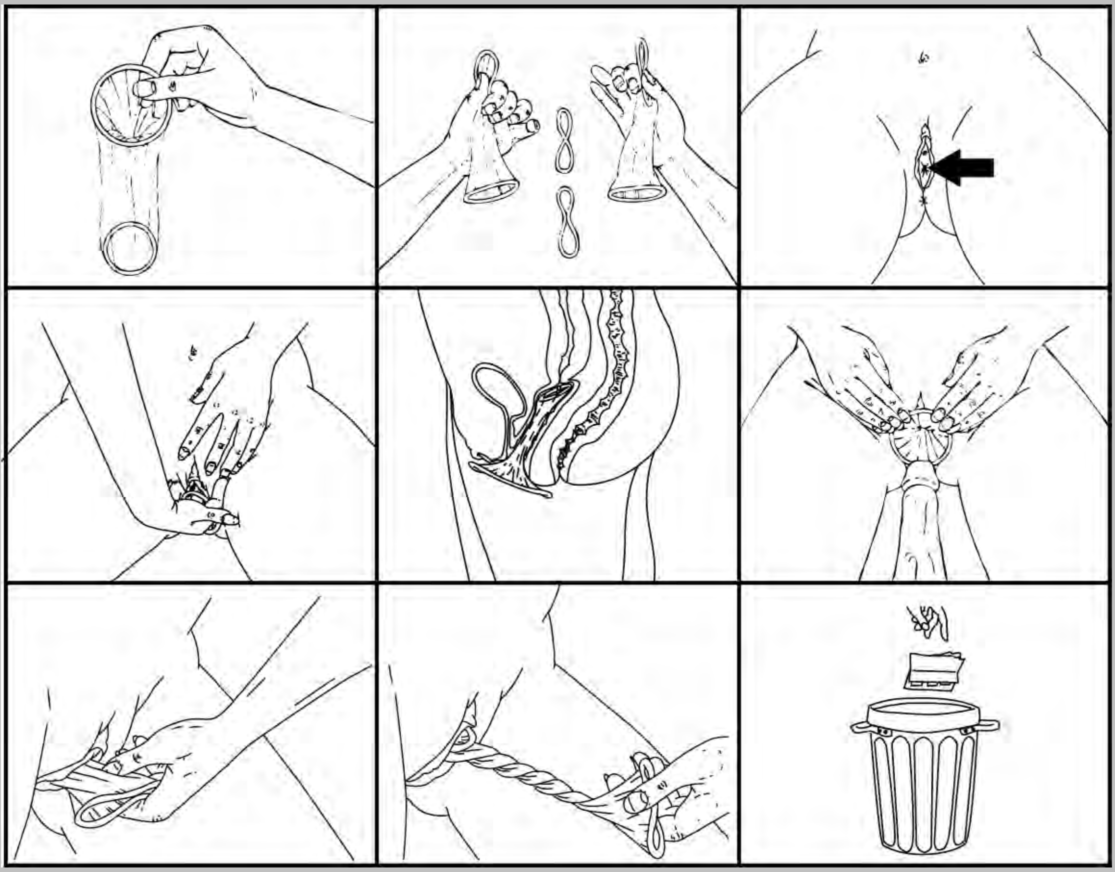
Also, it is important to:

- 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.

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

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 show people how to use it, you can use a box with a round hole cut in it or your hand.



Steps to use a female condom:

- Look at the condom package and check the expiration date to make sure it is still good and that the package does not have any damage.
- Open the packet. Do not use your teeth.
- Find the inner ring at the bottom, closed end of the condom. The inner ring is not attached to the condom.
- Squeeze the inner ring between your thumb and middle finger.
- 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.
- When you have sex, guide the penis through the outer ring. It has to be INSIDE the ring.
- After the man ejaculates (comes), before the woman stands up, squeeze and twist the outer ring to keep the semen inside the pouch. Pull the pouch out.
- Put the used condom in a latrine or bury it. Do not put it in a flush toilet.

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

Dual protection:

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

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

Using condoms plus a hormonal or long-term contraceptive method is one of the best ways to prevent HIV and unwanted pregnancy in male-female sexual relationships.

Reasons adolescents may not be able to negotiate safer sex:

- They may not have the right communication skills to talk about protection with their partners.
- Young women may not have control over when and how they have sex because men often make those decisions.
- Adolescents may believe that if they suggest having safer sex, their partners will think they don't trust them.
- Adolescents may be scared or embarrassed to bring up the topic of protection.
- Adolescents may want to get pregnant: For young women, it may be a way to keep a relationship. For young men, getting a girlfriend pregnant may be a way to prove their manhood.

In addition to using condoms and practicing safer sex, there are other ways to reduce the risk of HIV transmission to a sexual partner. These include:

- Making sure your partner gets an HIV test and repeats the test every 3 months if he or she is negative
- Making sure that you (and your partner if he or she is also living with HIV) are taking ART if eligible
- Taking your ART the right way, at the same time, every day to keep your viral load low and to reduce your risk of transmitting HIV to your partner (see the "treatment as prevention" section in the box below)
- Checking to make sure your partner is taking his or her medicines if he or she is also living with HIV and is on ART
- Preventing sexually transmitted infections (or STIs) and getting yourself and your partner treated right away if either person has an STI (there is more about STIs later in this Module)

Future HIV Prevention Options with ARVs

Treatment as Prevention

- **"Treatment as prevention"** is a term describing the use of ART by an HIV-positive person to reduce the risk of passing HIV to others.
- **The goal of "treatment as prevention" is to reduce an HIV-positive person's viral load.** When the amount of virus in the blood is very low (or undetectable), the person is less likely to pass on the virus.
  - Findings from an important study, known as **HPTN 052**, were released in 2011. The study assessed HIV transmission in nearly 900 discordant couples (where 1 partner is HIV-positive and the other is not). To enroll in the study, the HIV-positive person had to be relatively healthy and not yet eligible for ART. Half of the HIV-positive participants started ART immediately (at a CD4 between 350 and 550) and half waited or 'deferred' ART until they met eligibility criteria (CD4 <250). All of the couples received condoms and counselling on safer sex.
  - The results showed that when ART was started immediately, the HIV-negative partners in the couples were much less likely to acquire HIV compared with couples where ART was deferred.
  - The study showed a 96% reduction in risk of HIV transmission when comparing the 'immediate' ART group (when ART was started at a higher CD4 count) with the 'deferred' group (when ART was initiated at the lower CD4 count).
- **PLHIV on ART should always practice safer sex, but now there is good proof that taking ART can prevent transmission to sexual partners. Therefore, this is another important reason to start ART as soon as eligible and to adhere to it: to protect sexual partners from HIV.**

(Continued on next page)

PrEP

- **Pre-exposure prophylaxis, or PrEP,** is an experimental approach that uses ARVs to reduce the risk of HIV infection in HIV-negative people.
  - Results announced in 2011 by the **Partners PrEP study** demonstrated that HIV infection among discordant heterosexual couples can be prevented by taking PrEP daily. The study showed that when an HIV-negative person takes a daily tablet of the ARV tenofovir (TDF), alone or in combination with another ARV called emtricitabine, also known as Truvada (TDF/FTC), his or her risk of acquiring HIV infection is reduced. In this study, both HIV-negative men and women (who had HIV-positive partners) were protected against new infections when they took this medication every day.
  - Similar to the Partners PrEP study, the **CDC TDF2 study** in Botswana found that when HIV-negative heterosexual men and women took a once-daily tablet containing TDF/FTC (Truvada), it reduced their risk of acquiring HIV infection by roughly 63%.
  - The **iPrEx study** results released in 2010 also showed that in HIV-negative men and transgender women who have sex with men, taking a daily tablet containing TDF or TDF/FTC (Truvada) reduced the risk of acquiring HIV by 44%.
- **It is important to remember that PrEP is not yet recommended for use. More research studies are currently being carried out to determine how well PrEP works in other populations.**

Microbicides

- **Microbicides** are products that can be applied inside the vagina or rectum to protect against HIV and other STIs. They can be in the form of gels, creams, films, and vaginal rings.
- **Microbicides are still being tested in clinical trials and are not for sale yet.**
- **How microbicides work:** Different microbicides work in different ways. Most of the newer microbicides currently being studied to prevent HIV infection have an ARV in the product, which stops the HIV from copying itself or, in other cases, prevents the HIV virus from attaching to or entering our cells.
- **Why microbicides are important:** Vaginal microbicides would greatly empower women to protect themselves. Unlike male or female condoms, microbicides are a potential prevention option that women can easily control and that do not require the cooperation, consent, or even knowledge of their partner.
- In 2010, a study conducted in South African and known as the **CAPRISA 004 study**, showed that a microbicide containing the ARV tenofovir (TDF) was almost 40% effective at preventing sexual transmission of HIV to women during sex with an HIV-infected partner. It was also shown to be effective at lowering the risk of acquiring new herpes infections. The tenofovir vaginal microbicide is still being studied by researchers and is not available for use yet.

