

**PEER EDUCATION IN HIV
PREVENTION, CARE, TREATMENT AND SUPPORT**

**A Comprehensive Training Course for Expert Clients in Malawi
-Trainer's Manual-
2nd Version DRAFT
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ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral
AZT	Zidovudine
BCC	Behavior change and communication
CHBC	Community Home-based Care
CPT	Cotrimoxazole prophylactic therapy
EC	Expert Client
EFV	Efavirenz
EPTB	Extra-pulmonary tuberculosis
HBC	Home-based Care
HIV	Human Immunodeficiency Virus
HSA	Health Surveillance Assistant
HTC	HIV Testing and Counseling
IEC	Information, education and communication
IGA	Income generating activity
IPT	Intermittent presumptive therapy
ITN	Insecticide treated bednet
LTFU	Lost to follow up
MOH	Ministry of Health
MTCT	Mother-to-Child Transmission (of HIV)
NVP	Nevirapine
PEPFAR	President's Emergency Plan for AIDS RELIEF
PITC	Provider-initiated HIV testing and counseling
PLHIV	Person/People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
OVC	Orphans and other vulnerable children
QA	Question and Answer
STI	Sexually Transmitted Infection
TB	Tuberculosis

HOW TO USE THIS MANUAL

Guide to the facilitator

This manual is designed to be used by the facilitator to conduct training sessions for expert clients and other extension workers. The training should be conducted by Antiretroviral Therapy (ART), prevention of mother to child transmission (PMTCT) and HIV testing and counseling (HTC) coordinators from district health offices. This manual should be used alongside the training slides (Annex A).

The manual contains 13 units that are important for expert clients. Go through the topics in chronological order, as each one builds on the topics previously introduced. The topics represent the basic and most useful information on impact of HIV, roles of expert client, basic communication and counseling skills, HTC, HIV care and support, PMTCT, Pediatric care, Adherence to HIV care and treatment, stigma and disclosure, positive living, referral and record keeping, and linkages to community support services.

The structure of a topic – find your way

Each unit has a session outline which includes topic, specific objectives, methods and materials needed for the session. Facilitators should conduct sessions in an interactive way and should feel free to be creative. Facilitators should take note of the key activities for participants outlined in the manual, such as role plays, asking participants to discuss a concept in pairs, etc. At the end of each session there are key messages which facilitators should stress for participants' understanding.

INTRODUCTION

Overview of the global pandemic

The HIV pandemic remains a major public health problem worldwide, with especially devastating effects in sub-Saharan Africa, with 33.3 million people living with HIV by the end of 2009. Out of this, 68% of all HIV-infections and 85% of all estimated AIDS deaths occur in this region. However, the trend is changing. An estimated 2.8 million people became newly infected with HIV in 2009, nearly 20% fewer than the 3.4 million people infected in 1999. Additionally, new infections among children are decreasing as access to services for preventing mother-to-child transmission of HIV has increased. The total number of children being born with HIV has decreased: an estimated 370,000 [230,000–510,000] children were newly infected with HIV in 2009, a drop of 24% from five years earlier.

AIDS-related deaths have also decreased. The number of annual AIDS-related deaths worldwide steadily decreased from the peak of 2.3 million in 2004 to an estimated 1.8 million in 2009. The decline reflects the increased availability of antiretroviral therapy, as well as care and support to people living with HIV, particularly in middle- and low-income countries.

HIV and AIDS in Malawi

Malawi continues to suffer from the compounding problems of poverty, famine and AIDS. However, intensive efforts have been made over the past decade to increase awareness about HIV and to prevent its spread. These efforts appear to have had a positive effect. The national HIV prevalence has stabilized between 15% and 11% from 2003 to 2010. The current adult HIV prevalence rate is 11.0% among those aged 15 – 49 years.

The Joint United Nations programme on HIV (UNAIDS) estimated that in 2010 there were 920,000 adults and children living with HIV in Malawi and of these, 120,000 were children aged less than 15 years. 250,987 HIV-infected adults and children were alive and on antiretroviral therapy by the end of 2010. AIDS is the leading cause of death in the most productive age group, resulting in 60,932 adult and child deaths annually. The cumulative number of orphans, directly related to the AIDS epidemic, is approximately 700,000 and more than 60,000 are added to this pool each year. AIDS causes high death rates in infected children: 15% of under-5 deaths are directly attributable to HIV infection. Nearly 50% of infected individuals in Malawi are women of reproductive age and the paediatric HIV epidemic is largely the result of transmission from mother-to-child (MTCT).

The President's Emergency Plan for AIDS Relief (PEPFAR) supports the scale-up of PMTCT and paediatric HIV services as critical interventions in Malawi's HIV prevention, care, and treatment program. Mother-to-child transmission (MTCT) of HIV is responsible for more than 90% of childhood HIV infections and is the second most common mode of transmission in Malawi. More than 300,000 children are newly infected with HIV each year, predominantly through mother-to-child transmission. In the absence of any interventions, the rate of maternal to child HIV transmission in developing countries is estimated to be 25-35 percent. Thus, to reduce the risk of MTCT, it is imperative for health care workers to uphold recommended obstetric/midwifery practices when attending to all women, with known and unknown HIV status, in labour. Male partners also have a key role to play in supporting pregnant women to access all necessary medical services as well as to prevent infection during pregnancy and lactation.

Malawi's National HIV and AIDS Draft Strategic Plan 2012-2016 (NSP) has been developed to guide the management and implementation of the national HIV and AIDS response using evidence about the epidemic, the factors that influence the transmission of HIV in the country, and lessons learned from past implementation experience. One of the major national focuses is PMTCT and provision of care and treatment for mothers, ensuring that pregnant women understand PMTCT and accesses the services they need to keep them healthy, have HIV-free babies, keep their babies free from HIV, and have healthy families. Systems are being put in place to track patients lost to follow-up (LTFU). Stronger linkages between community-and facility-based HIV programs need to be created to ensure a continuum of care and support.

Despite national success of enrolling many patients on treatment, care and support, stigma, discrimination, fear of disclosure and lack of adequate support from their communities still affect people living with HIV negatively. A study done in Malawi found that the main reasons for defaulting on care were stigma (43%), care dissatisfaction (34%), poor understanding of disease or treatment (56%) and drug side effects (42%). A systematic review of 28 studies found several key reasons for poor retention of clients in PRE-ART care, including fear of being recognized as a client of HIV clinic, risk of losing employment and lack of resources. Clearly many factors contribute to the high rates of loss-to-follow-up seen throughout the country and a multi-faceted approach will be necessary to address these challenges comprehensively.

Experience with expert clients

Much of the evidence relating to the use of expert clients for high-prevalence settings comes from Swaziland, where the engagement of people living with HIV (PLHIV) as expert clients (EC) and continuous involvement of community HIV support groups have been shown to complement the work of health care providers. Expert clients have strengthened disclosure counseling and contributed to reduced stigma and discrimination against PLHIV, increased enrollment of pregnant women on ART, and improved intra-facility referrals and uptake and improved facility-community linkages. EC's efforts to improve counseling on infant diagnosis have succeeded in increasing the number of caregivers bringing exposed infants back to the clinic for testing at six weeks. Many pregnant or newly delivered clients have spoken about the importance of early testing for HIV-exposed babies. Discussions with EC, patients and multidisciplinary team members have revealed that EC can successfully counsel patients on certain aspects of living positively with HIV, including safer sex, and the importance of good nutrition. Expert clients may also assist with physically escorting patients from one section of the health facility to the other, which has been recognized as a key strategy for reducing loss-to-follow-up within the health care setting.

In addition, Malawi, like other countries in Sub Saharan Africa, has a severe shortage of human resources in the health sector. Task shifting, or engagement of other lower cadres of health workers to conduct routine functions in a health facility, has proved an important strategy to improve access to care. Expert clients may assist with treatment literacy education sessions and HTC group pre-counseling sessions, thus freeing up time for skilled health care workers.

Expert clients are uniquely placed to model positive behavior and share personal strategies for adhering to treatment and living well with HIV. In this way, psychosocial support from peers can help affected and infected people live longer, healthier lives. This improves the well being of families, helps decrease stigma and discrimination, and consequently improves the quality of life of infected individuals, affected families and entire communities. Good education and counseling of patients in HIV care and treatment programs, including children, particularly before and after the initiation of ART, is vital for adherence success and overall treatment. This manual therefore is developed with evidence that behavioral modeling and peer education increases access and adherence to care and treatment services:

- Expert clients are a great potential source of practical and psychological support for other patients living with HIV, who often feel more comfortable sharing feelings, concerns, experiences, and problems with other people who face similar situations.
- Expert clients can help improve adherence to care (e.g., honoring appointments, going to the clinic for tests, following and understanding care instructions, etc.) and can help health care providers follow-up patients who missed appointments.
- Expert clients can improve treatment literacy among patients by explaining different aspects of treatment in simple terms that are easily understood.
- Expert clients can work within the multidisciplinary care team to enroll pregnant women in care and treatment services by helping to dispel myths about treatment during pregnancy and encouraging women to protect themselves and their babies by enrolling in care and treatment.
- Expert clients can help enhance adherence to medications, especially ART, by providing counseling for real life challenges to adherence.

- Expert clients can help patients navigate services at health facilities and links between these services, such as between PMTCT, antenatal care (ANC), Under-5 clinics, ART clinic and other care and treatment services.
- Since expert clients come from the communities served by the hospitals and clinics, they can provide a vital link to community-based services, such as nutrition support and home-based care.
- Expert clients can build on their own experience and serve as role models to encourage “positive living” and healthy behaviors among patients, including secondary prevention of HIV.
- Expert client programs can create positive changes in the lives of the expert clients themselves, help to decrease stigma and discrimination in the community, and encourage community members to access HIV services.

A note on confidentiality

The success of Expert Client training depends on active participation and engagement of each participant. Participants should be encouraged and feel “safe” to share their own personal experiences as PLHIV enrolled in the PMTCT and/or care and treatment program, including the challenges they have face at the hospital, in their communities, and at home. All participants should feel comfortable discussing times when they have struggled with adherence, or with disclosure, or practicing safer sex with their partner. Trainers should remind participants that what is said in the training sessions is confidential and that no one will be judged or stigmatized for their comments or questions.

UNIT 1: THE IMPACT OF HIV

Time	Specific Objective	Methods	Materials
45 Min	By the end of this Unit, participants shall be able to describe the impact of HIV and AIDS epidemic at individual, family and community level.	Lecturing Group Discussions	Flip chart Markers LCD Projector Trainer's manual

1.1: THE IMPACT OF HIV (45 MIN)



Participant Activity

- Ask participants to sit in small groups and discuss how HIV has affected individuals, families and communities for 30 minutes
- Participants should be prepared to report back the main ideas to the rest of the group
- Give them 15 minutes to report back and make clarifications as needed
- Each group should only add NEW points, not repeat points already made
- Review the rest of the content in this section quickly, only discussing issues not already raised

Some of the impact of HIV and AIDS on individuals:

- Fear of telling others and being stigmatized, hiding one's status
- Weight loss
- More frequent and severe illness
- More trips to the clinic and hospital
- Need to take many pills every day if on treatment
- Failure to perform at work due to illness
- Violence
- Isolation from family and friends
- Loss of income and property due to death
- Feeling hopeless
- Feeling guilty and/or anger
- Pass the virus to other people, such as sexual partners and babies

For children, specifically:

- More frequent and severe illness
- High absenteeism rate from school
- Many trips to the clinic
- Stunted growth
- Stigmatized and discrimination (treated differently by other children, teachers, or family members)
- Need to take a lot of pills every day
- Not able to stay in school
- Not performing well in school

Impact on pregnant women

- Transmission of HIV from a mother to a baby
- Frequent visits to PMTCT clinic
- Stigma and discrimination
- Guilty feelings from transmitting the HIV to the baby
- Divorce or abandonment by husband or partner

Some of the impact of HIV and AIDS on communities and families:

- Loss of wages and family/community resources due to illness
- Poverty because of increased health care costs
- Increased number of orphans to care for
- Stigma and discrimination
- Not enough food because people can't raise animals or crops
- Children can't attend school because they are caring for sick relatives or working
- Teachers are sick or taking care of relatives who are sick
- Community health care systems are overstretched

1.2: UNIT SUMMARY

The key points of this unit include:

HIV and AIDS affect not only individual people, but also families and communities.

UNIT 2: THE ROLE OF EXPERT CLIENTS IN COMPREHENSIVE HIV AND AIDS PROGRAMS

Time	Specific Objective	Methods	Materials
5 Min	By the end of this unit, participants should be able to: Define a peer and peer education	QA Lecturing	Flip chart, Markers LCD Projector Trainer's manual
10 Min	Explain the advantages and disadvantages of peer education	QA Lecturing	
10 Min	Define expert client	QA Lecturing	
10 Min	Describe multidisciplinary HIV and AIDS care team	QA Group discussions Lecturing	
20 Min	Explain the roles of expert client in the health multidisciplinary care team	QA Group discussions Lecturing	

2.1: INTRODUCTION TO PEER EDUCATION (25 MIN)

Basic terms:

- A **peer** is a person who belongs to the same social group as another person or group. The social group may be based on age, sex, sexual orientation, occupation, socio-economic status, health status, or other factors.
- **Peer education** is the transfer of knowledge and skills to members of a social group by others within the same group.
- **Expert clients** are a type of peer educator who are themselves enrolled in care and have a good understanding of HIV and AIDS care and treatment services, and who have the skills to help other patients with their care and treatment.

Advantages of Peer Education/Expert Client Programs:

- **Accepted by audience:** patients have the opportunity to discuss their personal circumstances in a safer environment with someone who relates to their situation.
- **Enhance adherence:** Expert clients can support clients' adherence to care and treatment by sharing their own experiences.
- **Empowering individuals:** can increase people's confidence that they can make good decisions and take action, changing behaviors among Expert Clients as well as their clients to take care of their own health and that of their families.
- **Job opportunities:** training and work experience may improve the Expert Clients' job opportunities in the formal economic sector.
- **Improve service quality:** Expert Clients can help to improve the overall quality and effectiveness of health care programs.
- **Gain access:** Expert Clients can gain access to groups that are otherwise difficult to reach and encourage them to seek prevention, care, and treatment services. Similarly, expert clients can follow up with patients who have missed appointments.

2.2: THE MULTIDISCIPLINARY CARE TEAM (10 MIN)

No one person, no matter how skilled, can provide all the care and support that a patient needs. We all have different training, experience, knowledge, skills, and personal strengths. Also, no one person has time to do everything. This is why it's important for HIV and AIDS prevention, care, and treatment programs to have a multidisciplinary team that can reach every patient. **Multidisciplinary means a mix of different professionals and volunteers – doctors, nurses, counselors, health surveillance assistants (HSAs), expert clients, and others – working as members of a team.**

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

- **Clinical Officers** check on the patients' health status and make a care and treatment plan, to assess if a patient needs to be on ART and if so, which drugs they should take
- **Nurses** provide PMTCT counseling to women, provide adherence counseling to patients, perform health assessment when the patient comes to the clinic, take blood samples, provide support on positive living, weigh infants and give immunizations
- **Pharmacists** provide patients with medicines and information on how to take them

- **HSAs** serve as a link between district health services and the community, conduct community assessments for disease outbreaks, treat minor illnesses, conduct growth monitoring, immunization etc.
- **Lab technicians** take blood or other samples from patients, perform lab tests - like CD4 etc., record test results and report them back to the doctor and nurses
- **Counselors or social workers** provide HTC and counsel patients or clients on positive living with HIV and AIDS, disclosing HIV status to family members, helping when a patient feels depressed or hopeless or is thinking about suicide; provide referrals to community support services
- **Peer educators, such as Expert Clients** provide “real life” advice and psychosocial support to patients, help them with adherence and disclosure, talk about HIV and AIDS and care and treatment in understandable terms, link patients with need facility and community resources, and serve as the link between patients and clinical staff
- **Data clerks/information officers** make sure patients’ records are kept safe so that the team can give them the best possible care
- **Community-based workers and organizations** provide psychosocial support, material support, home-based care, and nutritional support in the patients’ home and community, mobilize the community to stop stigma and discrimination
- **Faith-based organizations and spiritual leaders** provide support and counseling to patient and his/her family
- **Family members and friends** accept the person’s status and provide support to live positively and access and adhere to care and treatment, to practice safer sex and infection prevention in the home, serve as home-based care providers
- **The patients themselves** can be educated and informed consumers of services and active participants in their own care

The multidisciplinary care teams need to work together, communicate with one another, and respect each individual’s contribution to improving the health and well-being of the patient. If one “link in the chain” is missing, the patient will not get the quality care he or she needs in the hospital, in the community, or in the home. It’s important that multidisciplinary care teams plan ways to work together, such as by meeting regularly to talk about the program and specific patient’s care.

2.3: ROLES OF EXPERT CLIENT IN THE MULTIDISCIPLINARY CARE TEAM (20 MIN)



Participant Activity

- Distribute the job description handout and ask participants to read it
- In small groups, give them 10 minutes to discuss it
- In plenary, ask participants if they have any remaining questions and discuss for 10 minutes
- Review the rest of the content in this section quickly, only discussing issues not already raised

Expert clients are responsible for the following general duties and responsibilities:

1. Participate as an active member of the multidisciplinary care team at all points of care delivery depending on the schedule of health facilities.

2. Provide health education sessions on topics such as HIV basics, ART, adherence, preventing opportunistic infections, PMTCT, safer sex and risk reduction, living positively, nutrition, and disclosure to ART and PMTCT clients (and their family members) through group and one-on-one sessions, in coordination with the multidisciplinary team.
3. Provide psychosocial support to clients during counseling sessions.
4. Prioritize pregnant women for care and treatment services, and facilitate follow-up mothers and infants after delivery.
5. Help patients with referrals, including walking them to the referral point, explaining why the referral was made and what services will be given at the referral point.
6. Act as a link between patients and the multidisciplinary care team, including presenting common concerns of patients/adherence challenges faced by patients in multidisciplinary team meetings.
7. Help promote family-focused care by asking all patients about family members and encouraging them to come for HIV testing and counseling, care and treatment.
8. Assist with identification and compilation of names of patients who do not return to the clinic for appointments, CD4 or other tests (and results), and medication refills.
9. Provide a list of these names to the supervisors for follow up by follow up team in the community (Community Facilitators and health promoters)
10. Collect referral forms from clinician's office and submit to the health supervisors on monthly basis.
11. Link patients and caretakers to community-based care and support services.
12. Keep basic records and compile monthly reports.

Even though the work of Expert Client should be family focused, pregnant women, HIV positive mothers and children should receive special attention as the most vulnerable group. The specific tasks associated with counseling and helping to care for pregnant women, HIV positive mothers and children are highlighted throughout this manual.

2.4: UNIT SUMMARY

The key points of this unit include:

- Expert clients are important givers and receivers of HIV and AIDS prevention, care, and treatment services.
- Expert clients make up an important part of the multidisciplinary care team and complement the work of other team members.
- Expert clients have many day-to-day roles and responsibilities to support patients in accessing and adhering to care and treatment.
- ECs Provide health education sessions and provide psychosocial support to clients during counseling sessions.
- One of the key tasks of ECs is to help prioritize pregnant women for care and treatment services, and facilitate follow-up mothers and infants after delivery.
- ECs also help referrals with referrals and linking patients to services at the health facility and in the community.
- ECs have an important role to play in reducing loss-to-follow-up by compiling lists of patients missing appointments and working with other members of the multidisciplinary care team to support patients to return to care.

UNIT 3: HIV BASICS

Time	Specific Objective	Teaching Methods	Learning materials
15 Min	By the end of this unit, participants should be able to: Define HIV and AIDS and describe the ways HIV is transmitted	QA lecture	Flip chart, Markers LCD Projector Trainer's manual Flip chart on HIV on CD4 cells
15 Min	Describe myths and rumors about HIV and know which are true and which are false	QA Discussions Lecture	
20 Min	Explain how HIV affects the immune system, including the impact of HIV on CD4 cells.	Discussions Lecture	
15 Min	Mention ways HIV can be prevented.	QA Lecture	
15 Min	Describe the major pieces of comprehensive HIV care and support and why this is important to PLHIV and their families.	Group discussions Lecture	

3.1: BASIC INFORMATION ABOUT HIV AND AIDS (30 MIN)

HIV stands for *Human Immunodeficiency Virus*.