Sources (for box on previous page):

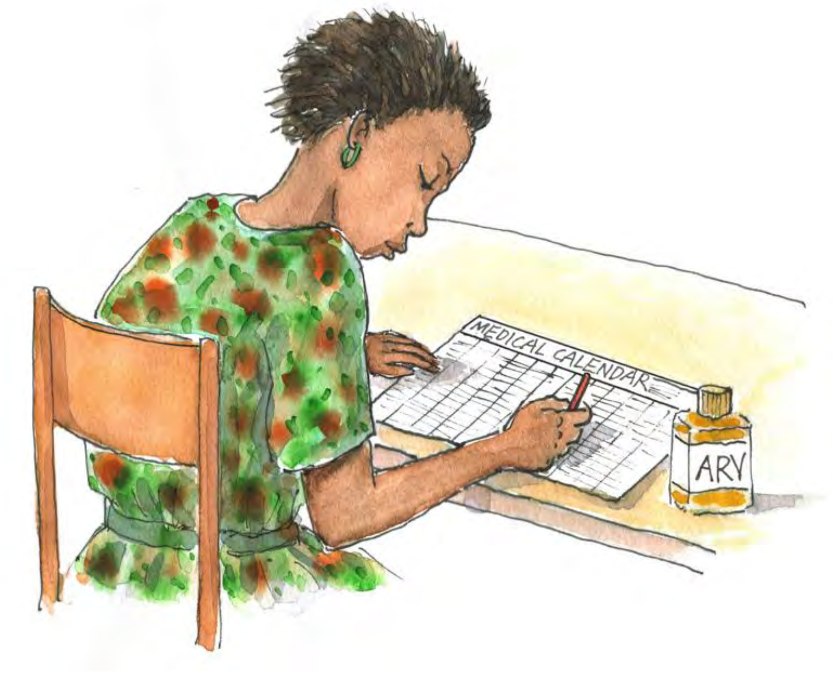
HIV Prevention Trials Network (HPTN). (2011). Initiation of antiretroviral treatment protects uninfected sexual partners from HIV Infection (HPTN Study 052) [Press Release]. Retrieved from http://www.hptn.org/web%20documents/PressReleases/HPTN052PressReleaseFINAL5_12_118am.pdf

University of Washington International Clinical Research Center (ICRC). (2011). Pivotal study finds that HIV medications as highly effective as prophylaxis against HIV infection against men and women in Africa [Press Release]. Retrieved from http://depts.washington.edu/astda/resources/PrEP_PressRelease-UW_13Jul2011.pdf

Centers for Disease Control and Prevention (CDC). (2011). CDC trial and another major study find PrEP can reduce risk of HIV infection among heterosexuals [Press Release]. Retrieved from http://www.cdc.gov/nchhstp/newsroom/PrEPHeterosexuals.html

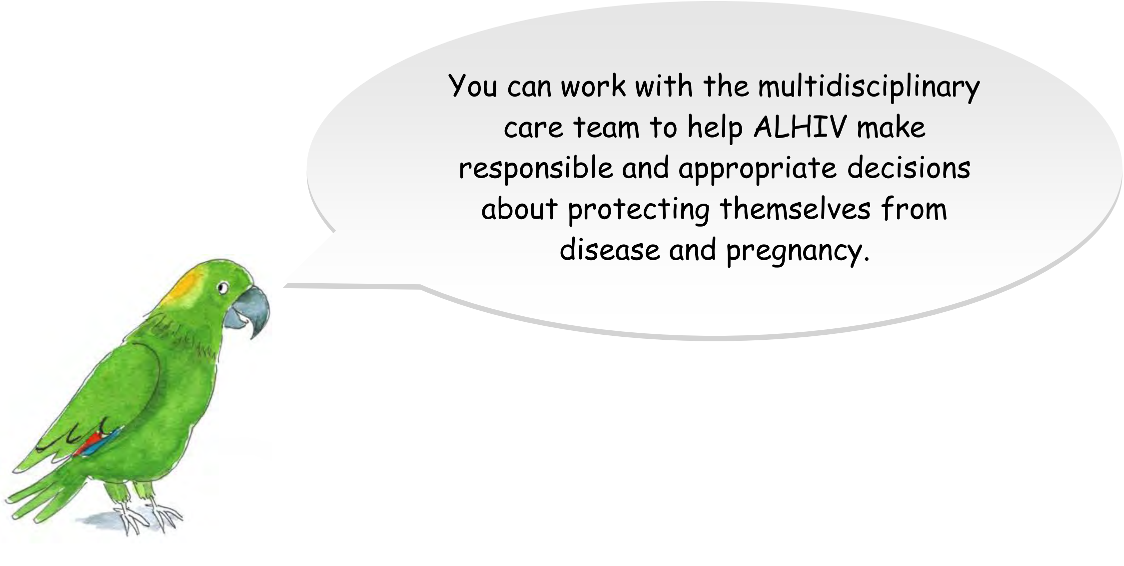
Grant RM, lama JR, Anderson PL, McMahan V, Liu AY, Vargas L, et al. (2010). *Pre-exposure chemoprophylaxis for HIV prevention in men who have sex with men.* New England Journal of Medicine. 363(27):2587-99.

CAPRISA. (2010). Study of microbicide gel shows reduced risk of HIV & Herpes infections in women [Press Release]. Retrieved from http://www.caprisa.org/joomla/Micro/CAPRISA%20004%20Press%20Release%20for%2020%20July%202010.pdf



Risks of adolescent pregnancy:

- Young girls are at higher risk for complications because they are not fully developed and their bodies may not be well prepared to handle pregnancy and to give birth.
    - Young mothers may face problems like: obstructed labor, long labor, anemia, pre-eclampsia or hypertension during pregnancy, consequences of unsafe abortion, spontaneous abortion, still birth, and pre-mature birth. Adolescents younger than 17 often have not reached physical maturity and their pelvises may be too narrow to accommodate the baby's head.
- Pregnancy often means the end of formal education because girls are sometimes kicked out of school when they become pregnant.
- Adolescent pregnancy changes a girl's choice of career, her opportunities, and may limit her future marriage options. Unmarried mothers sometimes have to take low paying and risky jobs or become sex workers to support their children.
- Sometimes the adolescent's partner refuses to take responsibility for the pregnancy, which can make things much harder for the mother and child.
- Young parents are often not prepared to raise a child, which in extreme cases can lead to problems like child abuse or neglect.
- Early marriages that happen because of an unplanned pregnancy are often unhappy and unstable.



Contraception and Family Planning

There are ways that people can prevent unwanted pregnancy and plan when they will have a baby. These are called **contraceptives** or **family planning methods.**

Key terms:

- **Contraception:** The use of a method or more than one method to prevent a woman from becoming pregnant.
- **Family planning:** When a woman plans the number of children she wants and when she wants them. Often this includes using a contraceptive or family planning method to prevent pregnancy or space births.
- **Birth spacing:** When a woman plans her births far enough apart so she and her baby are not at risk of the health problems that can occur when babies are born too close together. It is recommended that women wait at least 2 years after giving birth before becoming pregnant again.

The main types of contraceptives:

- **Barrier methods** prevent sperm from getting inside the woman. These include male and female condoms and the diaphragm.
- **Hormonal methods** are those that prevent eggs from being released inside the woman's uterus. These include pills, injectables, emergency contraception, and implants.
- **Long-term methods** have to be provided at a health clinic by a trained nurse or doctor. These include IUDs (intra-uterine devices) and implants.
- **Permanent methods**, like male and female sterilization, require surgery. These methods are not usually recommended for adolescents, who may change their mind about wanting to have children in the future. Permanent methods are best for adults who have already had children and know that they do not want to have any more.
- **Natural methods** do not require any materials (i.e. withdrawal and the "rhythm method," which is when the woman learns to recognize when she is fertile and avoids having sex during this time.). In general, natural methods do not work as well as the "modern" methods listed above.
- In some places, there are **traditional methods** that people use. These are mostly traditional herbs that are given to prevent pregnancy. They are not reliable because the dosage is not controlled and they have not been scientifically proven to work.

My notes:

Common issues adolescents have with contraceptives:

- Some adolescents may have side effects from contraceptive methods (i.e. weight gain, spotting, menstrual changes). However, these side effects are generally not major health risks to adolescent clients.
- Adolescents who are taking the ARV called efavirenz may need a second method of birth control, as efavirenz may change how well some birth control pills work.

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

- Refer clients to a nurse for family planning information and counseling.
- Talk about the importance of dual protection to protect against both pregnancy and HIV/STIs.
- Give clients condoms and show them how they are used.
- Remind clients to come to the clinic if they have any side effects or questions about their contraceptives. Just like with ARVs, it is important to adhere to contraception (e.g. taking pills at the same time, every day) and to never make the decision alone to stop—clients should always talk with the nurse first.
- Remind clients of 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 future child/children.

Case studies for role play and discussion:

1. K___ is a 17-year-old young 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 she may want them in the future. Her family is pressuring her to never have kids because of the risk the children could be HIV infected. What would you say to K___?

2. A noisy group of young boys is standing at the clinic door laughing and talking loudly. They push one of the boys towards you and say: "He needs some condoms." The boy looks embarrassed and doesn't say anything. What do you say to him and how do you proceed?

You can play a very important role in helping ALHIV to understand and practice safer sex and to avoid unwanted pregnancy.

My notes:

SESSION 10.4: Preventing and Treating Sexually Transmitted Infections (STIs)

Sexually transmitted infections, or STIs, are infections passed from one person to another during sex. Any type of sex—vaginal, anal, or oral—can cause an STI. STIs can also be passed from a pregnant woman to her baby before it is born or during the delivery.

It is very important for clients and their partners to understand the importance of quick diagnosis and treatment of genital problems and STIs. **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 (when a person in not able to have children)
- Premature or unhealthy babies
- Very bad pain in the abdomen
- Cancer of the cervix (the entrance to a woman's uterus)
- Death from a bad infection

Both young men and women can get STIs, but a young woman gets infected from a young man more easily than a young man gets infected from a young woman. Often people, especially young women, will have an STI and not know it because they have not had any symptoms. If a person does have symptoms, it is always best to practice safer sex with condoms and to go to the doctor.

The most common signs of STIs include:

- Unusual discharge from the vagina (some discharge is normal and normal discharge is usually white and thin. If a person has more discharge than usual or if it smells bad; is green, yellow, or has white clumps; or looks different than usual, he or she may have an STI or another type of infection.)
- A strange discharge from the urethra, the place where pee comes out (in a man, this is at the end of his penis and in a woman it is just above her vaginal opening)
- Pain or bleeding when peeing or during sex
- A rash, bump, or sore on or around the penis, vagina, or anus
- A red and itchy genital area or anus (itching may also be caused by scabies or lice)
- 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 cured. This will prevent the STI from spreading to others.

What to tell clients if they may have an STI:

- Always go to the clinic right away! Treat the STI early—usually with pills or creams—and do not wait until you are very ill.
- Help your partner to get checked by a doctor or nurse and to get treated.
- Make sure to take ALL of the medicine, 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 your medicines.
- Practice safer sex with condoms when you do have sex again.

My notes:

SESSION 10.5: Preventing Mother-to-Child Transmission of HIV (PMTCT)

Future 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 Peer Educators are never judgmental of a young person's decisions about having children. Peer Educators can work with doctors, nurses, counselors, and other members of the multidisciplinary care team to help young people understand their choices about having children and help them make healthy, informed decisions. Peer Educators can help support adolescents, who often experience double stigma because they are young, pregnant, and have HIV.

Mother-to-child transmission (MTCT) is the transmission of HIV from a woman living with HIV to her baby during pregnancy, labor, delivery, or after birth during breastfeeding.

PMTCT stands for Prevention of Mother-to-Child Transmission (of HIV).

ALHIV may have concerns or fears about their future, including getting married and having children. You can help them understand that there are ways to safely have children in the future, including using PMTCT services.

PMTCT services are important for ALHIV because:

- Without PMTCT and HIV care and treatment services, babies born to mothers living with HIV can become HIV-infected during pregnancy, labor, delivery, or breastfeeding.
- PMTCT services help young mothers have a safe pregnancy and delivery.
- Young pregnant women may have many fears and misconceptions about taking medicine during pregnancy. That is why they may need extra support to make sure they continue with appropriate care and treatment.

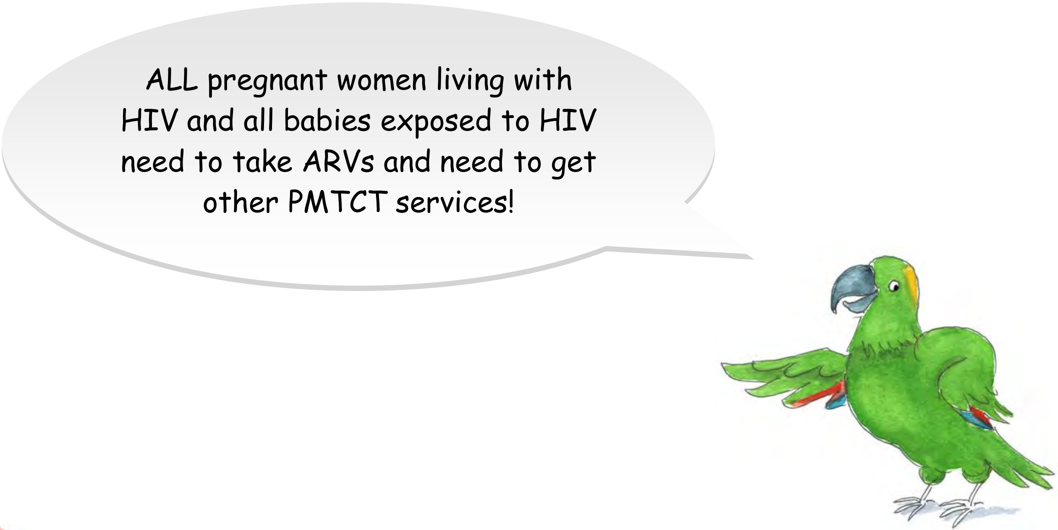
Key PMTCT Messages:

- Moms need to stay healthy!
    - The healthier the mom (meaning the less HIV she has in her blood and the higher her CD4 cell count), the less likely it is that her baby will become HIV-infected.
    - The sicker the mother (meaning she has a lot of virus in her blood and a low CD4 cell count), the more likely it is that her baby will become HIV-infected. A healthy mom is able to take care of herself and love and take care of her baby and the rest of her family.
    - Without healthy moms, we will not have healthy families or communities!
- All pregnant women need to take ARVs. 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.
- Mothers and their babies should keep coming back to the clinic for care and treatment and child health services.
- All HIV-exposed babies should get follow-up care at the clinic.

Case study for role play:

E___ is 16 years old, HIV-positive, and pregnant. She is terrified to tell her family that she is pregnant and doesn't really know what to do next. She is afraid that her baby will also have HIV. She is also scared that the ARVs she is taking might harm the baby and thinks she should stop taking them.

What would you talk about with E___?



My notes:

SESSION 10.6: Sexual Abuse and Gender-Based Violence

Key Terms:

- **Sexual abuse** includes all forms of sexual violence or exploitation (emotional, physical, and economic) against a person. It may or may not include rape. Any type of unwanted sexual contact is considered sexual abuse.
- **Rape** is when a person uses force, coercion, intimidation, or any kind of threat to have sexual intercourse with an unwilling male or female. Every country has an age of consent to take part in a sexual relationship (when a person is legally old enough to say "yes" to sex). In most countries this is between 16 and 18 years old. Some adolescents are forced to have sex, feel pressured to have sex in exchange for good grades or pocket money, are assaulted if they refuse to have sex, or sell sex in order to survive.
- **Date or acquaintance rape** is rape that happens between people who are dating or who know each other.
- Sometimes young children are the victims of **incest** (when a young person is forced to touch, kiss, or feel the sex organs of a relative or have sexual intercourse with a relative). Because of the older person's position in the family, he or she may be able to pressure the child into doing sexual things without actually having to use force. These crimes, including rape, are the fault of the perpetrator or older person and not the fault of the victim or child.
- **Gender-based violence** is any act done to a woman with the aim of hurting her because she is a woman. This may be physical or psychological harm, including threats and intimidation in public or private.

The practice of rape and sexual abuse is made worse by laws and practices that make women the property of men. Such laws and practices deny women the right to make their own decisions and keep them dependent on men. They also make it more difficult for women to report sexual abuse and rape to the police and, if they do, to get justice. Cultural attitudes toward women often result in women being unjustly blamed for sexual abuse and rape.