H = Human (refers to us)

I = Immunodeficiency (lack of protection from getting sick)

V = Virus (a type of germ in the body that can't be cured)

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 lack of protection from getting sick)

S = Syndrome (a group of symptoms or illnesses)

Some basic definitions:

HIV is the virus that gets into the body,

HIV-infected refers to when HIV has entered a person's body. A person who is HIV- infected might be very healthy and not have any signs of illness for a long time, but they can pass the virus to others. The average time from HIV-infection to developing AIDS can be many years. This is why the only way to tell if a person has HIV is with a blood test, not by looking at them.

AIDS is a group of serious illnesses and opportunistic infections that develop after the body is too weak to fight back.



Participant Activity

- In small groups, participants should discuss what myths, rumors and truths they know or hear about related to HIV for 10 minutes
- Give them 5 minutes to report back and make clarifications as needed
- Each group should only add NEW points, not repeat points already made
- Review the rest of the content in this section quickly, only discussing issues not already raised

Myths, rumors, and untruths about HIV and PLHIV:

- Traditional healers and holy water can cure people with HIV.
- A faithful couple in which both people are HIV-positive does not need to use condoms.
- Only promiscuous people get infected with HIV.
- Anyone with TB or pneumonia has HIV.
- An HIV positive woman must have been sleeping around.
- PLHIV should never have sex again.
- Having sex with a virgin can cure AIDS when they are positive.
- Being diagnosed with HIV is a death sentence.
- You can tell if a person has AIDS by looking at them.
- Feeling better after starting ARV treatment means an HIV-positive person has been cured.
- Being HIV-positive means a woman should never have children.
- All children born to women with HIV will get infected with HIV.
- ART is too strong for pregnant women to take, as it will hurt the baby.
- HIV infected infants will not live for very long.

3.2: FROM HIV TO AIDS – WHAT DOES HIV DO IN THE BODY? (20 MIN)

How can a person know if she/he has HIV or AIDS?

- HIV infection can be diagnosed with a simple blood test. This is usually called “HTC” or HIV rapid testing. Pregnant women are usually given an HIV test as a routine part of antenatal care. Remember, you can’t tell if people have HIV by looking at them!
- AIDS can be diagnosed by a doctor, clinical officers, medical assistants or nurses after examining a person’s health and taking a history.

What does HIV do to the immune system? *(Be sure to reference flip chart on HIV on CD4 cells)*

- The immune system is the body’s natural defense against diseases.
- The human body is made up of many tiny cells. Cells are the basic building blocks in our body – they give us energy and keep us healthy and alive.
- In a healthy person, the immune system fights off diseases that enter the body to keep the person healthy. A type of cell called the CD4 cell helps the body fight infections.
- Some people talk about the CD4 cells as “soldiers” that defend the body.
- HIV enters the blood stream and starts to attack CD4 cells.
- For a while, the CD4 “soldier” cells keep the HIV virus weak in the body.
- But, after some time, the HIV becomes stronger than the CD4 soldier cells and keeps making more of the virus and attacking more of the CD4 cells. The HIV keeps reproducing and there is more and more of it in the body.
- This makes people more likely to get infections and makes it harder for the body to fight these infections because they don’t have as many CD4 cells.
- Eventually, the HIV attacks so many of the CD4 soldiers, that there aren’t enough to fight back. The body is attacked by infections and germs that the person can’t fight off.
- These infections are what eventually make people develop AIDS.

The World Health Organization (WHO) has a system of categories which outlines the transition from HIV infection to AIDS. It is summarized below:

WHO Stage 1

HIV enters: Virus enters the body and sometimes a person’s lymph nodes may be enlarged.

WHO Stage 2

HIV-positive, high CD4 count, no major symptoms: A person carries HIV and can spread it to others, but feels healthy and has a lot of CD4 soldier cells. The person will not know that he/she is HIV-positive unless tested. This stage can last up to 10 years in adults, but a much shorter time in children, who usually become sick quickly. The person may present with other symptoms such as shingles, rashes and upper respiratory tract infections.

WHO Stage 3

HIV-positive, lower CD4 count, some symptoms: Person is healthy most of the time, but may start losing weight and getting sick more often as he/she has fewer and fewer CD4 soldiers. Also takes longer to feel healthy after being sick. Person may present with weight loss of more than 10% of body weight, oral thrush, diarrhea of more than 3 weeks, and TB.

WHO Stage 4

AIDS, very low CD4 count, lots of symptoms and infections: Person has many opportunistic infections and has a hard time getting rid of them, CD4 count drops below 250, and amount of HIV increases in

the body. Person may have extra-pulmonary tuberculosis (EPTB), Kaposi's sarcoma and other life-threatening opportunistic infections.

This speed of progression is a bit different for babies and children with HIV. Without treatment, babies and children with HIV will usually progress from HIV to AIDS very quickly. Also, there are different CD4 count cut offs for babies and children than there are for adults. All infants less than 24 months who are positive are eligible for treatment even if they are not yet sick.

Making sense of CD4 test results:

- People living with HIV should get a blood test to see the levels of CD4 soldiers when they first know they are HIV-positive and then regularly after that time (usually every 6 months). It's important for expert clients to help other patients come back for results and understand the CD4 test results.
- Healthy people with good immune systems have CD4 counts between 500-1500 (measured in the unit cells/mm³). People do not need to start taking ART when the CD4 count is this high but they should take Cotrimoxazole prophylaxis treatment (CPT), when they are advised to do so by health care workers.
- When a person's CD4 count goes below about 500, they may start getting opportunistic infections that the body has trouble fighting.
- When a person's CD4 count goes below 350 they will usually become quite sick and now need ART to stay healthy. It's important to get CD4 tests on a regular basis because usually the CD4 will fall first and then the person will get sick a bit later. If the person knows the CD4 is dropping, he/she can take steps to avoid getting sick, like taking ART.

HIV can be transmitted through these fluids if they are infected:

- Semen
- Vaginal fluids
- Blood
- Birthing fluids
- Breast milk

HIV is not transmitted in these body fluids (unless there is also HIV infected blood):

- Urine
- Feces
- Saliva
- Sweat

Ways HIV is transmitted: Sexual transmission:

- Unprotected sexual intercourse with infected person
- Direct contact with body fluid of infected person (blood, semen, vaginal secretions)
- ***Note: sexual transmission accounts for 87% of HIV transmission worldwide and is the main driver of HIV transmission in Malawi***

Mother-to-child transmission:

- During pregnancy
- During labor and delivery (note: most mother-to-child transmission happens at this stage)
- During breastfeeding

Blood-to-blood transmission:

- Transfusion with infected blood
- Direct contact with infected blood/body fluids
- Needle stick injuries (blood to blood)

Ways HIV is NOT transmitted:

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

3.3: HIV PREVENTION (20MIN)

Expert Clients have an important role to play in teaching people how to prevent HIV for themselves, their families, and in their communities.

The ABCs of preventing sexual transmission

- A** Abstinence
- B** Be faithful to one partner
- C** Consistent and correct condom use¹
- D** Delay sexual debut
- E** Early and complete treatment of sexually transmitted infections (STIs)
- F** Free and open communication between partners about sex
- G** Get to know you HIV status

Prevention of mother-to-child transmission (PMTCT)

- Make sure that every birth is planned and wanted. Communicate actively about family planning between couples.
- HIV testing before deciding to become pregnant
- Regular antenatal care with HIV testing
- Counseling for mothers and fathers on PMTCT
- Safer sex during and after pregnancy
- Family support and reducing stigma against pregnant women with HIV
- ARVs for mother from pregnancy and throughout life and nevirapine for the baby when at birth
- Delivery at a health facility
- Safe infant feeding – exclusive breastfeeding (no other fluids, foods, or herbs at all, including water) for 6 months. When the baby is 6 months old, give complementary foods and continue breastfeeding. Breastfeeding and supplementary feeding should continue up to 18 months.

¹ It is important to note that condoms occasionally break and using condoms correctly and consistently upon every occasion of sexual intercourse can be hard to do. Abstaining from sex until marriage and being faithful to a single HIV negative partner are good risk reduction behaviors to practice.

- Prevention and prompt treatment of breast infections
- Regular follow-up of mother and baby

3.4: INTRODUCTION TO COMPREHENSIVE, FAMILY-FOCUSED CARE (15 MIN)

The goals of comprehensive HIV care are to:

1. Improve the quality of life of people living with HIV (PLHIV);
2. Improve the lives of families and communities affected by HIV especially pregnant women and children; and
3. Prevent further spread of HIV.

Important points to remember about comprehensive care:

- It involves many types of information, resources, and services to address a range of needs – not just medical needs.
- Each PLHIV has different needs at different points in time, depending on the stage of illness and his/her specific circumstances. Remember, HIV is a chronic illness that lasts for a person's whole life.
- A "continuum of care" responds to the range of care and support needs in different places—such as at the hospital, clinic, community, and home – over the course of the person's life.
- It relies on a coordinated response from people with a variety of skills – such as doctors, clinical officers, medical assistants, nurses, counselors, HSAs, pharmacists, family members, community health workers, peer educators, other PLHIV, spiritual leaders, and volunteers.

Comprehensive care includes:

- Pre- and post-test HIV counseling, HIV testing, and follow-up
- Early infant diagnosis for babies (DNA/PCR)
- Prevention, diagnosis, and treatment of opportunistic infections and other illnesses, such as malaria
- Palliative care, including pain management
- ART (for those who need it)
- PMTCT, antenatal and reproductive health services
- Infant and Young Child feeding (IYCF) counseling
- Regular immunizations for babies
- Ongoing monitoring of health status (through lab tests, growth monitoring and physical exams)
- Ongoing follow-up of babies that have been exposed to HIV
- Hospitalization for those that are very sick
- Counseling on positive living and prevention
- Couples and disclosure counseling
- Referral and follow-up
- Home-based care
- Nutritional support
- Psychological support (including adherence support for patients on ART)
- Social and spiritual support
- Material or economic support (money, clothes, food, etc.)
- Legal support
- End of life care, including pain management
- Care and support for family members, including children

Family-Focused Care

Family-focused care means that all members of the multidisciplinary care team, including the expert client, think about the needs of all family members, and not just the patient. It also means thinking about the linkages between the individual patient, the patient's family, and the community as a whole. Expert Clients should make it a normal practice to ask patients about their family members and partners and encourage them to bring these people to the clinic for services, if needed.

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

Here are some examples of the benefits of a family-focused approach:

- An Expert Client may know that a patient's mother-in-law moved into the home and the doctor may know that the patient is getting sick more often. Only when the Expert Client and the doctor share this information with each other will they be able to see that the patient may be hiding her HIV-status from the mother-in-law and no longer can take medications openly. She may need help to disclose her status.
- A pregnant woman is seen for antenatal care and she tests HIV-positive. She is given PMTCT counseling. The counselor asks her if she has a partner at home or other children. The woman says that she has a young baby that seems healthy and a partner that's had a high fever and a lot of coughing. The Expert Client helps the woman figure out how to disclose her status to her partner and try to get him – as well as her baby - into the clinic for testing. Only by asking about the whole family can we identify other people in need of services and help the family as a unit.
- A pediatrician may know that a child isn't growing fast enough, while another doctor might have just found out that the mother has TB. The home-based care provider might have noticed that the mother isn't able to work in the garden anymore because she's too sick and the family doesn't have enough food now. Only by talking together and thinking about the whole family's well-being can they develop a support plan for the mother and the child.

3.5: UNIT SUMMARY

The key points of this unit include:

- Expert Clients should know the facts about HIV and help dispel myths and rumors among patients and in the community.
- HIV is a virus that enters the body. A person can be healthy and HIV-infected for many years before getting sick and developing AIDS. But they can still transmit the infection to others, so it's important for people to know their HIV-status by getting tested. Starting ART reduces the risk of transmitting the infection whether through sexual contact or MTCT.
- Babies and young children with HIV develop AIDS much faster than adults and should be started on ART even before they become sick.
- You can't tell if a person has HIV by looking at them. The only way to know is to get an HIV test.
- HIV attacks a person's immune system and makes it hard for the body to stay healthy and fight off diseases and infections.
- HIV attacks the CD4 cells in the body. The CD4 cells are like soldiers that protect the body from attacking illnesses. Eventually, HIV attacks so many of the CD4 soldier cells that the body can't fight infections anymore and develops AIDS.
- The doctors and nurses can tell if someone needs to start ART by checking the number of CD4 cells they have (through a blood test). The test can also be used to see if the treatment is working (more CD4 cells). Also if a doctor sees a person has some clinical signs and symptoms of AIDS, s/he may start a person on treatment.
- It's very important that Expert Clients know all the ways HIV can and cannot be passed from person to person to help patients prevent infections.
- HIV lives in semen, vaginal and birthing fluids, blood, and breast milk.
- HIV can be passed through unsafe sex with an infected person, from an infected mother to her child, from blood-to-blood contact.
- Even though there are many ways to get HIV, there are many ways to prevent it!
- Expert Clients play a key role with patients and their families and in the community to make sure everyone knows how to practice safe behaviors and prevent new HIV infections.
- Expert Clients should know all the package of comprehensive care and help patients and their families understand and access the services over time. Remember that needs may change over time.
- HIV is a family and community disease. It is important for Expert Clients to always ask about a person's family members and try to get them in for needed services.

UNIT 4: BASIC COMMUNICATION AND COUNSELLING SKILLS

Time	Specific Objective	Teaching Methods	Learning materials
15 Min	By the end of this Unit, participants shall be able to: Explain their own attitudes, values, and beliefs and discuss how these may affect communication with others.	Discussion	Flip chart, Markers LCD Projector Trainer's manual
10 Min	Differentiate between counseling and advising	Role play Discussion	
15 Min	Explain what is meant by shared confidentiality and why it's important.	Discussion Lecture	
15 Min	Demonstrate non-verbal communication and active listening skills	Role play Discussion	
20 Min	Demonstrate reflection, goal-setting, and summarizing skills.	Question and answer Lecture	
15 Min	Describe the difference between counseling and group education.	Lecture Discussion	
15 Min	State different teaching methods in health promotion and their advantages and disadvantages.	Lecture Discussion	

4.1: ATTITUDES, VALUES AND COMMUNICATION (15 MIN)

As an expert client, there are some key concepts you should be aware of:

- Being **self-aware** means knowing yourself, how other people view you, and how you affect other people.
- **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 OK 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, when a person assumes that a person with HIV must be promiscuous or sleeping around.

Expert clients should always:

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

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

4.2: COUNSELING VS. ADVISING (10 MIN)



Participant Activity

- In small groups, participants should discuss the meaning and aim of counseling for 10 minutes
- Review the rest of the content in this section quickly, only discussing issues not already raised

Definition and aim of counseling

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

Counseling includes:

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)

- Listening attentively
- Helping people tell their stories without fear of stigma or judgment
- Giving correct and appropriate information
- Helping people to make informed decisions
- Exploring options and alternatives
- Helping people to recognize their strengths and use these strengths to address challenges
- Helping people to develop a positive attitude to life
- Respecting everyone’s needs, values, culture, religion, and lifestyle

Counseling does not include:

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

4.3: SHARED CONFIDENTIALITY (15 MIN)

Shared confidentiality:

In order for patients to trust someone with their feelings and problems, it’s important for them to know that this information will be kept confidential. This means that the Expert Client and other members of the multidisciplinary care team will not tell other people what the patient says, that they are HIV-positive, or any other personal information. Confidentiality is especially important in HIV programs because of the stigma around HIV and discrimination against PLHIV in the home, at work and school, and in the community.

Because multidisciplinary teams take care of patients, sometimes they need to discuss a patient’s needs and health status with one another to provide the best care possible. Shared confidentiality means that necessary information about a patient is disclosed to another person involved in the patient’s care (a member of the multidisciplinary team, a community health worker, a treatment supporter, etc.) **with the patient’s consent**.

Expert Clients will come from the same community as the recipients of their services. This might make some people who know them uneasy, especially in the beginning. **Expert clients need to assure patients that they will not discuss their concerns, health, or problems with people in the community.**

4.4: NON-VERBAL COMMUNICATION AND ACTIVE LISTENING SKILLS (15 MIN)



Participant Activity

- As 4 participants to do a role play during a counseling session and to ask questions to a couple that

- have come for STI screening
- Allow 10 minutes for the role play
- Afterwards, ask participants if they noticed any open or closed questions

It is important for expert clients to differentiate between closed-ended questions and open-ended questions for effective communication.

Closed-ended questions:

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

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

Open-ended questions:

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

Open-ended questions are the best kind to ask during counseling and group education sessions. They help patients explain their feelings and concerns and help the expert clients get the information they need to help people make decisions. Here are more examples in the table below:

Closed-ended question	Open-ended question
Do you use condoms?	What challenges do you have using condoms with your partner?
Do you drink alcohol when you are upset?	What are some of the ways you relieve stress or anger?
Did your partner get tested for HIV?	How would you feel about asking your partner to get tested so you can both be as healthy as possible?
Do you want to have children in the future?	How do you feel about having a bigger family? What concerns do you have?
Do you have someone you can talk with about taking your medicines the right way?	Tell me more about the people you have disclosed to and how they could help you remember to take your medicines.
Do you know how to prevent transmission of HIV to your baby?	I want to make sure that I’ve explained everything well to you – can you tell me what you understand about ways you can protect your baby from HIV?
Do you breastfeed the baby exclusively?	Can you tell me more about how you feed the baby?

These are essential skills for actively listening and building trust with your client.

Non-verbal communication:

- Make eye contact.
- Face the person.
- Be relaxed and open with your posture.
- Use good body language – nod your head, lean forward.
- Smile!
- Don't look at your watch, the clock, or anything other than the person you're talking to.
- Turn your mobile phone off and never take calls during a counseling session.

Active listening skills:

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

**Participant Activity**

- As 4 participants to do a role play with a pregnant woman who has just received a positive HIV test result for 10 minutes
- Ask other participants to take note of non-verbal and active listening skills
- Discuss observations in plenary for 5 minutes

4.5: REFLECTION, GOAL SETTING AND SUMMARIZING SKILLS (20 MIN)**Reflecting skills:**

When counseling, it's important to ensure that the listener has understood correctly. A technique called "reflecting" is often used. To do this, the expert client repeats back to the person the main themes and feelings of what the person communicated. The advantages of reflecting include the following:

- Provides feedback to the person and enables the person to confirm that they have been listened to, understood, and accepted.
- Helps promote discussion.
- Shows understanding of the person's story.
- Helps the expert client check the clarity of their understanding.
- Can reflect the content of what is being said as well as the feelings the person has about the situation.

Goal-setting skills:

Another important component of counseling is goal-setting. Towards the end of a counseling session, the expert client works with the person to come up with next steps to solve their issues in the short- and long-term. Here are some key points about goal-setting:

- Should be developed jointly by the expert client and person receiving counseling.
- Can empower people to achieve what they want by agreeing to realistic short- and long and term goals.
- Must provide direction and be results-oriented.
- Goals must be clear enough to help people measure their own progress; people feel good when they achieve something they've set out to do.
- To start, the Expert Client could say, "OK, now let's think about the things you will do today based on what we talked about."

Summarizing skills:

To end a counseling session, it's helpful to summarize what has been communicated during a counseling session and clarifies the major ideas. Here are some key points for summarizing a counseling session:

- Summarizing can be useful in an ongoing counseling session, or in making sure you're clear on important issues raised during a counseling session.
- It works best when both the Expert Client and patient participate and agree with the summary.
- Summarizing gives an opportunity for the expert client to encourage the person to examine his/her feelings about the session.