Certain adolescents are at increased risk of sexual abuse, including rape:

- Adolescents who live in extreme economic poverty (forced into sex for money or forced to become street hawkers, who may be assaulted while working)
- Adolescents who live separately from their parents
- Adolescents with a physical or mental disability
- Adolescents with a mental illness
- Adolescents who abuse drugs or alcohol
- Adolescents who have family members who abuse drugs or alcohol
- Orphans
- Neglected adolescents
- Adolescents whose parent(s) was physically or sexually abused as a child
- Adolescents who live in a home with other forms of abuse, with sex work going on, or with transient adults
- Adolescents who are in a juvenile home or in jail
- Homosexual adolescents, who may be at greater risk because they are often socially marginalized

What to do if you think someone has experienced sexual abuse:

- Refer the person **immediately** to your supervisor or a clinical staff member of the multidisciplinary care team.
- Sexual abuse can have health consequences that need to be addressed urgently by a doctor. Work with the multidisciplinary care team to refer the adolescent to the necessary clinical, legal, and social services.
- If the person discloses and wants to talk, offer support, understanding, and compassion.
- Tell the person that it is not his or her fault.
- Help the person identify someone who could be a source of support.

What services might adolescents need who have experienced sexual abuse?

- A clinical checkup and clinical services
- ARVs, if they may have been exposed to HIV (and aren't already on ARVs)
- Legal or advocacy services, if the perpetrator is prosecuted by the police
- Immediate and ongoing psychological counseling
- Social support (support groups for survivors of abuse, etc.)
- Emergency shelter, if they are unsafe at home

Sexual abuse is a serious and complicated issue! You should work very closely with their supervisor and other members of the multidisciplinary care team if they know or think someone has experienced sexual abuse.

My notes:

Note: Some of the preceding information in this Module was borrowed and/or adapted from the following sources:

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

Colton, T., Costa, C., Twyman, P., Westra, L., & Abrams E. (2009). *Comprehensive peer educator training curriculum, Trainer manual, Version 1.0.* New York: ICAP.

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.

EngenderHealth and Planned Parenthood Association of South Africa. (2001). *Men as partners: A program for supplementing the training of life skills educators,* second edition. New York, NY: EngenderHealth.

Senderowitz, J., Solter, C., & Hainsworth, G. (2004). *Comprehensive reproductive health and family planning training curriculum. Module 16: Reproductive health services for adolescents.* Watertown, MA: Pathfinder International.

World Health Organization. (2010). *IMAI one-day orientation on adolescents living with HIV. Facilitator guide.* Geneva, Switzerland: WHO Press.

SESSION 10.7: Module Summary

Questions for optional homework activity, Condom Scavenger Hunt:

- Where are condoms available in the community?
- How much do the condoms cost?
- Which condoms do people in the community like? Which condoms don't they like?
- How hard or easy was it to find free condoms?
- How did you feel asking for condoms?
- Why don't some people in the community use condoms?
- Are these reasons different for youth and adults? Are they different for married and unmarried people?

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- We all have our own attitudes and values when it comes to sex and sexual behaviors. To be good Peer Educators, however, we must not put our values on our clients.
- Peer Educators need to talk openly and non-judgmentally with young people to help them practice safer sex, understand reproduction, and make informed choices about having children.
- Adolescence is a time of sexual experimentation. Everyone has sexual behaviors that are "OK for them."
- It is important for Peer Educators to know all of the body parts involved in sex and reproduction in women and men so that they can help clients understand the changes taking place in their bodies.
- **Safer sex** is anything that sexual partners do to lower their HIV, other STI, and pregnancy risk. Safer sex involves choosing sexual practices and protection methods that do not allow body fluids to pass from one person to the other her. Peer Educators can talk about and help adolescents choose safer sex methods.
- Part of the Peer Educator's job is to spread the truth about condoms, to give out condoms, and to help people learn how to use them to protect themselves and their partners from HIV, STIs, and unwanted pregnancy.
- There are many reasons adolescents may not be able to negotiate safer sex with their partners, including lack of good communication skills and/or fear or embarrassment about bringing up the topic of protection.
- In addition to practicing safer sex and using condoms, taking ART the right way, at the same time, every day can also lower the chances of passing/getting HIV through sexual contact. This is sometimes called "treatment as prevention."

- Microbicides and “PrEP” are new interventions that can protect HIV-uninfected individuals when they are exposed to HIV. We know from research studies that these interventions work to prevent HIV, but we are waiting to see how they can best be used in the general population. For now, microbicides and PrEP are not available for use in the general population.
- There are many physical, social, and economic risks of adolescent pregnancy, including spontaneous abortion, stillbirths, health complications for the mother (like high blood pressure), loss of education, and parents being unprepared to raise a child.
- Peer Educators are not trained family planning providers, but they can provide basic information on contraceptive methods and referrals to ALHIV. Peer Educators should always consult with doctors, nurses, counselors, and other members of the multidisciplinary care team when providing clients with information on getting pregnant, having children, and contraception.
- 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.
- When a person has a STI, especially one with sores, it is much easier to spread HIV.
- Peer Educators should always encourage clients to go to the clinic right away if they think they have a STI. They should also tell them to get their partners checked and treated as well.
- **Mother-to-child transmission (MTCT)** is the transmission of HIV from a woman living with HIV to her baby during pregnancy, labor, delivery, or after birth during breastfeeding.
- **PMTCT** stands for prevention of mother-to-child transmission.
- PMTCT services during pregnancy, labor and delivery, and after the baby is born help young mothers reduce the chance that their baby will become HIV-infected. Peer Educators should help educate young women about the importance of enrolling in PMTCT services and of adhering to their own and their baby’s care and medicines.
- **Sexual abuse** includes all forms of sexual violence or exploitation (emotional, physical, and economic) against a person. Any type of unwanted sexual contact is considered sexual abuse.
- If a client discloses sexual abuse, Peer Educators should always believe the person and offer emotional support and understanding. The Peer Educator should consult immediately with his or her supervisor or a clinical staff member of the multidisciplinary care team. The client will need both clinical care and emotional support.

MODULE 11: POSITIVE LIVING

LEARNING OBJECTIVES:

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

- Support clients to have a healthy mind
- Recognize serous signs of anxiety and depression, which require a referral to the multidisciplinary care team
- Support ALHIV to keep their bodies healthy
- Work with ALHIV to actively participate in their own care and advocate for themselves as part of positive living
- Support adolescents who are transitioning into adult care

CONTENT:

Session 11.1: Introduction: The Recipe for Positive Living
Session 11.2: Healthy Mind
Session 11.3: Healthy Body
Session 11.4: Taking Responsibility for Your Care and the Transition to Adult Care
Session 11.5: Classroom Practicum on Positive Living
Session 11.6: Module Summary

SESSION 11.1: 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.
- ALHIV 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 and spirit healthy (e.g. things we do to be happy on the "inside" and to feel a sense of peace and happiness)
    - Preventing new HIV infections
- Peer Educators play a key role in helping other ALHIV 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

My notes:

SESSION 11.2: Healthy Mind

Mental Health Issues in ALHIV

Many mental health problems develop in late childhood and early adolescence. ALHIV are especially at risk of developing many mental health problems and challenges. There is information below on two common mental health issues, anxiety and depression.

Key Definitions: Anxiety and Depression

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 for a long period of time and cannot go about your normal routine or do things that you enjoy.

Anxiety and depression

Almost everyone, especially adolescents, feel sad and stressed sometimes. Sadness and stress can come and go, and are normal parts of adolescence and even adulthood. But, if they last a long time and if they negatively affect how a person functions, copes, and maintains his or her normal routine, this stress and sadness may lead to anxiety and/or depression, which are much more serious.

Anxiety and depression are common reactions to living with HIV, especially when people are not feeling well and do not get the support they need from family, friends, health care providers, and their community. Our mental health and our physical health are closely related—this is why helping people deal with anxiety and depression can help with positive living.

Being depressed and anxious can cause symptoms that are very much like a physical illness or infection. When a person is very stressed for a long period of time, he or she may have anxiety. Symptoms may include:

- Not being able to eat
- Not being able to breathe
- Shaking and sweating
- Heart pounding fast
- Tingling in the hands or feet
- Not being able to sleep
- Not being able to concentrate on anything
- Feeling "jumpy" or "stressed"
- Feeling worried about many things

When a person is very sad for a long period of time, he or she may be depressed. Symptoms may include:

- Feeling like you just do not know what to do (helpless or hopeless)
- Feeling really tired with no energy
- Not being able to find good in anything
- Not enjoying the things the person used to
- Sleeping too much or not enough
- Getting angry for no reason
- Not being able to eat or eating too much
- Not feeling like being social with friends or family
- Not feeling like having sex
- Talking about running away
- Thinking about suicide (killing oneself)

If you think that a client is experiencing serious stress (anxiety) or sadness for a long period of time (depression), they should talk with a clinic doctor, nurse, or social worker IMMEDIATELY. Remember the principles of shared confidentiality when doing this.

If a client's problems and symptoms are mild, then you can help in the following ways:

- Give him or her a referral to meet with a counselor, social worker, or other member of the multidisciplinary care team.
- Listen well and give him or her emotional support. Use good communication skills (like reflection).
- Encourage the person to join a ALHIV association and a support group to meet other people living positively with HIV, to share his or her worries and feelings, and to find solutions.
- Link him or her with community support services, like groups that provide spiritual support, counseling, home care, or nutritional support.
- Remind him or her not to use alcohol or drugs because this will only make things worse.
- Encourage him or her to stay in school and to participate in school-related activities like sports or after-school clubs.
- Encourage the person to continue any religious or spiritual practices that make him or her feel peaceful.
- Remind the person that his or her feelings are normal and that he or she will feel better.
- Encourage him or her to have a good cry because this can help relieve stress and sadness.
- Encourage him or her to laugh, play, and socialize with friends because relaxation helps to lower stress.
- Encourage the person to do something that he or she enjoys at least once every day, like dancing, singing, writing in a journal, or reading.

Other mental health problems and disorders that ALHIV may face:

In addition to anxiety and depression, ALHIV may have:

- Behavioral problems, like violence, aggression, and being very impulsive
- Eating disorders, like eating too much, not eating enough, dieting to the point of starvation, or eating a lot and then vomiting
- Diseases in the brain and central nervous system that can result in a person having problems talking and expressing him- or herself, taking a long time to understand what another person is trying to say, having memory loss, not being able to pay attention, and not developing well
- Thoughts about suicide
- Problems with drugs and alcohol (see below)
- Problems coping with HIV, including social withdrawal, loneliness, anger, confusion, fear, and guilt

My notes:

Drugs and alcohol: A part of everyday life for many adolescents

- Many adolescents face a lot of challenges and temptations with drugs and alcohol.
- People sometimes drink or use drugs to take away their worries. However, using drugs or drinking alcohol to cope with sadness or stress will only make people feel physically and emotionally worse in the long term, even if it makes them feel better at first.
- When people take drugs or alcohol, they may become addicted, which means that their bodies start to need the substance and that they feel unwell if they do not get it.
- People who are addicted to drugs and alcohol often do not eat well because they spend most of their money on drugs and alcohol instead of on food. Also, drugs and alcohol can affect a person's appetite.
- Helping your peers learn about the risks of drugs, alcohol, and cigarettes before they start using them helps prevent addiction and harmful effects. This can be done through individual counseling or group health education sessions with adolescents (and caregivers).
- Talking with your peers about alcohol and drug use and providing counseling and referrals to adolescents who abuse drugs or alcohol are key components of adolescent HIV care and treatment. They are also important aspects of supporting ALHIV to live positively.

You should get help from other members of the multidisciplinary care team IMMEDIATELY when:

- Clients might hurt themselves or another person or if they say that they are going to do so
- Clients' depression or anxiety is so bad that they are thinking about hurting or killing themselves
- Clients' families seem like they cannot cope with them anymore and want to throw them out of the house
- Clients have unusual behaviors (e.g. they are violent or are acting out in other ways)
- Clients talk about running away from home
- Clients cannot eat or sleep
- Clients are abusing drugs or alcohol

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

- When they feel rejected or like they do not fit in with their peers
- When they feel upset, frustrated, or angry about living with HIV every day (e.g. having to take medicines every day, coming to the clinic instead of being with their friends)
- After learning that they or a family member is HIV-positive
- When preparing to disclose to friends or family members
- When they worry about dating, having sex, or one day having children
- When starting ART
- When they are having problems with personal relationships, like with friends or partners
- When a friend or family member is close to death or has just died
- When they face stigma, discrimination, or violence in school, at home, or in the community
- When they are sick
- When they have new symptoms or when the HIV disease progresses, like when there is a major drop in CD4 cells
- When they are hospitalized (particularly the first hospitalization)
- And many other times

These are all important times for Peer Educators to give clients emotional support. Ongoing support is also needed to help people live positively with HIV in the long term.

Peer Educators can also help adolescent have healthy minds by doing the following:

- Make sure that clients have access to adolescent-specific support groups and peer support.
- Make sure psychosocial support services are part of comprehensive HIV care and treatment.
- Make sure adolescent clients and caregivers have disclosure support.
- Make sure that adolescent clients (and caregivers) get ongoing adherence support.
- Encourage adolescents to go to and stay in school. Adolescents who stay in school will have more opportunities in the future. In addition to building academic skills, school also gives adolescents the chance to make more friends and to develop life skills.
- Talk with adolescents about their spiritual and/or religious beliefs and practices.

My notes:

SESSION 11.3: Healthy Body

Healthy behaviors:

Peer Educators should actively encourage ALHIV to live healthy, positive lives. Some of the many things ALHIV can do to keep their bodies healthy and to live positively with HIV are listed below.

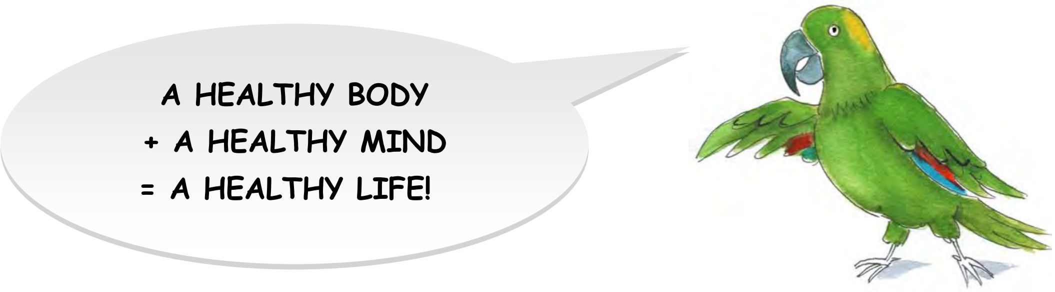
"Living positively" with HIV includes…
Health care
• Going to the hospital or clinic for checkups, lab tests, and to pick up medicines (and never missing an appointment)
• Taking medicines the right way (at the right time, the right number, etc.)
• Telling health care workers if taking any traditional remedies or supplements
• Telling a nurse or doctor if there have been any health-related changes, even small ones
Sexual health
• If sexually active, using condoms and practicing safer sex every time; using a contraceptive method in addition to condoms (dual protection)
• Getting tested for STIs and, if infected, getting treatment immediately and also referring partners for treatment
Staying active and socially engaged
• Doing physical exercise (walking, jogging, doing household chores) to build muscles, reduce stress, and improve appetite
• Staying socially engaged: making new friends and getting peer support through youth clubs, sports teams, and/or after-school clubs; joining an ALHIV association; talking about things openly
• Staying in school/at work and prioritizing education/career
Rest
• Getting enough rest
• Sleeping and resting under an insecticide-treated mosquito net if in a malarial area
Personal hygiene
• Washing hands with soap often, especially: – After using the toilet, touching the genitals, or touching any body fluid – Before preparing food or eating – After sneezing or coughing – After touching garbage – After touching animals
• Bathing regularly
• Practicing good hygiene during the menstrual period: – Changing sanitary pads or cloths regularly – Washing hands before and after changing sanitary products – Bathing daily during the monthly period (note: there is never a need to clean

inside the vagina, not even during the monthly period) – Safely disposing (by putting into a pit latrine or burning) or washing used sanitary pads/cloths
Oral health
• Keeping your mouth clean by brushing teeth, mouth, and tongue at least twice a day
• Treating severe oral lesions with gauze soaked in salt water to clean the mouth
Nutrition
• Eating enough healthy food and taking multivitamins
• Avoiding junk foods and processed foods. Fresh foods are better!
• Drinking at least 8 glasses of clean water each day; always drink water that has been boiled, that has been put in a plastic bottle in the sun for a day, or that has been treated with chlorine liquid or tablets (for example, "WaterGuard")
Food hygiene
• Washing food preparation, cooking, eating, and storage utensils with soap and hot water
• Washing raw fruits and vegetables well with clean water
• Covering food to prevent both flies and dust from contaminating it; not storing raw and cooked foods together
• Eating food as soon as it is cooked; not storing leftovers unless they can be kept in a refrigerator or a cool place
• Cooking food thoroughly, particularly meat, poultry, and fish (meat should have no red juices), but remember that overcooking vegetables decreases their nutritional value
• Keeping the house and compound clean—getting rid of any still water, keeping garbage covered and disposing of it at least once per day
• Keeping all food preparation surfaces clean. Use a germ-killing bleach solution (like Jik or Gentian Violet) diluted with water to keep household surfaces clean. If using Jik for home disinfecting, mix 1 part Jik to 10 parts water. When using Jik in health care settings (for example, disinfecting instruments like blades and needles), use 1 part Jik to 6 parts water and soak at least 10 minutes