4.6: TYPES OF HIV COUNSELING AND GROUP EDUCATION (15 MIN)

These are some of the main types of group education and counseling that expert clients will learn more about in this training:

- One-on-one PMTCT counseling or group education – to help pregnant women get a test for HIV, understand the test results, prevent HIV infection during pregnancy and beyond if negative, and get needed services for herself and the baby if positive, including prioritizing pregnant women for ART and infant follow-up.
- One-on-one adherence counseling or group education - assists patients to follow a care plan and to take medications consistently and correctly. This is usually done before a person starts ART, but should also be continued over time as people's adherence challenges will change.
- One-on-one disclosure counseling – when people are ready to tell another person about their HIV-status, it can help bring the disease out into the open, make it easier for a person and his/her family to seek and adhere to care and treatment, and reduce stigma and discrimination by being a positive role model. Disclosure counseling can be with one person to help that person prepare to disclose, or with more than one person, for example a couple, to facilitate the actual disclosure process.
- One-on-one supportive counseling or group education – providing ongoing practical, psychological, and emotional assistance and referrals to people to live positively with HIV.
- Couples counseling – can be on any of the above subjects, with couples that are both living with HIV or with discordant couples, meaning that one is HIV infected and the other is not. This type of counseling is especially important for women to be supported in seeking PMTCT and care and treatment services.

Supporting each other

Counseling is not an easy job. It's important that expert clients and other health care providers make a plan to support each other by developing a "care for the carer" plan at the health facility. Expert clients should meet with each other on a regular basis and the multidisciplinary team should meet to support each other and discuss difficult cases. However, remember to always maintain shared confidentiality.

4.7: HEALTH PROMOTION METHODS (15 MIN)

Effective communication is very important for health promotion. There are various techniques used in health promotion embedded in communication. The health promoter may choose one or several ways in which to disseminate the message to the audience such as lecture, discussion, demonstration, brainstorming, role play, and peer teaching. The table below highlights the definition, advantages and disadvantages of these learning methods.

ADVANTAGES AND DISADVANTAGES OF VARIOUS TEACHING METHODS

Type of teaching method	Advantages	Disadvantages
<p>Lecture method - formal presentation of information by a trainer so that participants can listen, observe and understand the concept, principle or procedures being presented.</p>	<p>One trainer can communicate with large number of participants.</p> <p>It is most helpful in introducing a new topic/information helping participants understand material to be covered with less difficult.</p> <p>A large content can be covered in a fairly short time and time spent on topics can easily be controlled.</p>	<p>If overused without participant's participation the method can easily lead to boredom as it uses one-way communication.</p> <p>Does not permit feedback from participants as a result it is difficult for the trainer to correct misconceptions developed during a lesson.</p> <p>Pace of lecture does not suit all participants and it is often difficult to achieve effective learning.</p>
<p>Discussion method - Involves participants in sharing information, ideas and experiences on an issue.</p>	<p>Develops learners' self-confidence, communication skills, critical thinking, self-expression and self-development.</p> <p>It helps the trainer to redefine his/her role as a guide, not always as a leader.</p> <p>It offers opportunity for participants to practice facilitation techniques and to take different roles, such as group leaders.</p>	<p>It is time consuming in terms of preparation and actual discussion.</p> <p>Participants may argue and discuss off the topic if the facilitator is not firm enough and it may be difficult to assess an individual participant's performance.</p> <p>Participants with strong emotions (personality) may dominate the discussion, while others fail to speak due to shyness.</p>
<p>Demonstration method - concepts and procedures are shown directly to learners.</p>	<p>It improves retention and increases interest in the lesson by providing a direct learning experience.</p> <p>Participants can practice a new skill under expert guidance.</p> <p>The interactive approach allows for immediate correction of error.</p>	<p>It may be time consuming and/or expensive.</p> <p>It is not suitable for very large groups because of space limitations and difficult in seeing and in hearing.</p> <p>Poor demonstration may result into loss of credibility of the instructor or procedure.</p> <p>Written directions can require lengthy preparations.</p>

<p>Brainstorming method - asking a question on a certain issue and guiding the participants to think of as many ideas about it as they can. Emphasis is on free expression of ideas and no criticism is permitted.</p>	<p>Everyone has an opportunity to contribute.</p> <p>Enables problem solving in groups and generates many ideas quickly.</p> <p>Helps stimulate creativity and imagination.</p> <p>Encourage open mindedness as participants come up with new ideas.</p> <p>Helps build individual and group confidence by finding solutions within the group itself.</p>	<p>Participants may feel embarrassed or afraid if they have not made any contribution or if they feel that their ideas may not be accepted the group.</p> <p>When ideas are being assessed, there may be arguments about validity of some people’s contributions.</p> <p>Some group members may dominate, others may withdraw.</p> <p>May create competition.</p>
<p>Role-play - spontaneously portrayal of a situation, a condition or circumstance by selected members of a learning group.</p>	<p>Gets learners to identify with situations thus allowing them the opportunity to perceive how others might feel, think and act. Often helps develop empathy.</p> <p>Helps learners to develop socially thus encourages interaction between group members (can be used with all groups regardless of their level of education.</p> <p>A real situation is created in a non-threatening atmosphere such that the participants try out new approaches or behaviors through anonymous identity learners practice handling difficult situations.</p>	<p>Tends to over-simplify complex situations.</p> <p>Some role-players may feel intimidated or embarrassed because of the attention that is focused on them.</p> <p>Role-play can be psychologically harmful if actors are not debriefed following the role-play. Participants should be reminded that it was drama and that comments were not personally directed at them.</p> <p>Sometimes the role-play may not help to achieve the objectives of the lesson if it fails to relate to the audience and intended purpose.</p>
<p>Peer education - a strategy used for training where the learner teaches fellow learners.</p>	<p>In the process of preparing to teach others, learners often develop a better understanding of content.</p> <p>Learners can share personal insight and use language and gestures that fellow learners understand easily.</p> <p>Some learners may identify with a peer and be more likely to heed the information or instructions provided.</p>	<p>If not well supervised, incorrect information may be communication to other learners.</p> <p>Inexperienced peer educators may get off-topic easily, leading sessions to run over time.</p> <p>Other learners may not feel that a peer educator is “credible” and may not information or instructions.</p>

The discussion and role play techniques will be especially important for expert clients' work. Here are some additional guidelines for using these learning methods.

Tips for successful group discussion:

- The trainer should introduce the topic to be discussed
- The trainer should clarify terms that may help the participants understand at is to be discussed
- Identify a facilitator and reporter for each discussion group
- Listen carefully while others are speaking
- Be objective, do not be emotional
- Do not allow particular individuals to dominate the discussions; encourage contributions from all
- The trainer should move around and provide assistance to groups as needed
- The trainer should avoid monopolizing the discussion
- The trainer should help participants to stick to the topic
- Bring the group together, let each group report its discussions; each should report *only* on points that have not yet been mentioned by the previous groups
- Summarize and conclude the lessons or discussions

Tips for successful role plays:

- Before involving participants in role-play, the trainer should organize the situation and the roles to be played in advance
- Assign roles to the participants (participants may volunteer or be selected on consent) and give them enough time to prepare
- Those not taking part in the role-play should be instructed to take notes on the most important part in the activity
- Create an atmosphere of freedom and security in the classroom so that participants are free to express their feelings during the lesson
- Should the activity get out of hand as the result of emotional reaction, the trainer should switch the roles among the participants in order to restore order and ensure security
- Certain parts of the activity may be improved if participants are given a chance to repeat the performance(debriefing)
- Evaluate and summarize the points learned

When selecting a teaching method, remember:

Age is very important. Adult learners learn best with concrete experiences and want to see the relevance of what they are learning to their lives. The trainer of adults should make training sessions learner-centered. Use learners' experiences to make their learning more meaningful. It's important for adult learners to discover things for themselves, rather than giving them facts and other information for memorization.

In addition to age and the do-it-yourself approach needed for adults, be sure to consider the following when choosing a teaching method:

- The learner's intellectual level and educational background
- The learner's social and cultural environments
- The trainer's knowledge, experience and familiarity with the teaching method

- General and specific objectives to be achieved
- Time available
- The physical setting within which the teaching is going to take place
- Availability of teaching resources
- Need to maximize the participation of the trainees
- Need for practical work to enhance learning

Public speaking

Many of us may feel a bit nervous when speaking in front of others. Remember these key public speaking tips to communicate clearly:

- Speak loudly
- Speaking clearly
- Using simple words
- Sound as though you are interested and enthusiastic

Teaching Aids

These are aids used by a trainer and a learner in a process of imparting and acquiring knowledge, skills and influencing attitudes. Teaching aids help a trainer to conduct the session more effectively by making it more interesting and relevant to the learner. Teaching and learning materials must be accurate and relevant. They should be appropriate for the particular age group. Also, they should be attractive so that they capture the learner's attention.

There are three categories of teaching aids:

1. Visual aids - flip-charts, pictures, and textbooks
2. Audio aids - human voice or tape recorder.
3. Audio-Visual Aids - video, film

Teaching and learning aids are extremely important. They arouse learners' curiosity and motivation hence sustaining learner's attention throughout the lesson. They simplify for learners what is complex and difficult and help reinforce memory. They assist the trainer to clarify points. Finally, teaching aids help learners in acquiring listening and observational skills.

Guidelines for effective use of teaching and learning materials

1. The use of any material should serve some specific objectives for learners to achieve.
2. Use of materials should be well planned. Know when and how to use it. **If you are using more than one put them in order to use.**
3. Emphasize what should be learned from a particular material.
4. Materials should be visible and available to the whole class.
5. Ensure they are working prior to the lessons.
6. If materials are to be brought by learners, inform them in advance to know what to bring.
7. After the session, leave materials in the room for the learners to study.

4.8: UNIT SUMMARY

The key points of this Unit include:

- Our own attitudes, values, and prejudices should not be a part of communication and counseling with patients and other community members.
- Counseling is a very important, two-way communication process that Expert Clients will use every day in their work.
- It is best to limit the use of closed-ended questions and instead use more open-ended questions during counseling.
- It's important for patients to know that what they say will be kept private.
- Patients should give consent for counselors to talk about their situation with other providers. Expert Clients should practice shared confidentiality.
- The best communication includes using good non-verbal communication and actively listening to the other person.
- Skills such as reflecting what the person is saying back to him/her, helping the person set goals and next steps, and summarizing what was discussed in the counseling session are all important skills for Expert Clients to have.
- Expert Clients are expected to be good leaders and facilitators of group education sessions, as well as one-on-one or couples counseling sessions
- There are several ways of disseminating messages to audience such as demonstrations, role play, lecturing and peer education
- Teaching aids and learning materials facilitate the process of imparting and acquiring knowledge, skills and influencing attitudes

UNIT 5: HTC, HIV CARE AND SUPPORT

Time	Specific Objectives	Methods	Materials
15 Min	By the end of this Unit, participants shall be able to: Explain HTC process and how HTC is the entry point to care and treatment.	Lecture QA	Flip chart, Markers LCD Projector Trainer's manual Pictures/cards of opportunistic infections (OIs)
45 Min	Demonstrate how to provide support and information to patients during and after post-test counseling and how to link them to care and treatment services.	Lecture Role play	
15 Min	Explain the difference between care and treatment services and who is eligible for care.	Brainstorming QA	
30 Min	Describe the components of clinical care to patients, including regular CD4 testing, and why these components are important.	Lecture QA	
20 Min	Explain how to motivate patients to return to the clinic for care, especially pregnant women, infants and small children.	Brainstorming Lecture	
30 Min	List common opportunistic infections, and explain how they can be prevented and treated.	Lecture Group discussion	

5.1: THE HIV TESTING AND COUNSELING PROCESS: ENTRY POINT INTO CARE (15 MIN)

While HIV tests should be available to all people on a voluntary basis through HIV testing and counseling (HTC), HIV testing is also becoming a routine part of clinical care, since so many people are living with HIV. For example, all pregnant women, all adults and children admitted to the hospital, and all people with TB should be offered and encouraged to get an HIV test. This is called **provider initiated HIV testing and counseling (PITC)** because the health care provider actively suggests that the patient get an HIV test, instead of waiting for the person to request an HIV test. This is a good strategy to get more people tested and counseled, and to get people who test positive enrolled in care and treatment as soon as possible.

HIV testing is an entry point to care and treatment, meaning that it's the first step in getting care and treatment services. We need to know for sure that a person has HIV before we link them with care and treatment.

Pre-Test Counseling

Expert clients (ECs) are not trained as HIV test counselors, but ECs should support the nurses, counselors and other healthcare providers assigned to this task at their sites. Expert clients can play an especially important role during and after post-test counseling, especially by sharing their personal experiences and thus helping patients/clients to make informed decision on testing, care, treatment and support. Expert clients should use family-focused approach when they talk to clients: it's important for all members of the family to be tested for HIV test. ECs can help families know what to expect.

Remember: HIV counseling and testing is the ENTRY POINT to care and treatment. In the pre-test counseling session, a trained counselor (usually a nurse or HSA) will do the following, in an individual session or in a group session:

- Introduction and orientation to the session
- Explore options for reducing risk and vulnerability, or if in a group discuss how HIV can be prevented
- Explain the meaning of a positive or a negative result
- HIV test preparation

During HIV Testing a trained person, usually a nurse, will:

- Explain the testing procedure and when the results of the test will be read (usually the same day).
- Draw a small amount of blood. Only a small amount of blood is needed, so the person doesn't need to worry about feeling weak or tired because of loss of blood.

5.2: POST-TEST COUNSELING AND LINKING PATIENTS TO CARE AND TREATMENT SERVICES (45 MIN)

After conducting the test, the health provider will tailor the post-test counseling to the patient's result.

For a NEGATIVE test result:

- Inform the client that the test results are ready.
- Show results clearly and simply.
- Explore the client's reaction to the test results.
- Review the meaning of the results.
- Explain the window period and the importance of coming back for another test.
- Discuss risk reduction plan. Emphasize the importance of abstinence until marriage and being

faithful to one HIV negative partner to prevent HIV infection.

- Discuss disclosure and partner referral.

For a POSITIVE test result:

- Review the meaning of the result (including an explanation of discordant results and next steps).
- Allow the client time to absorb and react to the meaning of the result.
- Explore the client's understanding of the result.
- Assess how the client is coping with the result.
- Acknowledge the challenges of dealing with a positive result.
- Discuss the meaning of a CD4 count and when and why the person should return to get CD4 test results.
- For pregnant women, discuss PMTCT strategies and remind the woman that not all babies get HIV from the mother if the woman is pregnant. There is hope for the mother and baby to be healthy.
- Explain ART eligibility and for pregnant women and the benefits of ART for the mother and baby.
- Discuss positive living and care and treatment.

Identify sources of support

- Assess whom the client would like to tell about his/her positive test results and when.
- Identify a family member or close friend that can help the client through the processes of dealing with coping, planning, positive living, and follow-up.
- Identify the client's current health care and social resources.
- Address the need for health care providers to know client's test result.
- Identify needed medical and social support referrals.
- Discuss which support groups are available.
- Provide appropriate referrals to support groups, community resources, and care and treatment services, including ART (what, when, where).

Discuss risk reduction plan

- Identify barriers to the risk reduction plan and provide support.
- Identify priority of risk-reduction behavior.
- Plan risk-reduction into specific and concrete steps.
 - Promote abstinence before marriage and faithfulness to one partner
- Identify reasonable, small steps towards changing the identified behavior.
- Talk about routine antenatal care, safe delivery, PMTCT and safer sex if the woman is pregnant or wants to become pregnant.
- Feeding recommendations are the same for all infants, regardless of HIV exposure or HIV infection status:
 - Give only breast milk up to age 6 months (no water, gripe water, dawale, bara, thobwa, mzuwa, etc.).
 - Give only medicines prescribed by a health professional
 - Gradually start complementing breast feeding with suitable hygienically prepared foods from age 6 months (such as Likuni Phala, fruits, vegetables, beans, ground nuts and soya)
 - Wean child around age 24 months
 - Wean gradually over a period of 1 month (no rapid cessation)
 - Replacement feeding (formula) is NOT recommended unless women are unable to breast feed.

- Explore behaviors that the client will be most motivated about.
- Role-play as needed, for example situation such as condom negotiation.
- Recognize the challenges of behavior change.
- Provide support for the person to share the plan with partner, family, and friends.

Discuss disclosure to exposed contacts and referral

- Explore client's feelings about telling partner(s) about the HIV-positive test result.
- Remind client that the result does not indicate the partners' or children's HIV status.
- Identify partners that are at risk and need to be informed of their risk of HIV infection.
- Discuss possible approaches to disclosure of sero-status to partners.
- Support client to refer partners and children for counseling and testing.
- Practice and role-play different approaches to disclosure.
- Anticipate potential partner reactions.
- Provide the client with ongoing support and linkages to support groups.
- Discuss safer sex and risk reduction with partner(s).



Participant Activity

- In pairs, practice and role-play different approaches to disclosure for 10 minutes
- Give each person a chance to play the role of the EC and the role of the patient
- Ask participants to take note active listening skills and whether the partner followed the guidance
- Discuss observations in plenary for 5 minutes

ECs are well-placed to help people plan next steps after their post-test counseling. Here are some important tips for ECs to remember when working with a post-test client with a positive result:

- Listen to the patient and provide support using good communication skills. Remember the basic counseling skills, including body language and kind language.
- Explain CD4 testing, why it's done, where it is done and when and where to pick up results.
- Explain importance of enrolling in care and treatment program and help people to do this.
- Ask about partners and children and encourage them to come for HTC and care services if needed.
- For pregnant women, discuss PMTCT and the idea that if the woman enrolls in care and treatment she is "saving 2 lives." Also, discuss the antenatal (ANC) plan and safe delivery plan. Promote exclusive breastfeeding for all babies.
- Agree on a next visit date, record this in your notebook, and make sure it's recorded in the patient's appointment card. Help identify barriers to coming back and work with patients to come up with solutions.
- Remind the patient which support group is operating in his or her area and encourage him or her to participate.

5.3: CARE AND TREATMENT – WHAT IS THE DIFFERENCE AND WHO IS ELIGIBLE? (15 MIN)



Participant Activity

- Discuss the difference between care and treatment in pairs for 5 minutes
- As participants to be ready to share one main idea per team
- Review main ideas in plenary for 10 minutes
- Go through the rest of the content quickly, only highlighting areas not already mentioned

There is much that people living with HIV (PLHIV) can do to stay healthy, even if the person is not on ART. All PLHIV should come to the health facility for regular checkups, tests, counseling, and for medicines to help prevent opportunistic infections and stay healthy. For men and non-pregnant women, it's important that they keep coming back to the clinic regularly, even if they are not yet eligible for ART. This is called the pre-ART stage of care. This way, we can monitor their CD4 count closely and help them to start ART right away, as soon they become eligible. This will help to keep them healthier.

Who is eligible for care?

All PLHIV need care, and a certain number of PLHIV also need treatment with ART. Once a person tests positive for HIV, he/she should be enrolled in the care program at the hospital and linked to needed community resources. Over time, the person will also need to be enrolled in treatment and we want to start treatment as soon as possible once a person is eligible. Waiting too long to start treatment results in poor health. Non-pregnant women, older children and adult men should return to the clinic at least once every 3 months for a check-up, counseling, and a CD4 test to see if they are eligible for treatment.

Who is eligible for immediate treatment?

To help eliminate the transmission of HIV to babies, pregnant and breastfeeding women with HIV should be enrolled in treatment immediately. Babies that have been exposed to HIV should also be enrolled in care from birth. Babies, young children and pregnant women should come back to the clinic even more often (once a month or more often if sick).

5.4: COMPONENTS OF CLINICAL CARE AND THEIR IMPORTANCE (30 MIN)

Components of clinical care (other than ART):

- General health check-up by the doctor and nurse
- Prevention and treatment of opportunistic infections, especially pneumonia, malaria, and TB for adults and children. Cotrimoxazole (CPT) is one of the most important drugs adults and children can take to prevent HIV related conditions.
- Infant diagnosis at under-5 clinics and care for babies exposed to HIV
- CD4 testing to see how much the HIV is affecting the immune system and if ART is needed
- Emotional counseling and support
- Positive living counseling and support
- Disclosure counseling and support
- Discussion and referral for testing and care of other family members (like children, partner, etc.)
- Nutrition counseling and support (direct support or through referrals)
- Linkages to support groups and community resources

Where is care provided?

Often care is provided at the ART or Mother infant pair (MIP) clinics. At some hospitals care services for PLHIV are provided through the out-patient department. This is a challenge because it's hard to follow up with people in this department and sometimes they will be charged for services outside of the ART clinic in case where there is user fee. Expert Clients should work with the multidisciplinary care team to advocate for all PLHIV to be provided with quality care services at the ART clinic and to encourage good referral linkages.