Unhealthy behaviors:

You should talk with clients about avoiding practices or behaviors that are not healthy. These include:

- Drinking alcohol
- Using drugs
- Smoking cigarettes
- Having unsafe sex
- Avoiding social contact and staying alone too much
- Sharing medicines, stopping medicines without talking to the doctor, or missing medicine doses
- Missing appointments at the clinic
- Taking traditional medicines that have not been discussed with the doctor or nurse
- Not eating enough healthy foods or eating too many sugary or fatty foods



My notes:

SESSION 11.4: Taking Responsibility for Your Care and the Transition to Adult Care

Why be involved in your own care?

We all know a lot about our own bodies and our own health. The more we know, the more we can find the services we need, understand the care plan, and follow up at home and at the clinic. Sometimes, and especially in very busy clinics, we need to help clients advocate for themselves, ask questions, and be involved in their own care.

How can you help older ALHIV be more involved in their own HIV care and treatment and help prepare them to transition to adult care? You can encourage older adolescents to:

- **Be involved:** Be a part of every decision that is made about your health.
- **Think ahead:** If you talk to your health care workers 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. If you do not understand the answer, ask your question again.
- **Learn more about your health and treatment:** Get as much information as you can about your diagnosis, care, and treatment. Ask your health care worker about the tests and treatment you need and how to get them.
- **Join a ALHIV association and a support group:** This will help you talk to others in similar situations and will help you deal with specific challenges (like adherence or side effects).
- **Understand which medicines you are taking:** Make a list of all the prescription medicine, traditional medicine, and anything else you are taking or doing for your treatment. Make sure you write down 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 get. Ask what the results mean.
- **Ask for more information about referrals:** Ask the doctor, nurse, social worker, or Peer Educator:
    - Why am I being referred? Is it necessary?
    - How quickly do I need to go to the clinic/hospital? Will I have to wait a long time?
    - Will they be familiar with my case so I do not have to explain everything?
    - Will they know I am HIV-positive or will I need to tell them?
    - Is there a referral form to take?
    - What will happen to me if I do NOT go?
    - Will I have to pay for treatment? How much will it cost?

- **Understand the treatment plan:** Before you leave the clinic, ask your health care worker to explain the treatment plan you will use at home. Know what you need to bring back to your health care worker the next time. Also make sure you understand your follow-up care plan and what medicines you must continue to take. Remember that Peer Educators are always available to help and that they can give you useful tools, like a copy of your Adherence Support Tree as a reminder of your adherence plan.
- **Follow up with a community health worker or Peer Educator:** This can help you remember things you may have forgotten and help you follow your care and treatment plan.

My notes:

Transitioning to Adult HIV Care:

- In some places, adolescents go to pediatric clinics where they may have been getting services since birth or for many years. After a certain age, these clinics may no longer be able to provide them with care and they may have to transition to adult services or to the adult ART clinic.
- This can be difficult for many reasons. Adolescents may have concerns about dealing with new providers or an unfamiliar environment, they may fear stigma, they may worry about the care they will receive, etc.
- The transition to adult care can affect clinic staff, adolescents, and their caregivers because at this point adolescents have to start taking more responsibility for their own treatment and adherence.
- Depending on the understanding and attitudes of the multidisciplinary care team, adolescents may be able to receive adolescent-friendly services at the adult clinic.
- Adolescents need to be educated, motivated, and supported to take care of themselves and to tell health care workers what services they need and the concerns they have. Being able to do so gives them a better sense of control, makes them feel better about their situation, and helps them be more successful in caring for themselves in the long term.
- You can work with the multidisciplinary care team to help prepare and support older ALHIV who will transition to adult HIV clinic/services.
- You can help adolescents transition to adult care through:
  - Discussion
  - Journaling activities, like creating a Transition Workbook about the adolescent’s health, future goals, sources of support, etc.
  - Peer support, for example linking them to specific support groups for transitioning and transitioned youth and accompanying them to the adult clinic for an orientation, to meet the clinic’s health care workers (including the adult Peer Educators and other lay counselors), and to talk about their specific concerns and questions
- Remember, you are a resource for other health care workers and you can provide information about individual clients. You can also represent youth and their needs to the multidisciplinary care teams at both pediatric and adult HIV clinics.

You can help the multidisciplinary care team prepare and support older adolescents who are transitioning to adult care by helping to address some of their concerns and by helping them be active participants in their own care!

My notes:

SESSION 11.5: Classroom Practicum on Positive Living

Case Study 1:

A 16-year-old young woman named L___ tells you that she is very stressed about school and all of the school she misses because of her appointments at the clinic. She also says that her boyfriend has been acting strange lately. She says she feels like her heart might jump out of her body and that she is having trouble eating and sleeping.

How would you support her?

Case Study 2:

A young woman named N___, who is 16 years old, just started coming to the ART clinic. Her mother died when she was 3 years old and she now lives at home with her younger sister and aunt. She tells you that she feels worried all the time that she might get sick or die and not be able to take care of her sister.

What would you tell her about living positively with HIV?

Case Study 3:

You learn that a client of yours can often be found at the local bar drinking and smoking pot/marijuana all night. You worry that he may be hurting himself and missing doses because he stays out so late and is drunk when he gets home.

What would you say to him about positive living and adherence?

Case Study 4:

K___ is an ALHIV who is 19 years old. Soon he has to start getting care and treatment at the adult clinic instead of at the pediatric clinic. He is nervous about this change because he doesn't know the staff there and because the clinic is so big. Work with the nurse to support him with this transition.

What would you say to K___?

As both recipients and providers of HIV services, you play a big part in teaching adolescents how to live positively with HIV! If we can think and talk of "living with HIV infection" instead of "being sick or dying of AIDS," it helps to reduce fear and makes all of us feel more hopeful about the future!

Note: Some of the preceding information in this Module was borrowed and/or adapted from the following sources:

International HIV/AIDS Alliance. (2007). *Our future: Sexuality and life skills education for young people, grades 8 to 9*. International HIV/AIDS Alliance.

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

Life Skills Subgroup of the AETC Adolescent HIV/AIDS Workgroup. (2006). *Adolescent transition workbook*. AIDS Education and Training Center.

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

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

SESSION 11.6: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- People with HIV can live full and healthy lives if they take care of themselves, access treatment and support, and feel supported to make healthy choices.
- Peer Educators play a key role in helping other ALHIV 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

- Peer Educators can help clients keep their minds healthy by making sure they speak with a counselor, social worker, or other member of the multidisciplinary care team; by offering emotional support; and by referring them to peer support groups, spiritual counselors, and other groups for ALHIV.
- Peer Educators should tell the clinical team if they think a client is showing serious signs of depression, anxiety, or of being very troubled.
- Peer Educators can help people keep their bodies healthy by practicing safer sex, eating well, staying clean, and keeping active (among other things).
- Peer Educators should help people stay away from unhealthy things like alcohol, smoking, unsafe sex, eating sugary and fatty foods, and being isolated from other people.
- Older adolescents living with HIV need support and help from the entire multidisciplinary care team, including Peer Educators, to prepare for the transition from the pediatric clinic to the adult clinic.
- Peer Educators can help ALHIV advocate for themselves, be involved and understand their treatment, ask questions, and understand referrals and other aspects of their care as they transition to adult care.

MODULE 12: COMMUNITY OUTREACH, EDUCATION, AND LINKAGES

LEARNING OBJECTIVES:

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

- Describe community-based support services that ALHIV and their families may need and the importance of each
- Describe the Peer Educator's role in linking clients with community-based support services
- Create a community treasure map and an inventory of community services for ALHIV
- Discuss how Peer Educators can serve as community HIV educators and advocates

CONTENT:

Session 12.1: Introduction: What Services Do ALHIV Need in Their Communities?
Session 12.2: Linking ALHIV 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 ALHIV Need in Their Communities?

Common support needs of ALHIV and their caregivers in the community, home, and school:

- Peer support groups
- Youth clubs and organizations
- Income-generating activities
- Vocational /skills training/apprenticeships
- Educational assistance/help with accessing education
- Recreational and sports activities
- "Chill" clubs where young people can get together, talk, and share
- Education and counseling for family members
- Nutritional and food support
- Legal advice and support
- Spiritual guidance and support
- Disclosure support
- Transportation to get to the clinic
- Social welfare for young mothers (e.g. child grants)
- Others

SESSION 12.2: Linking ALHIV to Community Support Services

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

My notes:

SESSION 12.3: Community Resource Mapping

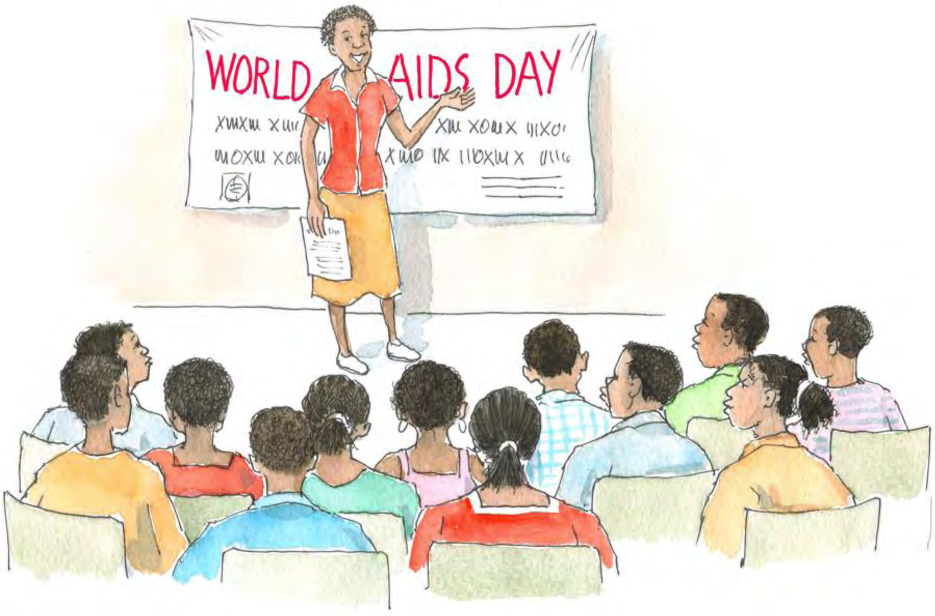
Community resource maps and inventories:

- 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 and youth associations, district HIV teams, regional health bureaus, or other coordinating organizations.
- You should carry an updated inventory of community support services at all times and should hang one up at the clinic for easy reference and referral.
- Remember, it especially important to map and partner with programs that focus on food distribution (e.g. community food banks), income generation, and education and vocational training support because these are all services needed by many ALHIV.

SESSION 12.4: Being a Community Educator and Advocate

How can Peer Educators mobilize the community around HIV?

- Use your position as a Peer Educator to speak at your school; at youth clubs and organizations; at community gatherings and group meetings; at religious services; and at other community events.
- Talk with community members and your peers about HIV, about how to prevent HIV, and what prevention, care, and treatment services are available for youth in the community.
- Talk to your peers and young people about how to protect themselves from HIV, STIs, and unwanted pregnancy. Help ALHIV get the care and treatment they need.
- Involve other community members in the fight against HIV. Talk with teachers and leaders of youth groups and organizations in the community about what they can do to help ALHIV and their caregivers.
- Get involved in community events like World AIDS Day activities and HIV testing campaigns, especially those focused on youth.



You are important community educators and advocates! You may be asked to speak to community groups and at community gatherings. This is a good opportunity to educate the community about HIV, to advocate for the needs of ALHIV and their families, and to help reduce stigma and discrimination!

My notes:

SESSION 12.5: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- Some common needs of ALHIV and their caregivers at the community and home levels include access to education, legal support, adherence support, poverty reduction and income-generating activities, peer support groups, nutritional support, and many other services.
- There are many community-based services in most places, but often groups and organizations do not know about each other or do not make formal plans to work together. A key part of Peer Education is advocating for strong linkages between health facilities and these community-based services for ALHIV.
- There are many ways to strengthen facility-community linkages, such as knowing what youth-friendly community services are available, participating in community meetings, keeping an updated resource map or list of services available, working with the multidisciplinary care team to meet with community leaders, and helping the multidisciplinary care team develop a strong two-way referral system between the health facility and community organizations for ALHIV.
- Peer Educators should stay up-to-date on which services are available for ALHIV and work with the multidisciplinary care team to make referrals.
- Peer Educators may be asked to speak to community groups or at community gatherings. Use your respected position to educate and mobilize the community and to advocate for the needs of ALHIV 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 Number, 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 basic daily and monthly reporting forms for Peer Education sessions, group sessions, and referrals

CONTENT:

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 could do better
- Report to other people (like our supervisor) what we have done
- See what the gaps are in our services and fill them

It is important for you to fill in daily registers and to prepare reports each month because they will:

- Be a record of general activities and time spent at the clinic (e.g., how many people you have provided education and information to, how many group education sessions you have helped lead, how many clients you have referred to peer support groups, etc.)
- Show your supervisor what you have done
- Help you plan for the next month
- Show how effective Peer Educators can be in helping ALHIV

You should keep good records to show what you have accomplished and you should use the information to help improve the overall program.

SESSION 13.2: Peer Educator Recording and Reporting Forms

There are at least 2 types of forms that you should fill in:

- A daily register for Peer Education sessions, group sessions, and referrals
- A monthly report showing the totals of their daily activities

Depending on the program, you may also need to fill in forms related to:

- Adherence and psychosocial support assessments (e.g. Talking and Adherence Tree tools can become part of the client's record)
- Attendance
- Others

Peer Educator Daily Recording Form (see *Appendix 13A* for a sample and adapt to your own setting):

You can write down all Peer Education and group sessions on this form. Every day you works at the clinic, you should use this form to record the following information:

- Your name, the clinic name, reporting week/year, and your supervisor's name
- Daily total of Peer Education sessions, by gender
- Number of referrals made and the gender of the client being referred (for example, a client was taken to the ART clinic, a client was referred to a support group, etc.)
- Number and type of group sessions conducted (for example, adherence, disclosure, positive living) and the total number of young people who attended the sessions

Peer Educator Monthly Reporting Form (see *Appendix 13B* for a sample and adapt to your own setting):

At the end of each month, you should add up the information from your Daily Recording Forms to complete a monthly report. The Monthly Reporting Form includes the following information:

- Your name, the clinic name, reporting month/year, and your supervisor's name
- Monthly total of individual sessions (total with female clients and total with male clients)
- Monthly total of referrals made (total with female clients and total with male clients)
- Monthly total of group sessions and the approximate number of participants who attended
- A brief description of any achievements or challenges you had during the month
- You should sign and date their monthly reporting forms and give them to their Supervisor.

All Peer Educator monthly reports should be reviewed by supervisors and shared and discussed with the multidisciplinary care team, including Peer Educators, to see what is going well and what improvements could be made based on the information. A summary of Peer Educator activities should also be presented to the entire multidisciplinary care team and discussed on a regular basis (e.g. during monthly team meetings). Remember, there is no point in collecting information if we do not use it to improve our program!

You should help each other fill out the forms and should ask each other, your supervisor, or other members of the multidisciplinary care team if you have questions.

Record-keeping Basics

- Keep records and reports confidential.
- 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.
- If you are unsure about something, ask another Peer Educator, a supervisor, or a member of the multidisciplinary care team for help.

SESSION 13.3: Module Summary

LOUISA SAYS, "REMEMBER THESE KEY POINTS!"

- Keeping good records can help Peer Educators show the work they have done, plan for what do next, and follow up with clients.
- It is important that Peer Educators keep good records of their work and submit monthly reports on time to their supervisor. These reports should be shared among and discussed by Peer Educators, supervisors, and the multidisciplinary care team.
- **There are at least 2 types of forms that Peer Educators should fill in:**
  - A daily register for Peer Education sessions, group sessions, and referrals
  - A monthly report showing the totals of their daily activities
- Peer Educators should help each other fill out the forms and if they have questions, they should ask each other, their supervisor, or other members of the multidisciplinary care team.