Everyone who is living with HIV should come back to a clinic or hospital at least every 6 months, even if they are not on ART. It's important to see a health care worker for a check-up and get CD4 tests done to see if ART is needed. Different types of counseling, like positive living and disclosure, are important to all PLHIV, not just those on ART.

5.5: MOTIVATING PATIENTS TO STAY IN CARE (20 MIN)



Participant Activity

- In small groups, ask participants to brainstorm reasons they could use to convince someone with HIV to go back to the clinic for 10 minutes.
- Remind participants to think of the components of clinical care they just learned about.
- Discuss observations in plenary for 10 minutes, with each group contributing new ideas.
- Move through the rest of the section quickly, only highlighting those issues not already discussed.

Remember to talk with patients about how important care is and that they should come back to the clinic or hospital often (at least every 6 months, or more for babies and children or as needed for adults) to get:

- A general health check-up by health care workers (best if this can be done at the primary health clinics).
- Prevention and treatment of opportunistic infections, especially pneumonia, malaria, and TB. **It's important that ALL babies exposed to HIV or adults and children living with HIV take Cotrimoxazole.**
- CD4 testing to see how HIV is affecting the immune system and if ART is needed (then we can start people on ART right away when they are eligible to keep them healthy).
- Early infant testing at 6 weeks for DNA/PCR (to test if HIV-exposed babies have HIV).
- Emotional counseling and support.
- Positive living counseling and support.
- Disclosure counseling and support.
- Nutrition counseling and support (direct support or through referrals).
- Linkages to support groups and community resources.

The HIV Care Clinic (HCC) is a further integration of services designed to facilitate access for clinical monitoring, preventive services and ART for family members affected by HIV. For this reason, the following services should be provided together at the same time in the same clinic:

- Follow-up for HIV exposed children
- pre-ART follow-up for children and adults
- ART

Family appointments can be given to encourage family members to attend together for HIV services. Family members can be seen in the consultation room at the same time or seen individually if there are sensitive issues to discuss.

All PLHIV need care, but not all will need immediate treatment with ART. Once a person tests positive for HIV, he or she should be enrolled in the HIV Care Clinic register. These people will be in the pre-ART program.

Initiation of patients and clients in pre-ART programme will depend on strong linkages and referral between services like community-based and facility-based pre-ART services, HTC, diagnostic services, ART, PMTCT, TB services, and other social services. Pre ART care and support aims at monitoring patients and clients who have accessed HTC services to preserve their immune status and detect in a timely manner when the patient needs to be initiated on ART. Community based Pre ART aims at preserving the immunity of a person who is infected with HIV. They require multi-sectoral and multi-disciplinary collaboration. It aims at retaining patients in care and reducing loss to follow up.

Pre ART interventions include:

- HTC such as community-based testing, door-to-door campaigns, provider initiated testing and counseling (PITC) and awareness campaigns as an entry point into care
- Provision of CPT to prevent opportunistic infections
- Provision of insecticide treated bednets (ITNs) to prevent malaria
- PLHIV support groups for adults and children
- Provision of counseling services such as:
 - Behavioral Change Communication (BCC) including condom promotion & distribution
 - Adherence counseling for CPT/IPT/future ART, adherence to appointments
 - Infant and young child feeding counseling
 - Couple counseling, including for discordant couple
 - Disclosure counseling and support
 - Counseling on life skills, life styles, coping skills, crisis interventions
 - Bereavement counseling, OVC care and support for child headed households
 - Counseling on safe pregnancy, infant feeding options and family planning
- STI management including condom use
- Prevention by supporting HIV positive persons to:
 - Prevent transmission of HIV virus to others
 - Prevent the possibility of HIV re-infection
 - Prevent other sexually transmitted infections
 - Make informed decisions about health choices, especially family planning
- Retention of patients in the programme through case management and defaulter tracing to reduce loss to follow up
- Providing linkages to skills building for income generating activities and nutrition supplementation

Roles of Expert Clients in HCC/Per-ART

Expert clients have an important role to play in the pre-ART stage of care. Sometimes, when people are not immediately eligible for ART, they fail to come back to the health facility for a very long time – even years. In

many cases, they don't return to the facility until they are quite sick and they start on ART very late. Expert clients have a very important job to encourage people to enroll in care and treatment and make sure that they come to the health facility for regular check-ups.

In addition, expert clients can help with the following key tasks:

- Provision of supportive care such as counseling, nutritional advice and treatment preparedness
- Working as a member of the multidisciplinary team to prioritize care and treatment
- Keeping records about which clients are lost to follow up
- Follow up of pre ART patients
- Link patients to the health facility, community and other support services as required e.g., support groups, legal services, income generating activities (IGAs), etc.
- Provide information, communication and education materials (IEC) to patient and family members on prevention of HIV, TB and malaria and importance of HIV testing and counseling
- Monitor patients/clients response to treatment and manage recognize and refer if needed simple ailments such as cough, fever, diarrhea, vomiting, skin problems and other common problems.
- Provide psycho-social support and nutrition counseling to patients/clients and families
- Contribute to reduce stigma and discrimination

56: PREVENTION AND TREATMENT OF HIV-RELATED CONDITIONS (30 MIN)

HIV related conditions are the infections that make PLHIV sick because the body's immune system is weakened and it cannot fight back. Remember that we discussed the impact of HIV on the CD4 "soldier" cells in the body – when the HIV attacks the CD4 cells, the person has trouble fighting back when a virus or germ enters their body. PLHIV, especially people not on ART, can get many of HIV-related conditions.

One of the best ways to live positively with HIV, whether a person is on ART or not, is to prevent HIV related conditions in the first place and treat them right away if they do happen. Usually, a doctor or nurse will give patients medicines to prevent these infections. They will also give some medicines to babies born to mothers with HIV to help prevent the babies from getting sick. Eating nutritious foods frequently, drinking clean water, sleeping enough, and practicing good hygiene also help prevent infections. This is covered more in the Unit on Positive Living.

The most common HIV-related conditions are:

- Tuberculosis (usually in the lungs; the person will have a bad cough, fever, and will lose weight; easily transmitted from person to person)
- Chronic fever
- Pneumonia or PCP (a very bad infection in the lungs that can develop quickly; causes coughing, weakness, shortness of breath; is often what causes death in a person with HIV if it's not treated)
- Meningitis (a deadly disease in the brain, can cause bad headaches)
- Some cancers like cervical, Kaposi's sarcoma and lymphomas
- Prolonged diarrhea - Can cause dehydration and weight loss
- Chronic anemia
- Skin problems (like rashes or shingles, warts, or sore lesions; can be caused from fungus and be very uncomfortable)

- Oral sores (very common among PLHIV; can be very painful)
- Malnutrition and weight loss

More about TB

TB is the most common HIV related condition amongst PLHIV. About 70% of people suffering from TB are also HIV positive. TB and HIV are so closely linked; therefore, services to prevent and treat both also need to be linked.

TB usually infects the lungs, but it can also infect other areas such as the stomach or lymph nodes. Usually people with TB have a productive cough that doesn't go away, night sweats, fever, and they lose weight. TB is spread through the air, especially from coughing, sneezing, and being in close contact with a person with TB. It's made worse when there is not good air circulation – like if there are no open windows. It's VERY easy to spread TB from person to person, and PLHIV are especially likely to get it if they are in contact with a person with TB. Young children are at a high risk for TB when they live with adults who have TB.

Expert Clients should do the following to help patients treat and avoid TB:

- Encourage patients to go to the hospital or clinic right away if they cough more than three weeks
- Support provision of INH prophylaxis to all HIV positive people.
- Counsel PLHIV on the risks of TB. Let them know they have a 50% risk of getting TB if they are exposed to it (like if a family member or someone at work has TB).
- Make sure PLHIV know how to prevent TB infection. This includes avoiding close contact with people who have symptoms of TB, like a cough that won't go away, fever, or weight loss.
- TB treatment can last from 6 to 9 months or even more depending on the type of TB, and as with ART, it's important to take the medicines correctly, every day to make sure they work.
- Explain that it is important to have a TB treatment supporter that can help remind the person to take the drugs every day just as it is important to have an ART supporter.
- Making sure there is a lot of fresh and moving air in living and working areas (open windows), and make sure to always cover the mouth when coughing or sneezing (and ask that other people do the same).
- If a person has TB and has started TB treatment, he/she can start ART within 2 weeks if stable.

5.7: UNIT SUMMARY

The key points of this Unit include:

- HIV testing and counseling is the entry point to care and treatment.
- Expert Clients have a key role to play in post-test support, especially pregnant women who test positive.
- Expert Clients should strongly encourage PLHIV to enroll for care and support services at the clinic or hospital, even if they feel healthy and are not on ART.
- Important components of care that can help all PLHIV include check-ups by health care workers, preventing and treating HIV-related conditions, especially by taking Cotrimoxazole and IPT; regular CD4 tests to determine if ART is needed, early infant testing for babies; counselling on positive living, nutrition, disclosure, etc., and referrals to support groups and community support.
- Coming back often for care also means that we can identify and start people on treatment as soon as they are eligible instead of waiting until they are very sick.
- HIV-related conditions attack the body when the immune system is weak. PLHIV can get many HIV related conditions, like skin problems, TB, pneumonia, thrush or sores in the mouth, or diarrhoea and vomiting.
- One of the best things PLHIV can do to stay healthy is to prevent HIV related conditions by living positively and adhering to treatment.
- TB is the most common HIV related condition among PLHIV and can be very dangerous if not treated right away.

UNIT 6: HIV TREATMENT

Time	Specific Objectives	Methods	Materials
15 Min	By the end of this Unit, participants shall be able to: Discuss myths about ART to patients and in the community.	Group discussion Lecture QA	LCD Flipchart Markers
30 Min	Explain when a person should start taking ART.	Lecture Discussion	
15 Min	Discuss the goals of ART & the health and social benefits for men and women.	Brainstorming QA Lecture	
20 Min	List common ART regimens drugs and explain how they are taken.	Lecture QA	
20 Min	List and describe common ART-related side effects and how they are managed.	Group discussion Lecture QA	

6.1: MYTHS ABOUT ART (15 MIN)



Participant Activity

- In small groups, have participants discuss the myths and facts they know about ART for 10 minutes.
- Participants should be prepared to share main ideas with the rest of the group.
- Discuss observations in plenary for 5 minutes and move through the rest of the section quickly, only highlighting issues not already raised during the discussion.

As a member of the multidisciplinary care team and a patient education, it's important for expert clients to be able to dispel myths about ART. Here are some of the most common myths about ART:

- ART is a last resort and is only good for people who are sick and dying.
- ART can kill you on the inside even though it can make you gain weight and look healthy on the outside.
- Without ART, there is nothing PLHIV can do to stay healthy.
- Pregnant women can't take ART because it will hurt the baby.
- People can share ARVs with family members.
- Once you are feeling better on ART, you can stop taking it.
- If you feel well enough on ART, you can have sex without condoms because the HIV won't spread anymore.
- Traditional medicines are just as good as ART.
- There are no ARVs for babies and children.
- There is nothing you can do about side effects of ART.
- If the ARVs make you sick, you should stop taking them.

Some facts about ART:

- ART stands for "anti-retroviral therapy" and ARV stands for "anti-retroviral." If a person is on ART, it means they are taking a combination of ARVs.
- ART should be delivered as part of comprehensive HIV care.
- ART is not just for sick and dying people. Even people who look and feel healthy may need ART. Only a doctor, clinical officer or a nurse can tell if you need to take ART by doing a check-up and looking at your CD4 count.
- ART is a lifelong treatment, because ART is not a cure for AIDS. There is NO CURE for AIDS.
- People can still pass HIV to others while on ART, even if they feel healthy.
- PLHIV must adherence to care and treatment for ART to be successful.
- Side effects and the body's reaction to ARVs must be monitored by a doctor or nurse.
- Pregnant women can take ART.
- While some traditional medicines can help people feel better, there is no replacement for ART.
- ART can help the immune system to be more active and able to fight illness.
- ART can reduce the number of sicknesses a person has and can improve his/her quality of life a great deal.
- There are special kinds of ARVs and dosage for babies and children based on weight. Children should not be given adult ARVs unless instructed by a doctor.

6.2: WHEN SHOULD PATIENTS START ART? (30 MIN)

Not everyone who is HIV-infected needs ART right away EXCEPT for pregnant women, breastfeeding women and children under 2 years old. We call these special groups “universally eligible” because they have been prioritized for immediate and lifelong ART. As we learned in the last session, there are still a lot of things to help keep people healthy and well if they are not on ART. Only a doctor or nurse, with the patient, can make the decision to start ART. For a client to start ART, the following criteria must be followed:

ART ELIGIBILITY CRITERIA:

Under 12 months

- **Universal ART:** Confirmed HIV infection (DNA-PCR needed), regardless of WHO stage and CD4 count or CD4 %
- **Presumed severe HIV disease (PSHD):** HIV antibodies (HIV rapid antibody test) and PSHD-defining clinical conditions (see WHO Clinical Staging Chart)

12 to under 24 months

- **Universal ART:** Confirmed HIV infection (HIV rapid antibody test or DNA-PCR), regardless of WHO stage and CD4 count

24 months to under 5 years

- Confirmed HIV infection (HIV rapid antibody test) **and**
 - WHO stage 1 or 2 and CD4 ≤ 750 cells/mm³ or $\leq 25\%$**OR**
 - WHO clinical stage 3 or 4 regardless of CD4 count

5 years and over

- Confirmed HIV infection (HIV rapid antibody test) **and**
 - Pregnant or breastfeeding women (regardless of the age of the child) regardless of WHO stage and CD4 count**OR**
 - WHO stage 1 or 2 and CD4 ≤ 350 cells/mm³**OR**
 - WHO clinical stage 3 or 4 regardless of CD4 count.
- **Patient readiness for ART:**

Patients should be part of the decision to start ART. All people getting ready to start ART should participate in one group education session and one individual counseling sessions to make a treatment plan and address barriers. Expert clients can help in this process by making sure that:

 - Psychosocial barriers to adherence have been addressed.

- Patient is ready and comfortable to start ART.
- Patient understands ARV therapy, possible side effects, limitations, adherence schedule and wants treatment, demonstrates readiness.
- Patient actively involved in his/her own care and treatment.
- Partner/family/social support available or for pediatric ART, alternative caregiver available.
- Schedule to take ART and other logistics like collecting monthly supply and storing pills worked out.
- Patient is not engaged in substance abuse that would impact adherence.
- Patient has no recent non-adherence to care or medication.
- Other severe health conditions or current treatment have been ruled out (such as for TB, in which case the TB or other infection is usually treated before a person starts ART).
- Determine if the patient is pregnant (ART can and should be started immediately in pregnant women).
- See if the patient has already taken ARVs, and assess which ones and adherence issues in the past.
- HIV related conditions are treated and prophylaxis is provided.

6.3: GOALS AND BENEFITS OF ART (15 MIN)

How does ART work?

As we learned, HIV attacks the body's immune system and CD4 "soldier" cells. The virus enters CD4 cells and reproduces itself to make more viruses.

ART works by:

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

The reason that ARVs contain several medications at one time (usually 3) and not just one or two is because the different drugs work in different ways. Some stop the HIV from entering the cell, some prevent the HIV from multiplying in the cell, and others prevent the HIV from leaving the CD4 cell to infect other cells. The HIV virus can learn to "resist" or fight the drugs easily but giving drugs that work at different places prevents this from happening quickly.

When a person takes ART correctly, it helps the CD4 cells to recover and fight against the HIV and the virus doesn't attack as many cells. This means the person has more and more healthy CD4 cells that can help the body fight and attack infections.

Goals of ART

- Keep the person healthy by increasing the number of healthy CD4 cells.
- Prevent the HIV from reproducing in the person's CD4 cells.
- Prevent the HIV from leaving one cell and infecting other cells.
- Prevent transmission of HIV from mother to baby.
- Prevent transmission between sexual partners

- Keep the immune system strong so the body can prevent and fight infections.
- Make a person feel healthier and able to work, take care of self and family, and be an active member in the community.

What does ART NOT do?

- ART does not cure HIV. Once a person has HIV, he/she will have it for life, even if the person feels healthy or has a very high CD4 count.
- Being on ART does not prevent the spread of HIV to another person completely. ART helps keep the HIV under control in a person's body and reduces the risk of transmission, but they can still pass it to other people. This is why it's important to always practice safe sex!

Benefits of ART

- Less illness.
- Fewer trips to the hospital or clinic.
- Increased lifespan and less chance of dying young.
- Return to a "normal" lifestyle (working, going to school, taking care of family and household tasks).
- Continue providing financial support to the family.
- Babies born to women living with HIV can be born without HIV.
- People can feel happier and have a sense of freedom from HIV.
- Improved social life including possibilities of marriage, having a family, and living a long, healthy life.

Children respond to ARVs very well and very quickly. They usually tolerate the medications better than adults!

6.4: COMMON ART REGIMENS (20 MIN)

Expert clients do not need to memorize every ARV that exists, but they should be familiar with the names, and instructions for the most common regimens in Malawi for adults, children and ARVs for PMTCT. Knowing more about the drugs can also help in communicating with the clinical staff, who may use names or abbreviations that are not familiar to patients. During group education and one-on-one counseling sessions, Expert clients should talk with patients about which medicines they the patient is taking, why the patient is taking the medicine, and how often and how the patient takes each one.

Common First Line ART Regimens in Malawi: Though patients are usually on three drugs, they are often available together in one pill called a Fixed-Dose-Combination (FDC).

Key facts about ART regimens:

- ART requires combining **3 different medicines** that act differently in order to avoid development of drug-resistant HIV.
- ART regimens are not changed unless there is a clear medical need. Unnecessary regimen changes limit future treatment options.
- **1st Line regimens** are the best. Patients can remain on the same 1st line regimen for many years if they are fully adhering.

All 1st line regimens:

- Are easy to prescribe and easy to take
- Have a low risk of side effects
- Require no lab monitoring for toxicity
- Patients with significant side effects the 1st line regimen are moved to an alternative regimen without delay.
- **2nd Line regimens** are for patients who have confirmed treatment failure on 1st line regimen (usually due to poor adherence in the past). **2nd line regimens:**
 - Contain a completely different class of ARVs
 - Are more complicated to prescribe and to take
 - Can have more side effects
- **3rd Line regimen** is 'salvage therapy' and a last resort for patients failing on 2nd line in spite of good adherence. **3rd line regimens:**
 - Very expensive
 - Can have more side effects and be difficult to take

Taking ARVs and missed doses:

- ARVs should be taken after the same number of hours every day (e.g. every 12 or every 24 hours). Most ART regimens can be taken in the morning and at night. It does not matter if they are taken before, after or with food.
- Missing a dose: what to do if a patient remembers to take his ARVs late?
 - **Less than half-way** to the next scheduled dose: take the missed dose immediately, and take the regular next dose at the normal time
 - **More than half way** to the next scheduled dose: skip the missed dose and take the regular next dose at the normal time

6.5: SIDE EFFECTS OF ART AND HOW TO MANAGE THEM (20 MIN)

One of the hardest parts of starting ART can be dealing with the side effects. A side effect is a reaction to the medicine in the body – it can be good or bad, expected or unexpected.

- Expert clients play an important role in helping patients to learn about, prepare for, and manage side effects.
- It's important for patients to know that starting ART is not an immediate cure for feeling bad. The ART will help them feel much better over time, but probably not right away.
- Most side effects will go away after a few weeks of starting ART. During this time of initial side effects, the patient needs to take their medicine correctly, every single day.
- There is a difference between minor or mild side effects that will go away (and patient

should keep taking the drugs) and more serious side effects that may mean the doctor or nurse will switch the drugs.

- **A patient should never make the decision alone to stop taking some or all of the medicines. This should only be done in consultation with health care workers at the ART clinic.**



Participant Activity

- In plenary, ask participants to mention some of the more common side effects and how they can be managed.
- Move through the rest of the section quickly, only highlighting those issues not already mentioned.

Some common side effects from ART and how to manage them

Nausea and vomiting: Usually goes away in 2-4 weeks. Expert clients should tell patients to:

- Take medicines with food.
- Eat small meals more often.
- Avoid fried, greasy and fatty foods.
- Avoid spicy foods.
- Drink a lot of clean, boiled water, weak tea, or lemon water.
- Don't drink much coffee or strong tea.
- **See clinician if there is fever, vomiting, inability to drink, or stomach pains**

Headaches: Usually goes away in 2-4 weeks. Expert clients should tell patients to:

- Rest in a quiet, dark room.
- Put a cold cloth over the face and eyes.
- Avoid strong tea or coffee.
- **See the doctor or nurse if it doesn't go away with paracetamol; or if there is fever, vomiting, blurry vision, or convulsions.**

Diarrhea: Usually will go away 2-4 weeks. Expert clients should tell patients to:

- Eat small meals during the day.
- Eat soft foods like rice and bananas.
- Avoid spicy, greasy, or fatty foods.
- Drink sips of clean, boiled water, weak tea, oral rehydration salts or lemon water.
- **See the doctor or nurse if there is blood or mucous in the diarrhea, if there is fever, if diarrhea occurs more than 4-5 times in a day or for 5 or more days in a row, or if the person loses weight.**

Rash and skin problems: Expert clients should tell patients to:

- Keep skin clean and dry.
- Only use mild soaps.
- Drink a lot of clean, boiled water to keep skin healthy.
- **See the doctor or nurse if the itching is severe, the skin is peeling, looks infected (for example has pus), is blistering, or has open sores; also if the patient has a fever or if the**

rash is in the eyes or mouth.

- **If taking the drug Nevirapine, come to see the doctor if there is any kind of rash.**

Can't sleep or has nightmares: Usually goes away 2-4 weeks (most common with patients taking Efavirenz). Expert clients should tell patients to:

- Take pills at bedtime.
- Avoid heavy meals before going to sleep.
- Avoid alcohol.
- Avoid foods or drinks with sugar or caffeine before going to sleep.
- Talk about feelings and worries with Expert Clients, friends, or family members.
- **See the doctor or nurse if the person feels depressed or suicidal.**

Tiredness: This can be caused by many things. Expert clients should tell patients to:

- Avoid alcohol and drugs.
- Do light physical activity, like taking a walk.
- Eat lots of fruits and vegetables and make sure to get enough iron.
- Take multivitamins.
- Try to get enough sleep at night and rest during the day if needed.
- **See the doctor or nurse if they have an alcohol abuse problem or feel depressed.**

Numbness or tingling feelings: Can be caused by taking D4T and DDI, but also other ARVs and TB medicines, or if there are other infections. Expert clients should tell patients to:

- Wear loose socks and shoes to protect the feet.
- Check the feet to make sure there are no infection or open sores.
- Keep feet uncovered when in bed.
- Soak feet in warm water and massage them if this feels good.
- Keep feet up.
- Don't walk too much at one time; take breaks.
- **See the doctor or nurse if the condition persists or they can't walk, are in pain, or weak.**
- **Also, if they are on d4T, they can visit the clinic as the doctor may want to decrease the dose.**

Yellowness of eyes and palms - See a doctor or nurse if a client presents this condition.

Remember, patients should not stop taking their ARVs if they have side effects! Some side effects are common and most will go away with time, but if the patient thinks that the side effects are serious, he/she should call or visit the clinic right away. **The decision to stop or change ARVs should be made by the patient and a health care worker together. Expert clients should refer all patients/clients to the hospital whenever there is a problem or side effects which cannot be managed at home.**

6.6: UNIT SUMMARY

The key points of this Unit include:

- There are many myths about ART in Malawi. Expert clients need to know the facts and share correct information about ART with others.
- ART is a lifelong commitment, meaning that people have to take the drugs every day for their whole lives, even when feeling well.
- ART is not a cure for AIDS but it helps prevent illness.
- HIV can still be spread when taking ART.
- Traditional medicines may be able to help with some symptoms, but they are NOT a replacement for ART. Sometimes these local medicines may interact with ARTs and make ART less effective.
- There are a number of criteria a person must meet to start ART. These include both medical criteria (stage of disease and CD4 count), and non-medical criteria (like the patient's ability to understand and adhere to treatment). Patients should be part of the decision to start ART with the health care team.
- Since HIV affects the body in different ways and the virus can learn to resist the medicine, different kinds of ARVs need to be taken to fight HIV.
- ART requires combining different medicines in one pill that act differently in order to avoid development of drug-resistant HIV.
- It's important to take ARVs every day, at the same time of day.
- Some people on ART have side effects that make them feel very bad. Most side effects go away within a few weeks of starting ART or a new drug. Expert clients can help patients understand, prevent and manage side effects.
- Patients should never stop taking their ART without consulting a nurse or doctor.

UNIT 7: PMTCT

Time	Specific Objective	Teaching Methods	Learning materials
20 Min	By the end of this Unit, participants will be able to: Explain the importance of PMTCT and name the key components of the Malawi National PMTCT Programme	Lecture Group Discussions	Trainer's manual Power point presentation LCD Projector Flip chart Markers PMTCT visual aids
30 Min	Describe the four components of a comprehensive approach to the Prevention of Mother- to- Child Transmission of HIV, including key messages	Lecture Group Discussions	
30 Min	Explain PMTCT strategies before pregnancy, during pregnancy and during labor and delivery	Lecture Group Discussions	
30 Min	Explain PMTCT strategies during infant feeding	Lecture Q&A	
30 Min	Describe PMTCT strategies during the post-natal period, including mother-infant-pair follow up	Lecture Group Discussions	
20 Min	Explain how to help link PMTCT and ART services	Discussion	

7.1: IMPORTANCE OF PMTCT AND KEY COMPONENTS OF MALAWI'S PROGRAM (20 MIN)

Maternal to Child Transmission (MTCT) is the transmission of HIV from a woman living with HIV to her baby during pregnancy, labor and delivery, or during breastfeeding. Here are some key facts about MTCT in Malawi:

- About 80,000 children below the age of 15 are infected with HIV.
- About 30,000 babies delivered each year from HIV positive mothers.
- Without comprehensive PMTCT services, about 30-45% of these babies will become HIV-infected.
- Without treatment, about half of HIV-infected babies will die before they reach age two.
- Mother-to-child transmission is the second most common route of HIV transmission (the first is transmission through unprotected sex).

Almost all HIV infections among young children are passed to babies from their mothers during pregnancy, labor and delivery, or breastfeeding. This means the best way to prevent babies being infected is to prevent their mothers from being infected with HIV (primary prevention). **If a woman becomes infected with HIV while she is pregnant or breastfeeding, she has a very high risk of passing the infection on to her baby soon after she is infected with HIV.**

Note that NOT all babies born to HIV-infected mothers are infected with HIV. In fact, even if nothing is done to prevent mother-to-child transmission of HIV, only about 1 in 3 babies will be infected (between 25-50%). The good news is that simple actions can further reduce this risk!

The National PMTCT Program in Malawi has several key elements:

1. Comprehensive maternal and child services, including:
 - a. Antenatal care
 - b. Labor and delivery care
 - c. Infant follow-up
 - d. Family planning
2. Routine counseling and HIV testing
3. Promotion of positive living with couple testing, safer sex, disclosure, etc.
4. Initiation of antiretroviral drugs
5. Nutritional education including infant feeding
6. Link to follow-up care for the HIV-infected mother and HIV-exposed child after delivery including infant HIV testing

The rest of this unit will explain how expert clients can be involved in supporting comprehensive PMTCT services.

7.2: COMPONENTS OF THE COMPREHENSIVE APPROACH TO PMTCT (30 MIN)

PMTCT stands for the Prevention of Mother-To-Child Transmission of HIV. PMTCT programs provide services to reduce the number of babies infected with HIV and to improve the health of women.

There are four parts to the comprehensive approach to PMTCT:

1. Prevention of HIV transmission to HIV negative women (primary prevention)
2. Prevention of unintended pregnancies among HIV-Positive women by using family planning.

3. Prevention of HIV transmission from HIV positive mothers to their babies during pregnancy, labor and delivery, and infant feeding
4. Provision of treatment, care and support to women infected with HIV, their children, and their families.

Malawi is following a new system to further improve PMTCT. If we work together to implement this, 95% of babies born to HIV infected mothers can be HIV-negative! Expert clients can play a key role in achieving this result. **Here are some key messages expert clients can help communicate:**

- ❖ All pregnant women with HIV will be started on antiretroviral drugs and continue treatment for life.
- ❖ Antiretroviral treatment is very important for the woman's health. It is also the best way to prevent HIV transmission to babies.
- ❖ Even pregnant women with relatively strong immune systems will start ART to help protect their babies from HIV transmission during pregnancy, delivery and breastfeeding.
- ❖ Women should continue their ARV treatment, even after their babies are born, for their own personal health

Benefits of PMTCT

Providing family-centered, comprehensive HIV care, treatment, and support for mothers, babies, and families has a lot of benefits:

- Fewer babies with HIV
- Healthier mothers, babies, and families
- Improved care, treatment, and support for all mothers and children
- Stronger families and communities
- Reduced number of orphans and vulnerable children

7.3: PMTCT STRATEGIES BEFORE AND DURING PREGNANCY AND DURING LABOR (30 MIN)

The first parts of the PMTCT strategy focus on preventing HIV transmission. Remember, we can help prevent HIV transmission by:

- Abstaining from sex
- Being faithful to one HIV negative partner
- Using condoms consistently and correctly²
- Making sure all people understand HIV prevention and have access to services, including condoms and HIV counseling and testing
- Going for HIV counseling and testing regularly, especially before marriage and pregnancy.

The second part of the PMTCT strategy is to prevent unintended pregnancies among HIV positive women through family planning and reproductive health programs:

- Promote risk reduction behaviors and safe pregnancies
- It's important to remember that all women have the right to have babies, including women with HIV.
- Also remember that women on ART should be provided with good family planning services as part of their care.

² It is important to note that condoms occasionally break and using condoms correctly and consistently upon every occasion of sexual intercourse can be hard to do. Abstaining from sex until marriage and being faithful to a single HIV negative partner are good risk reduction behaviors to practice.

- Make sure people know about sexually transmitted infections (STIs) and get treatment for themselves and their partner(s) right away. Being infected with an STI can increase a person's risk of getting HIV.

PMTCT strategies during pregnancy

For the work of expert clients, the core elements of routine counseling and HIV testing are especially important:

- All women coming for antenatal care are educated in a group about HIV and the importance of knowing their HIV status
- HIV pre-test counseling, HIV testing and post-test counseling is provided
- HIV counseling is a routine part of antenatal care
- HIV testing is voluntary and the results are confidential
- Partner/couple testing is strongly encouraged

If a woman tests HIV negative, the following key points should be mentioned:

- Stay negative – practice risk reduction behaviors all the time, including during pregnancy and breastfeeding
- If a woman gets HIV while she is pregnant or breastfeeding, the risk to the baby is high
- Be sure to deliver in a health facility
- Retest for HIV later in pregnancy

Here are some general health tips for all pregnant women:

- Follow the health worker's nutrition advice and supplements (iron folate, multi-vitamins)
- Sleep under an ITN every night to prevent malaria
- Help protect yourself and your baby from TB and tetanus by getting immunizations and keeping your home environment clean and well-ventilated
- Get immediate treatment for any sexually transmitted infections (STIs)

For women testing positive, several additional messages are very important:

- Be sure to attend all scheduled antenatal visits – at least 4 during pregnancy
- HIV-infected women, like all women, should deliver their babies in a health facility with trained midwives and health care workers. Trained midwives can monitor progress of labor and ensure any needed interventions or referrals are made for the health of the mother and/or baby as soon as possible. **Because most HIV infections are due to mother-to-child transmission during labor and delivery, it is especially important that women with HIV deliver in a health facility.**
- HIV-infected women, like all women, are also encouraged to attend the family planning service with their husbands (partners) as part of comprehensive health care.
- ARVs will be provided immediately for all pregnant women to help the baby stay HIV-free as well as to protect the woman's health
- Inform the woman of any mother's groups, support groups or other social support in the community.

Remember to promote the PMTCT motto of “saving 2 lives” – the mother's and the baby's - by enrolling in PMTCT services, taking ARVs, and coming back to the clinic often.

PMTCT during labor and delivery

Most MTCT of HIV happens around the time of labor and delivery. Expert clients need to work with the multidisciplinary team, and providers in the labor and delivery unit, to make sure women understand and access safe delivery care.

Expert clients should help women to understand and access these services:

- Plan to deliver the baby in a health facility with a trained provider. Talk to partners and other family members about how important it is for the mother and baby to have a safe delivery.
- Encourage mothers with unknown HIV-status to get tested right away.
- Encourage mothers who did not start taking ARVs during pregnancy to take them during labor and delivery, according to the health care worker's instructions.
- Promote good infection prevention practices for all births– keep the delivery area clean, washing hands, cleaning instruments, etc.

74: PMTCT STRATEGIES DURING INFANT FEEDING (30 MIN)

HIV is present in breast milk and can be transmitted to babies through breastfeeding. Most of the HIV transmission during breastfeeding happens when the mother or other caregivers practice mixed feeding for their babies. **Mixed feeding** means giving babies breast milk together with other liquids, like water, herbal mixtures, or juice or other foods like cow's milk, formula milk, or soft porridge. **Exclusive breastfeeding** means only giving the baby breast milk (Except for medicines prescribed by a doctor) up to 6 months.

Expert clients should emphasize that there is much lower transmission from HIV positive mothers to babies through breastfeeding where:

- The mother is on ART and adheres well to treatment
- The baby **ONLY** gets breast milk up to 6 months (exclusive breastfeeding)
- Breast infections are prevented and treated right away
- Thrush (white spots, yeast) in the baby's mouth is treated right away

Here are key messages about infant feeding for expert clients to explain to mothers:

- HIV positive mothers should take ART to reduce HIV transmission. Remember to take ARVs every day, at the same time to make them work best.
- Continue taking ART throughout pregnancy, breastfeeding and after to protect the baby from HIV and keep the mother healthy.
- Breastfeed exclusively for the first 6 months of the baby's life
- Introduce nutritious complementary foods once the baby reaches 6 months and continue breastfeeding until the baby reaches 2 years of life.
- Feeding recommendations are the same for all infants, regardless of HIV exposure or HIV infection status:
 - Give only breast milk up to age 6 months (no water, gripe water, dawale, bara, thobwa, mzuwa, etc.).
 - Give only medicines prescribed by a health professional
 - Gradually start complementing breast feeding with suitable hygienically prepared foods from age 6 months (such as Likuni Phala, fruits, vegetables, beans, ground nuts and soya)
 - Wean child around age 24 months
 - Wean gradually over a period of 1 month (no rapid cessation)

- Replacement feeding (formula) is NOT recommended unless women are unable to breast feed.
- If one breast has a problem, feed on the unaffected breast. Express breast milk of the affected breast and discard to prevent breast engorgement and maintain milk flow.
- Don't feed baby from infected breast. Go to health facility for treatment.
- Ask the health worker to ensure correct positioning and attachment to the breast to prevent breast problems
- Even if the baby is tested and found to be HIV-infected, the mother should keep breastfeeding for as long as possible
- Women should watch out for breast infections (cracking, sore nipples, strange discharge from nipples, pain, etc.) and come to the clinic right away if this happens.
- Attend monthly mother - infant pair follow-up for clinical and nutritional care



Participant Activity

- In pairs, ask participants to role play counseling a mother about feeding her newborn baby for 10 minutes
- Take turns so that each person plays the role of the EC and the patient
- In plenary, discuss the challenges you encountered and how you might manage them when counseling patients in the clinic for 5 minutes

7.5: PMTCT STRATEGIES DURING THE POSTNATAL PERIOD (30 MIN)

Care for HIV-exposed infants

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

Here is a summary of the key steps in caring for HIV-exposed infants:

- Health workers will actively screen all children under 24 months for HIV exposure by enrolling all children born to and/or breastfeeding from HIV infected mothers as soon as possible. Health workers will do one DNA-PCR test as soon as possible from age 6 weeks to detect perinatal HIV infection and to allow for early ART initiation. The visit schedule for HIV exposed babies should be as follows:
 - Monthly visits until age 6 months. Visits should follow the immunization schedule so that mothers and infants do not have to come to the clinic too often.
 - Monthly visits from age 6 to at least 24 months.
 - The health worker will schedule more frequent visits if the child is not doing well.
- Follow up for HIV exposed infants is provided for all infants with the 1st visit scheduled at 6 weeks. This 1st visit includes a check up, immunizations and start of cotrimoxazole (CPT) for

babies born to HIV infected mothers. If early infant diagnosis is available, blood will also be taken for an HIV test and sent to specialized laboratory.

- An HIV-exposed infant will continue CPT until the health worker is sure that the child is negative.
- At 12 and 24 months of age, provided the child has stopped breastfeeding, the child should have an HIV test.
- If the child continues to breastfeed after 24 months, CPT is continued for 3 months after breastfeeding has stopped, and the child is given an HIV test 6 weeks after cessation of breastfeeding.
- In both situations, if the HIV test result is positive, the child will continue life-long CPT. If ARV therapy is started, CPT will still continue.
- Babies born to HIV positive mothers will be discharged only after the baby tests negative for HIV.
- Babies confirmed to be infected with HIV are referred to HIV treatment services for further assessment and ongoing care.

HIV testing among infants is different than for adults

- For the first year or so of life a baby has the mother's antibodies in the baby's blood
- This is why all babies born to HIV-positive women will have a positive HIV test result if tested with an HIV antibody test (rapid test) until about 12 months of age
- A positive rapid HIV test result before 12 months of age could be due to the mother's antibodies and just means that the baby is "HIV exposed" or born to an HIV-infected mother, **but it cannot be used to diagnose a baby as infected with HIV.**
- A negative HIV test result means the baby is truly **NOT** HIV infected, as long as it has been done at least 6 weeks after complete weaning.
- By 24 months of age, the mother's antibodies are gone and positive HIV test (rapid test) results do mean that the baby is HIV-infected.
- There is a different test that is used that tests for the actual HIV virus, not the antibodies. This is called a PCR (polymerase chain reaction) test. This test is very important for HIV-exposed infants because it helps us determine if the baby has become infected with HIV.

PMTCT strategies during the postnatal period for the mother and family:

- If possible, link women with community health workers who can visit them regularly in their homes in the days/weeks after birth. **Women who have heavy bleeding or signs of infection should come back to the hospital or clinic right away. Babies who have a fever are crying or sleeping all the time, or are not eating well should also come back to the hospital/clinic right away.**
- Make sure that women are enrolled in the HIV Care Clinic and treatment programs, have adherence support, and are on/continue taking ART.
- Counsel the mother and family on follow-up of the baby, including Cotrimoxazole prophylaxis after the baby is 6 weeks old, importance of routine child care visits for immunizations, etc., and HIV testing options for the baby and the timing and meaning of these tests.
- Encouraging the mother to tell health care workers that she has HIV and that the baby has been exposed. This will help ensure that she and the baby get the right care at every visit.
- Provide emotional support.
- Discuss family planning options.
- Linkages to support groups, nutrition for the mother, and income generating activities.

For the baby:

- Make sure the baby goes for checkups and gets immunizations on schedule.

- Make sure the mother tells all health care workers that the baby has been exposed to HIV.
- Look for and treat oral thrush in the baby.
- Make sure the baby is getting good nutrition and growing well.
- NVP syrup is given to all babies born to HIV infected mothers:
 - NVP syrup shields the baby from HIV infection during the most risky time
 - Health workers give NVP syrup to the baby 24-hourly for the first 6 weeks of life
 - All babies should take NVP syrup for the same duration regardless of the mother's ARV regimen and regardless if the mother was taking ARVs at all
- Counsel the mother on early infant diagnosis and testing the baby. The baby may need 2 tests:

Once the baby is 6 weeks old, a test is conducted to see if the baby is HIV- infected. The test tries to find out which children are HIV-infected as early as possible so they can get the care and treatment they need. It is called DBS Dry spot /DNA PCR test. Remember, even if the baby is HIV-infected, the mother should continue breastfeeding. The test will have to be repeated later, about 6 weeks after the baby is weaned from breastfeeding.

76: LINKING PMTCT AND ART SERVICES (20 MIN)

We've talked about the need for pregnant women to enroll in PMTCT and be linked to care and treatment. Even though this is important to prevent MTCT and to take care of the mother and family over time, there are many challenges with these linkages at hospitals and clinics in Malawi.