My notes:

APPENDIX 13A: Sample Peer Educator Daily Recording Form (adapt to local setting)

PEER EDUCATOR DAILY REPORTING FORM

Peer Educator Name: ______________________________ **Clinic Name:** ____________________________
Reporting Week/Year: _____________________________ **Supervisor's Name:** _______________________

Today's Date: ____________________		
Number of one-on-one sessions conducted:	Females (tick): OOOOOOOOOOOOOOO	Males (tick): OOOOOOOOOOOOOOO
	TOTAL: _____ with female clients	______ with male clients
Number of referrals made:	Females (tick): OOOOOOOOOOOOOOO	Males (tick): OOOOOOOOOOOOOOO
	TOTAL: _____ with female clients	______ with male clients
Group sessions conducted:	How many sessions: ___________	Topics covered (list): ______________________
	Approximate # of participants: __________________	

Today's Date: ____________________		
Number of one-on-one sessions conducted:	Females (tick): OOOOOOOOOOOOOOO	Males (tick): OOOOOOOOOOOOOOO
	TOTAL: _____ with female clients	______ with male clients
Number of referrals made:	Females (tick): OOOOOOOOOOOOOOO	Males (tick): OOOOOOOOOOOOOOO
	TOTAL: _____ with female clients	______ with male clients
Group sessions conducted:	How many sessions: ___________	Topics covered (list): ______________________
	Approximate # of participants: __________________	

APPENDIX 13B: Sample Peer Educator Monthly Recording Form (adapt to local setting)

PEER EDUCATOR MONTHLY REPORTING FORM

Peer Educator Name: ___________________________________ **Clinic Name:** _______________________________
Reporting Month/Year: ________________________________ **Supervisor's Name:** __________________________

Number of one-on-one sessions conducted this month: **TOTAL:** _____ with female clients ______ with male clients

Number of referrals made this month: **TOTAL:** _____ with female clients ______ with male clients

Group sessions conducted this month: **TOTAL** number of sessions: _________________________
Approximate total # of participants: ___________________

Major achievements during the month:

Major challenges during the month:

Other comments:

Peer Educator's Signature: _____________________________________

Date report submitted: ____

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 to ALHIV
- 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

You should remember these points:

- We are guests at the health facility and must respect the wishes of the facility’s health care workers and managers.
- Keep all discussions and observations during the practicum confidential. Only share with other participants, trainers, or preceptors.
- Never wander off without the preceptor. Always inform the preceptor if you need to take a break or leave the facility for any reason during the practicum.
- Always introduce yourself to health care workers and clients. Tell them that you are a Peer Educator in training and explain a bit about the program if the person is interested.
- Always ask clients for their verbal consent to talk with you or to participate in a group session. Remember that during the practicum any client can refuse to participate or stop participating at any time.

My notes:

SESSION 14.2: Supervised Practicum

SESSION 14.3: Practicum Debriefing

Congratulations to everyone for completing the practicum! Remember, you will be given ongoing support, mentoring, and training to sharpen your skills and to also learn new ones as you gain experience!

My notes:

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 Adolescent Peer Educator training
- Discuss your vision and hopes for the Peer Education program and for your future as a Peer Educator
- Agree on next steps for when you return to your respective health facilities
- 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 Adolescent 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 Objectives

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 a clinic's multidisciplinary care team
2. Understand needs and challenges of ALHIV and how to help make clinic services more youth-friendly
3. Give one-on-one peer education and assist with facilitation of group education to ALHIV so they better understand, use, and adhere to HIV prevention, care, and treatment services
4. Demonstrate knowledge about issues related to sexual and reproductive health and show that you are comfortable talking about them
5. Help address the psychosocial needs of ALHIV and caregivers
6. Disclose your own HIV-status to clients, support ALHIV through the disclosure process, and help members of the multidisciplinary care team support caregivers who disclose their perinatally-infected child's status
7. Be a role model for positive living, disclosure, and adherence to care and treatment
8. Help ALHIV and family members live positively with HIV
9. Link ALHIV to required health services or support services within the community and clinic settings
10. Keep basic records of daily and monthly activities

There is also a supervised practicum (Module 15) included in this training. By the end of the practical sessions – which will take place in the clinic setting, you will be able to:

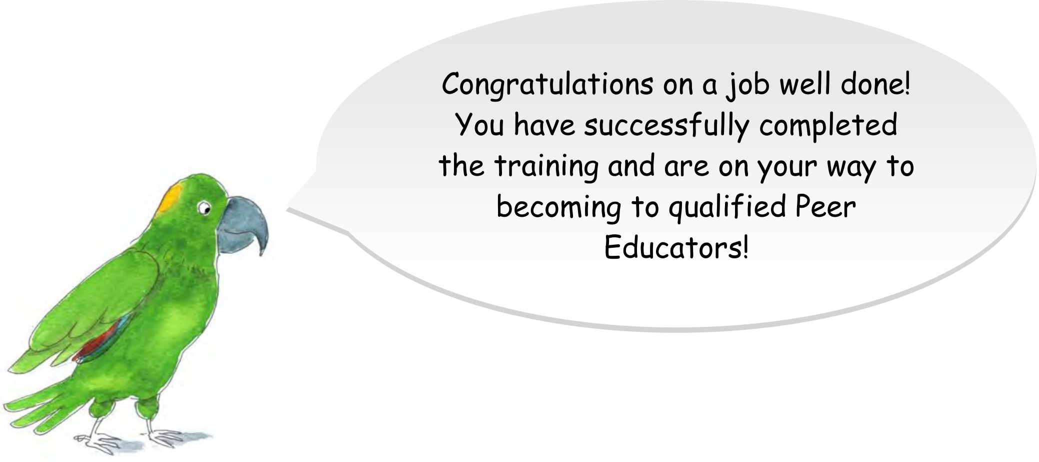
1. Practice skills learned during the training in a health facility offering HIV prevention, care, and treatment services to young people
2. Show competency in the major skills taught during the training, with supportive supervision and mentoring
3. Identify skill areas where further on-the-job practice and mentoring are needed

SESSION 15.2: Next Steps for Adolescent Peer Educators

Remember that you will continue to get ongoing training and mentorship from your Program Coordinator or Manager and members of the multidisciplinary care team!

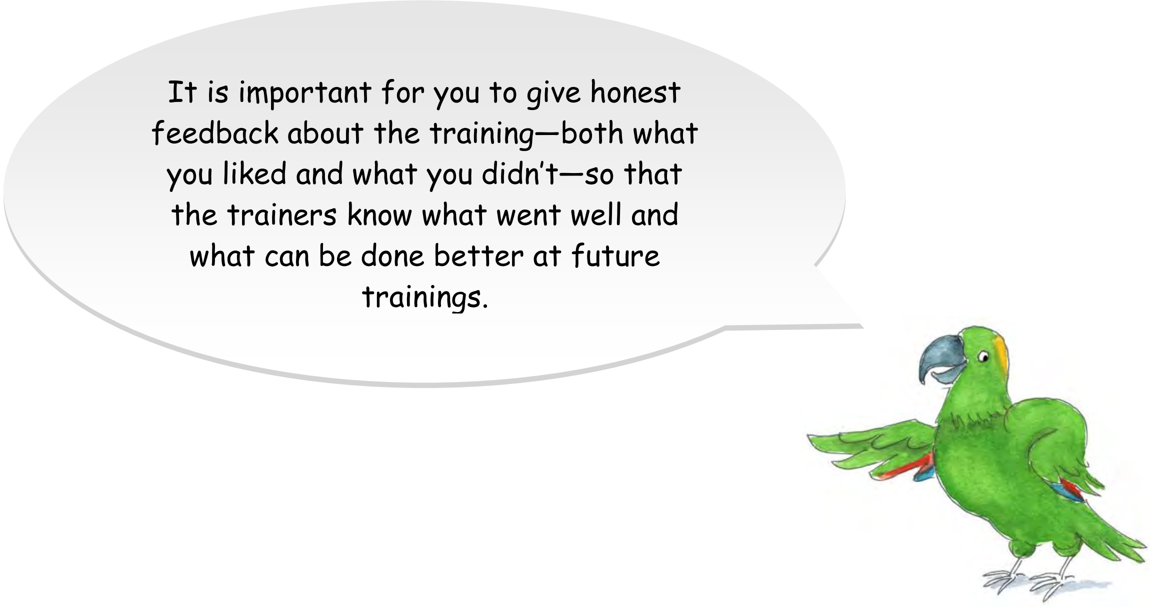
My notes:

SESSION 15.3: Final Learning Assessment/ Post-Test



My notes:

SESSION 15.4: Training Evaluation



SESSION 15.3: Graduation and Closing

My notes:

My notes:

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