Some of the challenges of linking PMTCT and ART services include:

- Services are located in different parts of the hospital and it's difficult for women to go to multiple service delivery points on different days.
- Services are given by different providers with no one person coordinating the mother or the baby's care.
- Records don't always give information on where else in the hospital a patient has been seen or the results of visits to other hospital services.
- There are no formal referral systems in place from one service to another in the hospital and even if a referral is made, there is no way to follow-up to see if the mother and baby went for other services to which they were referred.
- Mothers and families aren't always given the counseling they need to understand how important it is to enroll in and adhere to care and treatment.

Some possible solutions to link PMTCT and ART services and ways for expert clients to help:

- Facilities can strengthen the care portion of services so that women are still seen regularly for care and get medicines
- Facilities can use intra-facility referral forms and follow-up systems between PMTCT, ART, and other services (like TB, family planning, etc.).
- Expert clients can provide quality information and counseling to women on the benefits of PMTCT and ongoing care and treatment for herself and other family members.
- **Expert clients should literally walk with patients from one part of the hospital to another and help them understand why they are being referred and what to expect.**
- Expert clients can also work with other multidisciplinary team members to prioritize pregnant women for care and treatment, for example, ensuring that they are not made to wait long hours at the clinic or that there are family care and treatment days where the mother and baby can be seen at the same time by one doctor.

- Expert clients can keep their own records about which women they should follow-up with. For example, they can keep a list of all pregnant women to come for group counseling and make sure that each comes to scheduled appointments or that women who are especially sick are prioritized.
- The multidisciplinary team, including expert clients, can hold case discussions about pregnant women and how to get them enrolled in and adhering to care and treatment.

7.7: UNIT SUMMARY

The key points of this Unit include:

- The PMTCT motto is “SAVING 2 LIVES” – the mother’s and the baby’s.
- MTCT can happen during pregnancy, around/during labor and delivery, and during breastfeeding, especially with mixed feeding in the first 6 months.
- Most HIV transmission happens during labor and delivery.
- There are many things that can be done to prevent MTCT before pregnancy, during pregnancy, during the time of labor and delivery, and during the postpartum period and infant feeding.
- Pregnant and lactating women should be prioritized for HIV care and treatment with ART
- ARVs will not hurt the baby and this is one of the best ways to prevent MTCT.
- All pregnant and lactating women living with HIV in Malawi need ART for life.
- Women should exclusively breastfeed the baby for as long as possible, up to 6 months before they introduce other foodstuffs.
- At 6 months, the mother should add other foods and continue breastfeeding.
- Baby should be weaned at 24 months.
- All HIV-exposed babies should be followed-up and given Cotrimoxazole until we know their HIV status.
- Babies exposed to HIV may need two tests to tell if they are HIV-infected: one when they are 6 weeks or older and another once they are over a year old and have stopped breastfeeding.
- Expert clients should help women receiving PMTCT services enroll in the care and treatment program. Walking clients from one area of the health facility to another can help in this.
- Expert clients should make sure women receive follow-up services for themselves, their babies and other family members.
- Expert clients can help women join support groups and access other services in the community.

UNIT 8: PEDIATRIC CARE TREATMENT

Time	Specific Objective	Teaching Methods	Learning materials
20 Min	By the end of this Unit, participants shall be able to: Explain why it's important to give special attention to babies and children with HIV	Lecture QA	Trainer's manual Power point presentation LCD Projector Flip chart Markers WHO Clinical Staging Chart
30 Min	List different ways HIV-exposed and infected babies and children can be found and brought into care and treatment.	Lecture QA	
30 Min	Describe the basic points of caring for babies exposed to HIV	Brainstorming QA	
20 Min	Explain the key issues for pediatric ART	Lecture QA	
20 Min	Describe how to help families prepare for pediatric ART	Lecture QA	

8.1: THE IMPORTANCE OF CARING FOR BABIES AND CHILDREN WITH HIV (20 MIN)

As discussed in the last unit, there are about 30,000 HIV exposed babies delivered each year in Malawi. Children are different than adults, who sometimes live for years with HIV before getting sick. Without treatment, about half of HIV-infected babies will die before they reach age two. Also, caring for sick children and having a child die are very hard emotional experiences for families.

Children are the future of Malawi and we need to keep them healthy to build strong communities and a strong nation. Babies and children with HIV who are in care and take ARVs can live long, healthy lives and grow up to be healthy adults. Expert clients can play an important role in identifying and following children with HIV to help ensure their survival and good health.



Participant Activity

- In small groups for 10 minutes, have participants discuss some of the challenges in getting children into care and treatment and retaining them in care and treatment.
- Participants should be prepared to share main ideas with the rest of the group.
- Discuss observations in plenary for 5 minutes and move through the rest of the section quickly, only highlighting issues not already raised during the discussion.

Challenges to pediatric care and treatment

- Mothers in PMTCT programs don't always bring their babies back to the clinic. Sometimes even if they do, the health care workers don't know that the baby has been exposed to HIV.
- It can be hard to identify HIV-exposed babies in need of care and treatment. If we wait too long to provide treatment and care, the babies will probably die.
- Rapid HIV tests don't tell if a baby is infected (remember, they check for antibodies, which may be in the baby's body from the mother). These tests are only useful if the baby is one or more years old. Younger infants require a special test, DNA-PCR, often called "DBS" or "EID"
- Early infant diagnosis is now available in Malawi, but many mothers don't have the facts about early testing or know where to go for testing. Sometimes it can take time to get results back.
- Often children with HIV are orphaned and have several caregivers. This can be a challenge for coordinating who is bringing the child to the clinic and helping him/her with adherence. This makes the child's follow up difficult.
- Health care workers may not be used to working with children or know about pediatric care and treatment.
- The caregivers of children with HIV are often HIV-infected themselves. Children have to rely on adults to give their medicines and bring them to the clinic for appointments, which may be a challenge, especially if the caretaker is sick.
- It's hard to talk about HIV with children or tell them their status.
- Doses of ARVs change over time for children because they are based on the child's weight. Some caregivers have a hard time keeping track of this.
- Many caregivers don't want to tell their children, other family members, or people in the community that the child has HIV. Hiding an illness can make it more difficult to get care and support services.

8.2: HOW TO IDENTIFY HIV-INFECTED BABIES (30 MIN)

Remember that all babies born to women with HIV are exposed to HIV and therefore at risk of being HIV infected. However, if the mother and baby receive ARVs, care and treatment, many babies will escape HIV infection. **It's extremely important to explain follow-up care to mothers and families very well and make sure that they are not lost after the baby is delivered.** There is a lot that can be done to keep the baby healthy when he/she has been exposed to HIV. There are tests that can be done to tell if the baby itself is HIV-infected and needs ART.

Finding babies and children and bringing them into care and treatment

PMTCT programs are one of the best ways to find babies exposed to HIV who should be tested and enrolled in care and treatment. But, there are other places where Expert Clients should help the multidisciplinary team and community workers find sick babies since not all will get PMTCT services or come back for follow-up, including in:

- Under 5 clinics and mobile clinics
- Pediatric in-patient wards
- Adult ART clinics (by asking patients about their children)
- Nutrition Rehabilitation Unit, Community Therapeutic Care (CTC), as children with HIV are often malnourished
- Outpatients Clinic (OTP)
- Health centers where babies and children are taken when they're sick
- Community health volunteers and community-based organizations for example support groups, especially those working with orphans
- Traditional healers who may be a first point of contact for sick children
- TB /DOTs clinics
- Post-natal wards

In each of these places, health workers should be trained to recognize symptoms of HIV in babies and children and refer them to the ART clinic. Health workers, including expert clients, should check the HIV status of the mother in the health profile or encourage them to go for an HIV test. Since expert clients will work mainly at the hospitals and health centers, they play a key role in following up with health care teams and families with sick children and getting them in care and treatment. It's important to remember that while most babies and children living with HIV were infected through MTCT, others may have been victims of sexual abuse. Expert clients should always turn to a professional counselor or other member of the multidisciplinary care team in these situations.

HIV testing in babies and children

Because most babies born to women with HIV will test positive for HIV in the first 12 months of life, it's best to test babies less than 12 months using **early infant diagnosis**, also called **DNA PCR tests with Dried Blood Spots, or DBS**. This service is available in Malawi, so expert clients play a key role in helping mothers and caretakers understand the test and the results. This is the only way to know if a baby under 12 months is actually HIV-infected.

For babies under 12 months of age:

Counsel the mother on early infant diagnosis (DNA PCR Testing) and testing the baby. The baby may need 2 tests:

- Once the baby is 6 weeks old, a small amount of blood can be taken from the baby's heel and a test conducted to see if the baby is HIV-infected. **The test tries to find out which children are HIV-infected as early as possible so they can get the care and treatment they need to keep them**

healthy.

- Once the mother is counseled by the nurse and the baby's blood is taken, the sample will be sent out to be tested. It can take up to one month to get the results back. Sometimes it takes longer and mothers should be encouraged to follow up all test results. **Expert clients can help keep track of any mothers who have not come to get the baby's test results. Such cases must be followed up.**
- Physicians, clinical officers, medical assistants, nurses, HSAs and Expert Clients should make sure mothers understand that the results will take time and schedule an appointment for the mother and baby to return to the clinic to pick up results.
- If the result of the test is positive, the baby is HIV-infected and all HIV positive infants under 24 months should start ARVs right away regardless of the stage of HIV and their CD4%. If the result of the test is negative and the mother is still breastfeeding, she should keep breastfeeding and then retest (DNA PCR Test) the baby 6 weeks after she's stopped breastfeeding completely.
- Some mothers are scared to have their babies tested because of lack of information about what services will be available to the baby if the test is positive. **Expert Clients need to explain to mothers (and other caretakers) that all babies under 24 months are immediately eligible for ART. The sooner they know the baby's HIV status, the more quickly the baby can take medicines to avoid being sick.**
- During counseling, expert clients should help the mother think about her support system - who will help her look after the baby if the baby is HIV-infected? Who will help come to clinic appointments? These people can be their treatment supporter when the baby starts taking medicines.
- Expert clients should follow-up to see if the mother or caretaker has picked up the results. If not, they should encourage her to know her to get her results.

For children between 12 and 24 months of age:

- Once children are over 12 months old, they can be tested for HIV with the standard rapid test used on adults.
- If the child is still breastfeeding, they should be retested six weeks after the mother has completely stopped breastfeeding using rapid test.
- There are special consent issues for HIV testing in children and caregivers need to be given special pre- and post-test counseling focusing on pediatric issues. After counseling, the caregiver can give consent to have the child tested. Both parents do not need to give consent to have the baby tested. Any main caretaker of the child (mother, dad, and auntie, others...) can give consent, even if it is not the mother or father. Children testing positive with rapid test should be referred to ART clinic to start treatment immediately if they are less than 24 months old.



Participant Activity

- In pairs, ask participants to practice explaining the main points of HIV testing for infants for 10 minutes.
- Ask them to cover the following:
 - When the test is conducted
 - Why it is important
 - What happens for children < 24 months who test positive for HIV
- They should be prepared to report back any challenges to the rest of the group
- In plenary for 5 minutes, share any challenges or areas for clarification from your practice session
- Provide guidance/clarification on any misconceptions or difficulties

8.3: CARING FOR BABIES EXPOSED TO HIV (30 MIN)

The most important thing for babies exposed to HIV and babies and children with HIV is that they **come back to the clinic very often**. Babies with HIV will get sick often and they need to be seen at the clinic more often than adults with HIV. Expert clients should counsel mothers and other caretakers about bringing the baby back to the clinic every month for a check-up and whenever they are sick.

Under 12 months

- **Universal ART:** Confirmed HIV infection (DNA-PCR needed), regardless of WHO stage and CD4 count or CD4 %
- **Presumed severe HIV disease (PSHD):** HIV antibodies (HIV rapid antibody test) and PSHD-defining clinical conditions (see WHO Clinical Staging Chart)

12 to under 24 months

- **Universal ART:** Confirmed HIV infection (HIV rapid antibody test or DNA-PCR), regardless of WHO stage and CD4 count

24 months to under 5 years

- Confirmed HIV infection (HIV rapid antibody test) **and**
 - WHO stage 1 or 2 and CD4 ≤ 750 cells/mm³ or $\leq 25\%$**OR**
 - WHO clinical stage 3 or 4 regardless of CD4 count

5 years and over

- Confirmed HIV infection (HIV rapid antibody test) **and**
 - Pregnant or breastfeeding women (regardless of the age of the child) regardless of WHO stage and CD4 count**OR**
 - WHO stage 1 or 2 and CD4 ≤ 350 cells/mm³**OR**
 - WHO clinical stage 3 or 4 regardless of CD4 count

Caring for babies exposed to HIV

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

- Health workers give NVP syrup to the baby 24-hourly for the first 6 weeks of life
- Mothers who delivered at home should be encouraged to come to the hospital immediately.

At 6 weeks of age:

- Start all HIV exposed and infected children from age 6 weeks regardless of clinical stage or CD4 count on CPT.
- CPT is one of the best ways to keep babies healthy and prevent illness. **Babies exposed to HIV or with confirmed HIV infection should take Cotrimoxazole EVERY DAY.**
- The dose of Cotrimoxazole will depend on the baby's weight. This is one reason why it's important for the mother or caretaker to bring the baby to the clinic every month – so the baby can be weighed and the dose changed to have the best impact on the baby's health.
- Where available, babies should get early infant diagnosis with DBS as soon as possible after 6 weeks of age as explained.
- All exposed infants should be enrolled in HIV Care Clinic (Special register).
- CPT for HIV exposed children is only stopped when a child who has been weaned from breastfeeding is confirmed negative. At this point the child is discharged from exposed infant follow-up.

Ongoing:

- If the baby has been tested using DNA PCR and is HIV-infected, the child should start ART immediately.
- Children with Rapid Test positive result and are between 12 and 24 months should be referred to ART Clinic to start ART immediately.
- For children who are above 24 months and have tested positive, CD4 test needs to be done.
 - It's important for expert clients to understand the difference between adult and pediatric CD4 test results and help explain to parents and caretakers. CD% will be interpreted by the health care workers.
- Make sure the baby goes for checkups and gets immunizations on schedule.
- Health care providers should look for and treat HIV related conditions.
- Make sure the baby is getting good nutrition and growing well. The doctors or nurses will **weigh, measure, and examine the baby at every visit** to see if it is growing and developing normally. The baby's height and weight measurement should be recorded on a growth chart at each visit. This is one of the best ways to see if a baby is healthy. Expert clients may be asked to help weigh and measure babies and will have a chance to do so in the practicum.

Eligibility and when to start CPT

- All infants born to HIV infected mothers (without confirmed HIV infection) from age 6 weeks
 - Aim to start CPT straight after finishing NVP syrup. Even if the infant never took NVP prophylaxis, he/she should still start CPT.
 - Continue on CPT until confirmed HIV-negative diagnosis and discharged from HCC follow-up (around age 24 months).
- Confirmed HIV infected children from age 6 weeks and adults take CPT for life, unless otherwise indicated by the health worker.

Family-focused care

Having a sick baby and/or knowing that the baby may have HIV can be a very hard thing for parents and caretakers. It's important for expert clients to spend time talking with the family about how they are feeling and making sure they understand what is happening with the baby (tests, medicines, side effects, etc.) in easy to understand terms. Remember, HIV is a family disease and parents of sick babies will often themselves be sick and in need of care and treatment and support to adhere, disclose to others, or seek community support services. Parents and caretakers should be active in the baby's care and monitoring as they often know best when "something isn't right" with the baby (the baby is crying all the time, the baby isn't eating, the baby isn't sitting up or playing, etc.). **Whenever**

the baby isn't doing well, parents and caretakers should be encouraged to trust their instinct and bring the baby to the clinic right away.

Expert clients should also ask about all caretakers of the baby, as they often change. All caretakers should know what's going on with the child's health and care and treatment plan.

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

- Come back to the clinic often
- Early HIV testing from six weeks
- Cotrimoxazole every day
- Weigh and measure at every clinic visit
- Focus on the whole family

8.4: KEY ISSUES IN PEDIATRIC ART (20 MIN)

As with adults, the use of ART in babies and children with HIV is essential to keep them healthy and strong. But, the use of ART in babies and children is not always easy and is more complicated than ART in adults. Pediatric ART regimens are not always available and can be more difficult than for adults. Also, children depend on caregivers to give their ART and take them to the clinic, and doses and regimens change often with children depending on their age and weight. Expert Clients need to be advocates for access to pediatric ART in Malawi and help babies, children, families, and other caregivers get the services they need.

Key issues to remember:

- Success depends on teamwork and the relationship between a child and the caregiver(s). There are often many caregivers in a child's life – like the “committee of aunts” involved with the child on a daily basis. All members of the family and all caretakers must be prepared to give the child ART at the same time every day. The child must cooperate and take an active role in his/her own treatment as well.
- There are many barriers to adherence with pediatric ART. Children may not want to take the medicines, they may be away at school for many hours of the day, or caretakers may be at work or not always be with the child when the medicines need to be given.
- Caregivers may also be living with HIV themselves. If the parent or caregiver has not disclosed his/her HIV status, it makes it hard to tell people about the child's HIV status. The family or other caregivers will not know what kinds of care and treatment the child needs if they do not know the child's status.
- ART preparation and support is very important for pediatric ART before the child starts the ART and ongoing care.
- Pediatric ARVs are available in syrup and pill form.
- The dose of different ARVs will change often in children because it depends on their weight. It can be hard for caretakers to remember the right dose to give since it changes as the child grows.
- Older children may not know or understand their HIV status and caregivers may have difficulty disclosing it due to fear of upsetting the child.

When to start ART

Only a nurse or clinician can decide if a pediatric patient is eligible for ART through exams and tests, like

the CD4%. Babies and children with HIV will start ART since they get sick quickly and are at great risk of illness and death. Once the doctor decides the patient is eligible, the caretakers need to be well-prepared for the challenges ahead. Expert Clients can help caretakers understand pediatric HIV and make an ART adherence plan with the multidisciplinary care team. Success with pediatric ART depends on a partnership among the caregiver(s), the child, and the multidisciplinary care team.

Common pediatric ART regimens in Malawi

There are special types of ARVs for babies and children in Malawi – some are in the form of syrups and some are pills. Many are in the form of fixed dosed combination that combines three different medicines into one pill. Remember, all babies and children with HIV should also take Cotrimoxazole. The dose of each ARV depends on the child’s weight, so there is no “standard” dose like in adults. The only way to know the right dose is to visit the clinic often so the child can be examined and weighed to decide on the right dose.

Just like with babies and children in care, the most important thing for pediatric ART is that people come back to the clinic often to see the doctor. Like with adults, it’s very important that ARVs are taken the right time, the right way, at the same time every day!

8.5: PREPARING FAMILIES FOR PEDIATRIC ART (20 MIN)

Adherence can be difficult for children and their caretakers. Pediatric ARVs may be hard to give as the doses change over time, based on the child’s weight and development. Telling a child that s/he is living with HIV can also be hard for a parent or caretaker. There is more about pediatric disclosure in Unit 11. Even though there are many challenges, Malawi’s pediatric HIV treatment program is growing every day with more and more babies and children getting access to the HIV care and treatment they need to live longer and be healthy.

Expert clients can help caregivers and children on ART in many ways:

- Help counsel and educate families on HIV, adherence, why it’s important, and how to follow treatment plans.
- Remind families how important it is to ask the doctor, nurse, expert client or other member of the team if they don’t completely understand something. No one should feel embarrassed to ask questions.
- Help prepare the child and caretakers for ART and give peer support. Work with the multidisciplinary care team to help the family find answers to questions such as:
 - **Who will give the child the medicines?**
 - Ideally, many people should be trained to give the child medicine, not just the mother for example. But, this might be hard if the mother has not disclosed her own or the child’s HIV-status.
 - **Which medicines will be given?**
 - Help the family with medicine identification, storage, measuring, and giving it to the child.
- Expert client should provide answers to the following questions:
 - When will the medicines be given?
 - How will the medicines be given?
 - How are syrup measured?
 - Do pills need to be broken or crushed?
 - Does one of the medicines taste really bad?
 - Should they be taken at the same time?
 - What if the child spits out the medicine?

- **Ask about adherence at every visit and work as part of the multidisciplinary care team to support adherence.** Children may have different issues with adherence over time, as they grow. For example, an infant may easily swallow syrup, but then when they get older refuse to swallow a pill because it tastes bad. Remember to always treat patients and their families with respect and never to judge.
- **Offer counseling, psychosocial support, and linkages** to community resources (like nutrition support and educational support for children) at each visit.



Participant Activity

- Ask 4 participants to do a role play for 10 minutes of a counseling session with a family with a six year old child about to start ART
- Remind them to cover the following counseling tips and content they've just learned
- In plenary for 5 minutes, ask observers to provide feedback on key issues missed or areas for improvement
- Provide guidance/clarification on any misconceptions or difficulties

8.6: UNIT SUMMARY

The key points of this Unit include:

- Children with HIV have different medical, social, and psychological needs from adults.
- Without treatment, most children with HIV will die before their 2nd birthday.
- With care and treatment, children with HIV can become healthy, productive adults.
- Early infant diagnosis and treatment should be accessible to all babies born from HIV positive women.
- The only way to tell if a baby under 12 months (1 year) of age is HIV-infected is through DNA PCR testing, which can be done when the baby is 6 weeks old.
- All children testing positive with DNA PCR should be referred to ART to start ART treatment immediately.
- Rapid HIV tests in children under 12 months if positive can only indicate that the child is HIV exposed. The test should be repeated when the child is over 12 months and 24 months and the mother has stopped breast feeding for over six weeks.
- All children between 12 and 24 months testing positive with rapid test should be referred to ART clinic for ART treatment.
- HIV makes babies and children sick quickly, so we need to identify them early and get them enrolled in care and treatment as soon as possible.
- PMTCT programs are a good place to find exposed and infected babies. We also need to look for sick children in under 5 clinics, adult ART clinics, inpatient wards, outpatient departments, TB clinics and by reaching out in the community.
- HIV exposed babies and children with HIV need to come back to the clinic regularly (once a month or more often if child is sick).
- HIV exposed babies and children with HIV should take Cotrimoxazole every day (to prevent infections)
- HIV exposed babies and children with HIV should be weighed and measured at each visit
- Only an ART provider can decide that a child is eligible for ART – this is done by examining the child and doing a test to see the CD4% for children above 24 months.
- Focus on the whole family - Pediatric ART depends on a partnership among the caretaker(s), the child, and the multidisciplinary care team.
- There are special ARVs for babies and children. They should not be given adult ARVs unless prescribed by the doctor.
- The type and dose of ARVs for children depends on age and weight. This will change often over time so patients need to come back to the clinic regularly.
- Expert clients play a key role in helping caretakers prepare to give ART to babies and children and adhere to the care and treatment plan in the long term. Adherence will be discussed more in the next Unit.
- Expert clients can also provide emotional support to caretakers, as caring for sick children and/or giving children medicine every day is not easy.

UNIT 9: ADHERENCE TO HIV CARE AND TREATMENT

Time	Specific Objective	Teaching Methods	Learning materials
10 Min	By the end of this Unit, participants shall be able to: Define adherence and non adherence to care and treatment.	QA Discussions	Trainer's manual Power point presentation LCD Projector
20 Min	Identify common barriers to adherence and work with patients to come up with practical strategies to overcome barriers.	QA Discussions	Flip chart Markers
10 Min	Facilitate follow up with patients who do not come to the clinic for appointments	Discussion	
10 Min	Explore the special challenges adolescents may present	Discussion	
20 Min	Prepare people to start taking ART through group education and one-on-one counseling sessions.	Role play Discussion	
30 Min	Provide ongoing adherence support to all patients enrolled in care and treatment.	Discussion	

9.1: ADHERENCE BASICS (10 MIN)

Adherence is the word used to describe how faithfully a person sticks to their care and treatment plan. Every patient (including expert clients!) needs to be an active participant in his/her care plan. Adherence relates to care and to treatment (medicines) and depends on a shared decision-making process between the patient and health care providers.



Participant Activity

- For 5 minutes, ask participants to discuss the difference between “adherence” and “compliance” and decide which each prefers.

Some people use the word “compliance,” but we prefer to use the word “adherence” as it indicates more than just following orders from the doctor. Adherence means that the patient is an active participant in developing and sticking with his/her own care plan.

Adherence to care means:

- Entering into and continuing on a care and treatment plan.
- Taking medicines to prevent and treat opportunistic infections.
- Participating in ongoing education and counseling.
- Attending appointments and tests (like regular CD4 tests) as scheduled.
- Picking up medications when scheduled and before running out.
- Modifying lifestyle and avoiding risk behaviors.
- Making a commitment to preventing new HIV infections.

Adherence to treatment means:

- Taking ART medications correctly, as prescribed, for the person’s whole life, even if the person feels healthy.
- Missing any dose is risky – patients should aim for 95-100% adherence to their ART and not take “treatment holidays” (stop taking the drugs for short or long periods of time).

Why is adherence important?

- To lower the amount of HIV in a person’s body.
- To avoid the body becoming resistant to certain medicines (meaning the medicines don’t work in the body the way they are supposed to).
- To increase the CD4 soldier cells and decrease the amount of HIV in the body.
- To make sure the person gets all the benefits that OI medicines and ARVs have to offer (feeling better, not getting OIs, etc.).
- To prevent mother-to-child transmission of HIV.
- To monitor the person’s health and also help find community support resources for individuals and families.
- To keep the person looking and feeling good so they can get back to normal life.

Remember, a person should not take ARVs without adherence assessment and support at every visit! Expert clients have a key role to play in helping people, especially pregnant women and children to adhere to their care and treatment plans.

Non-adherence means:

- Missing one or many appointments at the hospital or health center, lab, or pharmacy.
- Not following the care plan and making poor lifestyle choices.
- Missing a dose or doses of medicine.
- Stopping medicine for a day or many days (a “break”).
- Taking medicines at the wrong times.
- Taking medicines without following instructions about food or diet.
- Sharing the medication with other members of the family

It’s important not to judge patients if they are non-adherent. Instead, expert clients should try to uncover the root causes of non-adherence and help find ways to resume good adherence as soon as possible.

What happens when a person doesn’t adhere?

- The levels of drugs in the body drop and HIV keeps multiplying and spreading.
- The person can develop “resistance” to one or all of the drugs, meaning that the drugs won’t work anymore, even if they are taken correctly again. We can say that HIV is a very “smart” virus – it only takes a couple of missed doses for it to take over the body again, multiply, and learn how to be stronger than the ARVs.
- The CD4 count will drop and the person will start getting more opportunistic infections.
- The person may have to start taking a different kind of ARVs, but it’s best to avoid any resistance through perfect adherence.

Remember: Development of drug resistance must be avoided at all costs. There are not many other drug options in Malawi if a person develops resistance to the drugs they are started on!

9.2: BARRIERS TO ADHERENCE AND HOW TO OVERCOME THEM (20 MIN)



Participant Activity

- In small groups for 10 minutes, ask participants to discuss some of the barriers to practicing perfect adherence and brainstorm solutions.
- Tell them to be prepared to share their main ideas in plenary.
- In plenary for 5 minutes, ask participants to report back. Each group can contribute new ideas.
- Move through the rest of the section quickly, only highlighting areas not yet already mentioned.

There may be many possible barriers to adherence. Some are listed below to help expert clients think about challenges which patients may face and how to work around them.

Barriers related to access

- Transportation problems
- Can't get out of work to go to the clinic
- Lack of partner/family support to go to the clinic
- Haven't disclosed and partner/family doesn't understand/support many trips to the clinic
- Stigma – don't want to be seen at the ART clinic
- Not enough money to get to the clinic or pay for services at certain health facilities
- No food to take medicines with
- No one to watch children or take care of daily activities while at the clinic

Barriers related to the patient's life

- Patient or caregiver doesn't understand HIV or adherence and has doubts about ART
- Patient or caregiver is in denial
- Patient or caregiver doesn't think they can do anything to help themselves (low self-esteem) or children they care for
- Patient or caregiver doesn't feel well enough to get to the clinic
- Bad adherence counseling given because of lack of time
- Patient or caregiver does not know how to take or give medicines to a child the right way
- No social support from friends or family
- Pressure from family to share medications with sick partner or other children
- Pressure from partner not to take ART or not to give ARVs to a child (because partner doesn't believe in ART or thinks it's dangerous)
- Keeping HIV a secret/stigma
- Other things to do – work, kids, cooking
- Forgetfulness
- Travel or being away from home, especially for adolescents
- Changing schedules or routines

Barriers related to the medicine

- Side effects
- Too many pills/doses to take
- Hard to swallow pills
- Patient believes new symptoms are caused by the ART

Barriers related to health service provision

- Have to wait a long time at the clinic
- Pregnant women don't want to go to the ART clinic and find it hard to get services in multiple places
- Bad attitudes and stigma among providers at the clinic
- Perceived low quality of services
- Lack of confidentiality and fear of disclosure to others
- No place for children at the clinic
- Shortage of supplies at the health clinic (like not enough lab supplies or medicines)

To help address some of the challenges highlighted above, there are many things that can be done to support people to adhere to care:

Create a good care setting

- Welcoming and comfortable environment (waiting time isn't too long, there is a place to wait in the shade, expert clients and staff are welcoming).
- Pregnant women are given priority treatment when they come for care where they are allowed to go before other patients.
- Easy to access and services are "One-Stop-Care ," meaning that a patient can get many health needs taken care of in one visit, or that his/her child can also be seen during the visit.
- Childcare facilities at clinic.

Good communication

- Follow good communication and active listening skills.
- Ask open-ended questions about adherence to help patient sharing, for example, "Some people find it hard to come to the hospital every month because they have so much to do at home. How has this been for you?"
- Restate answers to ensure understanding (reflective listening).
- Show concern and respect.
- Never judge someone during counseling.

Shared confidentiality

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

Patient education and peer support

- The Expert Client program can help patients understand their illness and help them adhere to care and treatment.
- Support groups and one-on-one counseling sessions are good for adherence support.

Strong outreach and follow up

- Develop tracing systems when patients miss appointments – plan ahead with the team.
- Keep contact information updated and organized.
- Respect patients' wishes about how they prefer to be contacted.

Remember, it is NOT ethical to disclose a person's HIV status without his/her consent!

9.3: FOLLOWING UP WHEN PATIENTS DON'T RETURN TO THE CLINIC (10 MIN)

An important role of Expert Clients is to help clinical staff follow up on patients who miss appointments for consultation, lab tests, or to pick up medicines.

At a patient's first visit at the clinic, the nurse, clerk or another team member should take down the

following information and make sure it's updated and kept in a safe place:

- Full name and address, including the physical address, for example, area, river, mountain, shop, church, etc.
- If available, phone number for patient and/or friends or neighbors
- Name, address, and phone for close family and friends
- Name, address, and phone of person's workplace or other place where they spend time
- Contact information of patient's community health worker and treatment buddy if there is one
- How the patient or caregiver wants to be contacted. Is it by phone? Is it ok to be visited at home? Can the care providers contact a friend or family member if needed? Remember, it's important to keep things confidential.

If a patient misses an appointment:

- If a patient hasn't contacted the clinic to reschedule or come to the clinic within one week of the appointment, the patient should be called if they have a phone or contacted as otherwise arranged (see above).
- The expert client should help compile the names of patients that have missed their appointments for follow up.
- Discuss patients who miss appointments often at the multidisciplinary team meetings. How can the team work together to help the patient come to his/her appointments?
- Discuss missed appointments and adherence with patients and caregivers when they do return to the clinic for care.

9.4: SPECIAL CHALLENGES IN WORKING WITH ADOLESCENTS (10 MIN)

Adolescents can be challenging to work with. Not kids and not yet adults, adolescents very much need of medical care for their chronic illness. The teen years can be an especially high risk time of life as they may experiment with alcohol, drugs, sexual relationships, and much more.



Participant Activity

- In pairs, ask participants to discuss the best practices/tips for working with adolescents for 5 minutes.
- In plenary for 5 minutes, ask each pair to share one tip. Remember, groups should not repeat points previously made.
- Move through the rest of this section quickly, only highlighting issues not already mentioned.

Expert clients, like all members of the multidisciplinary care team, can establish a valuable relationship with teens in the clinic. Expert clients may be more approachable than other members of the care team, and they have personal insight and perspective to share. Here are some tips in working with adolescents:

- Trust is everything! NEVER lie to a teenager
- Build the therapeutic relationship with the TEEN (not necessarily with their guardians)
- If you tell them that information they share is confidential, then it must be kept confidential!
- Be NON-JUDGEMENTAL
- They already likely have a "mother" so you can be their clinician/nurse/counselor...

- You do not need to agree with what they are saying or their decisions. Your role is to listen and help patients, including adolescents, make good decisions

Disclosure

Disclosure is a PROCESS, not an EVENT! Older children and adolescents may be asking questions about the hospital, asking why they need to take medications, refusing to come to clinic, refusing to take medications. These could be signs that probably we waited too long and should have disclosed sooner.

Adherence strategies for fully disclosed teens

- Acknowledge that they have a very hard job to take the medicines and tell them you want to help them with ideas of how to remember to take the medicines.
- First make SURE they know why they take the medicines, i.e., review disclosure and basic HIV info.
- Most teens KNOW they NEED to take their medicine, but it can be hard nonetheless.

Adherence challenges for teens

- Pill fatigue: it's just not fair, and they're tired of taking the pills
- Routine changes: new guardians, new homes, boarding schools
- Unexpected changes and little planning: before guardians planned ahead and brought medication, now teens are responsible and can find this transition tough
- Once they trust you, ask them when they are most likely to forget and then develop ways to remember, for example: Calendars for marking; cell phone alarms, radio announcements; drawings on the wall; treatment partners.

Positive prevention for teens:

- Encourage abstinence until marriage for all adolescents.
- Help HIV positive teens avoid teenage pregnancy through practicing abstinence outside marriage, faithfulness to one partner and promote planned pregnancies within marriage with access to health care. Remember, having a baby during adolescence is very challenging. Having an HIV-exposed infant can be even more difficult.
- Provide HIV positive teens with information about safe pregnancies to reduce HIV transmission to the child.
- Some adolescents, especially girls, may trade sex for materials goods (cell phones, clothes), school fees, or even food. We call this **transactional sex**, and it often involves a much older partner providing things to younger partner. Such relationships can carry high risk as the older person may have had many sexual partners and has a higher risk for STIs, including HIV. Help adolescents avoid the dangers of such relationships by encouraging abstinence, faithful relationships with peers and safer sex.
- Remember to counsel young people on abstinence outside marriage, faithfulness within marriage (or relationship) and information about how to prevent re-infection and infecting others with HIV.

9.5: PREPARING PEOPLE TO TAKE ART (20 MIN)

Once the health worker decides a person needs to start ART and the person agrees that he/she wants to start ART, the expert client can help the patient prepare for treatment and make an adherence plan with the multidisciplinary team and the patient. Patients planning to start ART should participate in at least one group education session and one individual counseling session at the clinic. Counselors or

clinicians are responsible for doing both group and one-on-one sessions. An expert client can help if a counselor or clinician agrees.

Topics covered in pre-ART session counseling session

- Understanding HIV and the patient's own health status
- Developing a trusting relationship between patients and the multidisciplinary care team.
- The process of care and treatment, or the "patient pathway to care and treatment" (includes what happens during care, when is blood drawn and why, when people should come back to the clinic, etc.)
- The importance of attending one health care facility until the person is stable and has established a good adherence pattern
- Disclosure status and support
- Identifying sources of social support, including a treatment buddy and support groups
- Beliefs and attitudes about treatment and ART
- Understanding the treatment plan (what medicines need to be taken, how many times per day/week, at what time, with food or without, etc.)
- Possible side effects from different ARVs and what to do if the person has side effects or problems taking ART
- Possible barriers to adherence and problem solving
- How will the person remember to take pills (alarm, buddy, pillbox, diary, and etc?)
- Finding ways to make the care and treatment plan a part of everyday life
- What to do if the person misses pills and how late is too late to take a missed dose
- Access to support services, such as support groups, income generation, etc., if needed

These sessions should be adapted for the special needs of pregnant women and children living with HIV. See the previous units for more information on the special needs of these groups.

Also, remember that adherence planning is not something that happens only once. Expert Clients and other members of the multidisciplinary care team should always be asking patients about adherence, changing the plan as needed, and helping patients to overcome old and new challenges.

Remember to council clients on the six basic rules for ART success:

1. ARVs need to be taken every day.
2. ARVs should be taken at the same time.
3. HIV is a chronic disease and ARVs need to be taken for life.
4. See the doctor or nurse if you have ongoing side effects.
5. Never share ARVs with other people.
6. You can still pass HIV to others even when on ART and if you feel well, so remember to use a condom every time you have sex.³

³ It is important to note that condoms occasionally break and using condoms correctly and consistently upon every occasion of sexual intercourse can be hard to do. Abstaining from sex until marriage and being faithful to a single partner are good risk reduction behaviors to practice.

9.6: PROVIDING ONGOING ADHERENCE SUPPORT FOR PATIENTS (30 MIN)

The goal of ART is >95% adherence: even a few missed doses each month can make ART less effective or can increase the chances of drug resistance and getting very sick.

The adherence motto is “EVERY DOSE, EVERY DAY, FOR LIFE!”

Expert clients should talk with patients about adherence at every visit. ECs play an important role by helping patients plan for adherence, stick to their treatment plan, stay positive and focused, and by answering any questions they or their caretakers and families have. ECs can also help patients avoid side effects or know how to manage them if they happen, as discussed in the last unit.

How should Expert Clients ask patients about adherence?

- Make adherence a normal part of every session.
- Don't judge a person; make him/her feel comfortable.
- Share that everyone has problems taking medicines the right way all the time.
- Build a trusting relationship and ask people to be completely honest with you about adherence.



Participant Activity

- Ask 2 participants to do a 10 minute role play of an Expert Client and a patient. Start off with the following questions from the EC:
 - “Many patients taking these medications, including me, find it difficult from time to time. What has your experience been?”
 - “How many doses have you missed in the past day? Week? Month?”
 - “On an average a week, how often do you miss your medications? How often are you late?”
 - “Do you ever share your medicines with sick family members, like your husband/wife or kids?”
- In plenary for 5 minutes, ask observers to share any comments about the EC's performance. Did the EC use open-ended questions, non-judgmental responses and body language? Can participants discuss ways to improve the discussion?

What to do when a dose is missed:

- “Take the missed dose if your next dose is scheduled for more than 6 hours away. For example, if you normally take your medicine at 7am, and you remember at 1pm you should still take the dose when you remember.”
- “Don't take the missed dose if your next dose is scheduled for less than 6 hours away for twice a day medicines. For example, if you normally take your medicine at 7am and you only remember at 2pm, you should just wait until the next dose at 7pm.”
- “Never take a double dose (2 doses at a time).”

Examples of question an Expert Client can ask about challenges to adherence:

- “When/why is it most difficult to remember your medications?” (e.g. side effects, fears, hard to

pick them up from the hospital)

- “It is not easy to take medicine every day. What kinds of problems make it hard to take your pills?”
- “It’s not easy to take medicines every day. What things help you to take your pills?”
- “It’s great that you are feeling better now that you started ART. What things make it hard to remember to take your medicines now that you’re feeling better?”

Strengthen patient counseling/education:

- Make sure the medicine plan fits the patient’s lifestyle.
- Give a lot of detailed information about how to take medications, including timing, food, restriction, drugs interactions, etc.
- Come up with a plan to handle side effects.
- Remember family-focused care and encourage the person to bring his/her partner and children to the clinic for testing and treatment, if needed. This will lower the chance that the patient shares their medicines with family members.

Easy access to a reliable medicine supply:

- Make sure patients understand where, when, and how to obtain medicines.
- Help patients plan how to store their medicines safely at home.

Make it easy to remember when to take medicines

- Come up with ways to help patients remember to take medications, including daily cues (like when they eat breakfast and dinner), reminders (like a watch or alarm clock), partners, support groups, and others.
- Help patients set up calendars, or diaries to plan when and which drugs to take. They can be ticked off when each dose is taken.

9.7: UNIT SUMMARY

The key points of this Unit include:

- Adherence means how faithfully a person sticks to the care and treatment plan.
- Adherence support is most successful when it's provided by a number of people on the multidisciplinary care team in partnership with the patient. Adherence support should be part of every visit because adherence barriers and strategies will change over time.
- Adherence includes active understanding and participation of the patient in his/her care and treatment plan.
- Adherence to care is important to make sure a person stays healthy, understands how to live positively, knows when to start ART, and gets psychosocial support at the clinic and in the community.
- Adherence to treatment is important to lower the amount of HIV in a person's body and make sure the person gets all the benefits that OI medicines and ARVs have to offer (feeling better, not getting OIs, etc).
- At least 95% adherence is needed for ART to work the right way and keep a person healthy.
- Non-adherence means missing one or many doses, not following the care plan or returning for appointments at the clinic, taking medicines the wrong way, etc.
- Non-adherence to treatment can lead to drug resistance, preventing the ART from working and making the person very sick.
- There are many barriers and challenges to good adherence, including things related to the patient's life, things related to the medicines, and things related to the health care system and HIV program.
- Before starting ART, patients need to attend group education and one-on-one counseling sessions to understand the treatment plan and identify strategies to overcome adherence barriers.
- Expert Clients should ask patients about adherence at every visit.
- Encourage patients to be honest about their adherence, even when it's not perfect. Never judge someone about missing doses or appointments.
- Involve friends or family members (if the patient is comfortable with this). Social support and disclosure are very important to adherence.
- Coordinate with the clinical team to follow up when patients miss appointments.
- Expert Clients can help patients and caretakers find practical solutions to adherence, like pill boxes, medicine diaries, or having a treatment buddy.
- Expert Clients should tell everyone about the 6 Basic Rules for ART Success:
 1. ARVs need to be taken every day.
 2. ARVs should be taken at the same time.
 3. HIV is a chronic disease and ARVs need to be taken for life
 4. See the doctor or nurse if you have ongoing side effects
 5. Never share ARVs with other people
 6. You can still pass HIV to others even when on ART and if you feel well, so remember to use a condom every time you have sex.⁴

⁴ It is important to note that condoms occasionally break and using condoms correctly and consistently upon every occasion of sexual intercourse can be hard to do. Abstaining from sex until marriage and being faithful to a single partner are good risk reduction behaviors to practice.

UNIT 10: STIGMA AND DISCLOSURE

Time	Specific Objective	Teaching Methods	Learning materials
10 Min	By the end of this Unit, participants shall be able to: Reflect on our own experiences with stigma.	Q&A Lecturer	Trainer's manual Power point presentation LCD Projector Flip chart Markers
15 Min	Describe how stigma negatively affects access and adherence to PMTCT, care, and treatment services for adults and children.	Q&A Lecturer	
15 Min	Explain strategies to overcome different forms of stigma at the individual	Role play	
10 Min	Explain the difference between partial and full disclosure	Q&A Lecture	
30 Min	Explain the advantages and disadvantages of disclosure	Role play Q&A Lecture	

10.1: OUR OWN EXPERIENCES WITH STIGMA (10 MIN)

Defining stigma

To **stigmatize** someone means to label them and to see them as inferior or not good enough because of something about them. A lot of times people stigmatize others because they don't have the right information and knowledge and/or because they are afraid. We have all felt rejected or isolated at some point in our lives and we have all probably rejected or isolated another person because we perceive them as different.



Participant Activity

- In plenary, invite participants to share an experience when they stigmatized others or were stigmatized themselves?
- Ask them to recall how this experience made them feel.

We know that stigma is one of the biggest challenges to living with HIV or being affected by HIV all over the world, including in Malawi. Stigma is a big reason why people don't access HIV testing, PMTCT, care and treatment, and community-based services. Expert clients need to help other patients understand and deal with stigma. They can work with the multidisciplinary team and the community to fight stigma and make sure people have access to the services they need. It is especially important to help pregnant women and children infected with HIV as these are the most vulnerable groups.



Participant Activity

- In pairs, ask participants define the following for 5 minutes:
 - Stigma towards others
 - Self-stigma
 - Secondary stigma
- Compare participants' answers with the following definitions.

There are different kinds of stigma:

- **Stigma towards others** - Rejecting or isolating other people because they are different or perceived be different.
- **Self-stigma** - People take cruel and hurtful views placed upon them by other people as their own views of themselves. Often self-stigma can lead to isolating oneself from the family and the community.
- **Secondary stigma** - People, such as NGO workers, clinical officers and nurses at the HIV clinic, children of parents with HIV, and caregivers and family members are stigmatized by their association with PLWHA.

10.2: HOW DOES STIGMA AFFECT HIV SERVICES? (15 MIN)



Participant Activity

- In small groups, ask participants to brainstorm the ways in which stigma prevents people from accessing HIV services (5 minutes).
- They should be prepared to share the main ideas of their discussion with the rest of the team.
- In plenary, share the main ideas from the groups, adding new ideas (10 minutes).
- Move through the rest of this section quickly, only highlighting issues not already mentioned.

Stigma prevents good access to HIV prevention, care, and treatment services for many people. For example, stigma:

- Prevents people from getting an HIV test
- Makes it hard for people to tell their partner(s) their test result
- Makes it hard for parents to disclose to their children
- Prevents PLHIV from accessing care, treatment, counseling and community support services because they want to hide their status
- Discourages pregnant women from taking ARVs or accessing other PMTCT services
- Prevents people from caring for PLHIV

How can stigma affect care and treatment?

- When stigma prevents someone from knowing their HIV status, enrolling in care, or getting a CD4 test, then fewer people have access to ART.
- Stigma can cause feelings of hopelessness and depression (covered more in the next Unit), that can make it hard for people to start or adhere to ART.
- People may fear that if they take ART, more people will know they are living with HIV.
- If a people can't disclose their status because of stigma, they will have to keep their ART a secret, and this will impact adherence and the amount of support they receive.
- Children with HIV cannot get the care and treatment they need if there is stigma attached to their illness or if the family has not disclosed to caretakers and teachers.
- Women—especially pregnant women—and young people, are often the most stigmatized. This makes it even harder for these groups to access and adhere to care and treatment. The same applies to children as often their HIV status is not even disclosed to them. Older children that know their status often hide it from their peers as they are afraid of rejection.
- Stigma among health care providers can result in low quality services at health facilities, making people less likely to access the care they need.
- Stigma can extend to caregivers of PLHIV as well – making it less likely that people will want to care for PLHIV or seek services themselves.

Expert Clients and all PLHIV have an important role to play in reducing stigma among individuals, at the health care facility, and in the community. Being a positive role model is one of the best ways to fight stigma! Making sure everyone knows about and has access to quality, affordable HIV and PMTCT, care,

and treatment services also helps fight stigma.

10.3: STRATEGIES TO DEAL WITH STIGMA (15 MIN)

Some common individual strategies for dealing with stigma:

- Talk back
- Educate people
- Talk to people you feel comfortable with
- Ignore people who stigmatize you
- Join a support group
- Try to explain the facts
- Avoid people that you know will stigmatize you



Participant Activity

- Ask participants what other strategies they can suggest.

At the health facility:

- Encourage health care workers, including expert clients, to talk about their own attitudes, feelings, fears, and behaviors in an open way. Help them to address their fears and to avoid burnout.
- Promote health care workers to be open about their status and for everyone to support one another.
- Implement an HIV workplace policy that includes non-discrimination and access to prevention, care, and treatment services for all staff.
- Get feedback from expert clients and other clients about the services and attitudes at the facility and use these to make improvements.

In the community:

- Get community involved in the fight against HIV.
- Promote PLHIV as role models and active community participants.
- Work with Community Health Workers and Volunteers on improving linkages between health facilities and the community.

With faith-based and religious groups:

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

10.4: DISCLOSURE OVERVIEW (10 MIN)

What is disclosure?

- Disclosure is when a person reveals his or her HIV-status to one or more people.
- Disclosure is an ongoing process – meaning that a person may first want to disclose to only one person and then over time disclose to others. It is not a one-time event and PLHIV need ongoing support on disclosure.

Partial and full disclosure

Disclosure is a process and not a one-time event. Disclosure to one or many people usually works the best when it is planned and the person feels comfortable and able to deal with any reaction.

- **Partial disclosure** means telling your HIV-status to one or a few people, but not to everyone. Most people opt for partial disclosure as a first step. For example, a person may want to tell their close family members about their HIV-status, but not people at work or in the community.
- **Full disclosure** means being open with everyone about your HIV-status. People who fully disclose their status can have a big impact on reducing stigma and advocating for other PLHIV. However, there are also risks and people shouldn't fully disclose unless they are well-prepared and feel a lot of support.

10.5: ADVANTAGES AND DISADVANTAGES OF DISCLOSURE (30 MIN)



Participant Activity

- In small groups, ask participants to discuss the advantages and disadvantages of disclosure (15 min).
- They should be prepared to share the main ideas of their discussion.
- In plenary for 10 minutes, ask groups to report back, only mentioned new ideas not covered by previous groups.
- Move through the rest of this section quickly, only highlighting issues not already mentioned.

Advantages of disclosure may include:

- Avoiding the burden of secrecy and hiding.
- Avoiding anxiety about accidental or unwanted disclosure.
- Access to emotional and psychosocial support.
- Ability to talk about symptoms and concerns openly.
- Easier access to health care.
- Enhanced adherence to care and medication, and ultimately making the person healthier and able to live positively with HIV.
- Ability to discuss safer sex and family planning choices with one's partners.

- Ability to refer partner and children for HIV counseling and testing, and to care and treatment if needed.
- For pregnant women, ability to get support for safer infant feeding from family members and friends, and linkages to food support programs when the mother wants to wean the baby.
- Freedom to ask a friend or relative to be a treatment buddy.
- Access to patient support groups and community organizations.
- Can serve as a role model for other people on disclosure.

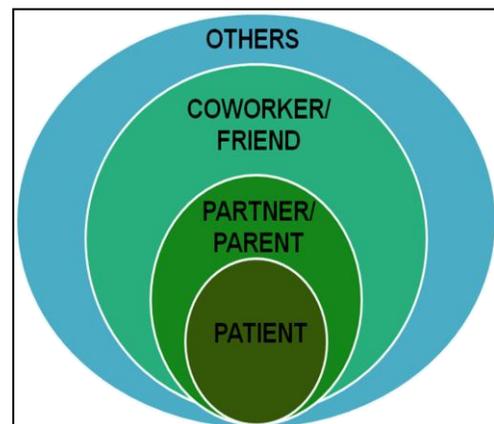
Disadvantages of disclosure may include:

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

Deciding about disclosure

A good way to understand disclosure and help people decide who they will disclose to is by creating **disclosure circles**:

- The center of the circle is the patient him/herself.
- The next circle out is a person or people the patient is very close to, such as his/her mother or a partner.
- The next circle includes larger groups of people who the patient is not as close to, such as people at work or others in the community.
- There can be many layers to the circles of disclosure.



General approach to disclosure counseling:

- Use good communication and counseling skills (e.g. good body language, ask open-ended questions, summarize and reflect, etc.).
- Discuss the advantages and disadvantages of disclosure specific to the person’s life.
- Help the person to identify barriers and fears about disclosure.
- Explore possible options to overcome barriers.
- Encourage the patient to take the time needed to think things through.
- Talk about sexual partners who need protection from HIV infection.
- Identify sources of support.
- Support the person to make his/her own decisions about disclosure.

Keep in mind that disclosure to children depends on what stage of development they are in. For example, a young child of 6 or 7 years may only need to know that she is sick and has to go to the doctor and take medicines to feel better. An older child, perhaps age 10 or 11, should know that he has HIV, understand

the disease and the medications, and actively participate in his own care and treatment.

Prepare patients who choose to disclose by:

- Helping to decide whether partial or full disclosure is best, using the disclosure circles exercise above.
- If partial disclosure is chosen, helping to decide whom to tell first, when, where and how to tell them.
- For parents or caretakers, decide what type of information is most understandable for a child given the child's age and development.
- Plan for a good place and time to have the conversation, for example, when the children are asleep and when no one else can hear.
- Assisting the patient to anticipate likely responses.

Disclosure role plays

One of the best ways for expert clients to help patients prepare for disclosure is through role plays:

1. Ask the patient how he/she will start the conversation. For example, "I wanted to talk to you about something because I know you can help and support me." Or, "I went to the clinic today for a check-up and they talked to me about how it's important for everyone to get an HIV test because you can't tell if someone has it by looking at them."
2. Pretend to be the patient's partner or relative and give a variety of responses. This will help the patient be prepared different reactions.
3. Provide practical suggestions based on your own experience. Offer ongoing support and reassurance.



Participant Activity

- In pairs, practice the exercise below for 5 minutes:
 - The EC should ask the patient how he/she will start the conversation. For example, "I wanted to talk to you about something because I know you can help and support me." Or, "I went to the clinic today for a check-up and they talked to me about how it's important for everyone to get an HIV test because you can't tell if someone has it by looking at them."
 - Pretend to be the patient's partner or relative and give a variety of responses. This will help the patient be prepared different reactions.
 - Provide practical suggestions based on your own experience. Offer ongoing support and reassurance.
- Move around the room while participants are doing the role play.
- Provide any guidance or clarification as needed in plenary.

10.6: UNIT SUMMARY

The key points of this Unit include:

- Stigma is one of the biggest challenges to living with HIV or being affected by HIV.
- Stigma comes in many forms – it can be from one person to another, a person stigmatizing himself/herself or stigma by association. Programs can also stigmatize people, as well as communities and religious groups.
- Stigma at all levels makes it hard for people to accept, access, and adhere to prevention, care and treatment services.
- Expert clients have an important role to play as positive role models, reducing stigma among individuals, at the health care facility, and in the community.
- Expert clients can help patients deal with stigma in their own lives.
- Disclosure can help a person:
 - Access care, treatment and support;
 - Improve adherence to care and treatment;
 - 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; and
 - Help normalize HIV prevention, care, and treatment services.
- Expert clients can help people weigh the advantages and disadvantages of disclosure and be a supportive counselor throughout the process.
- Partial disclosure to a small number of trusted people is usually a good first step in the disclosure process.
- Disclosure with children is also important, and the amount and level of information that a child should be told about HIV depends on the child's age and development.
- Role playing is a great way for expert clients to help patients practice disclosure and be prepared for possible responses.

UNIT 11: POSITIVE LIVING

Time	Specific Objective	Teaching Methods	Learning materials
15 Min	By the end of this Unit, participants shall be able to: Explain the “recipe” for positive living	QA Lecture	Trainer’s manual Projector/LCD Flip chart, Markers, condoms cup, basin, hand towel, soap, bucket with a tap, JIK, chlorine, empty bucket, water
20 Min	Explain to patients how to keep their minds and bodies healthy.	QA Discussion	
30 Min	Explain safer sex practices	Discussion Demonstration	
30 Min	Describe how patients can advocate for themselves and encourage “self care” as a part of positive living	Discussion	
30 Min	Describe the purpose and process of infection prevention	Lecture Discussion Brainstorming Demonstration	

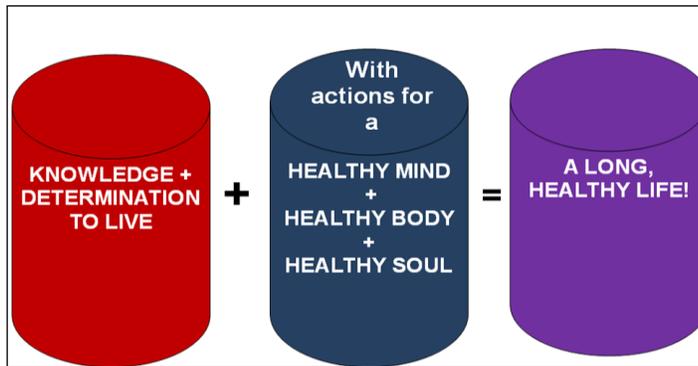
11.1: WHAT IS POSITIVE LIVING? (15 MIN)



Participant Activity

- There are people who have lived with HIV for many years enjoying very good health and quality of life. This lifestyle is often referred to as “positive living.”
- In pairs, ask participants to guess the ingredients for positive living for 5 minutes

Here is the “recipe” for positive living:



Expert clients can discuss and reflect on the different “ingredients” in the “recipe.” Consider how ECs live positively with HIV in their own lives and take care of their minds, bodies, and souls to stay strong and live a healthy life. Expert clients can be wonderful role models to help patients live positively with HIV.

Positive living means having a positive outlook to living and life. It also means living responsibly with HIV.

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. Here are some of the key components of positive living:

- Keep the mind and soul healthy
- Keep the body healthy
- Prevent illnesses
- Adhere to care and treatment

11.2: HEALTHY MIND AND SOUL (20 MIN)

Expert clients can help patients deal with their feelings after learning they are living with HIV (after receiving test results, for example). ECs may also help patients cope with disclosure, as discussed in the last unit. These are important times for ECs to provide emotional support, but ongoing support is also needed to help people live positively with HIV in the long term.

Sometimes patients may need your help when they feel anxious or depressed:

- **Anxiety** is when a person feels nervous, has a lot of fear, or doesn’t want to do things that he/she normally enjoys. Sometimes people also use the word “stress” to describe feelings of anxiety.
- **Depression** is when a person feels extremely sad and hopeless.

Anxiety and depression are common reactions to living with HIV, especially when a person isn’t feeling well and doesn’t get the support he/she needs from family, friends and the 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 and improve a person’s overall health.

Signs of anxiety:

- Doesn’t want to eat or has little appetite
- Feels like the person can’t breathe
- Shaking and sweating
- Heart pounding fast
- Can’t sleep
- Can’t concentrate on anything
- Feels “jumpy” or “stressed”
- Feels worried about many things

Signs of depression:

- Feels like the person just don’t know what to do (helpless or hopeless)
- Very tired, no energy
- Can’t find good in anything
- Doesn’t enjoy the things he/she used to
- Sleeps too much or not enough
- Gets angry for no reason
- Doesn’t want to eat or eats too much
- Doesn’t feel like being social with friends or family
- Doesn’t feel like having sex
- Talks about running away
- Thinks about/talks about suicide



Participant Activity

- In small groups, ask participants to brainstorm some of the ways they can help patients with anxiety or depression (10 minutes).
- In plenary, ask groups to share the main ideas from their discussions for 5 minutes.
- Each group should only add NEW points.
- Move through the rest of the section quickly, only highlighting issues not already mentioned.

What to do:

- Talk with the multidisciplinary care team about the patient’s symptoms.
- Provide continuous supportive counseling to the patient so they feel “heard.” Use good communication skills, such as reflection.
- Encourage the patient to join a support group to meet other people living positively with HIV.
- Link the patient with support services like groups that provide spiritual support, counseling, home care, and/or nutritional support.
- Remind patients that they shouldn’t use alcohol or drugs because this will only make things worse.
- Make a plan with the person to stay hopeful and get to feel good again.

- Encourage the person to continue any religious or spiritual practices that make them feel peaceful.
- Talk with family members – they may feel discouraged and need support too.
- Remind them to provide ongoing support and love to the person.
- Remind the patient that his/her feelings are normal and that he/she will feel better soon.

When the expert client needs to make a referral

Each member of the multidisciplinary care team needs to help take care of a patient's mental health. Expert clients should look for danger signs that anxiety and depression may be out of control and consult with the clinic doctors, nurses, community-based counselors and spiritual advisors immediately. ECs should seek help from the team right away when:

- The patient might hurt him/herself or another person.
- The depression is so bad that the patient is thinking about killing him/herself.
- The family cannot cope with the person anymore and wants to throw him/her out of the house.
- The patient can't eat or sleep
- There is any kind of emotional crisis.

By sharing their own experiences and being a trusted counselor, expert clients can help people find hope and joy, accept their situation, and want to live for the future!

There are many healthy behaviors PLHIV can do to keep their bodies healthy and live positively with HIV, including:

- Use condoms and practice safer sex, every time!⁵
- Get STIs treated right away and tell your partner to get them treated too.
- Get a TB test and treat TB right away.
- Use a family planning method if they want to limit or space children.
- Go to the hospital or clinic for check-ups, lab tests, and to pick up medicines.
- Never miss an appointment!
- Take medicines the right way (at the right time, the right number, etc.).
- Tell the nurse and doctor if there are any changes, even small ones, in your health.
- Stay busy and active.
- Get enough rest.
- Join a support group and talk about things openly.
- Stay clean – wash regularly and wash hands often, especially after going to the toilet and before making food.
- Wash raw fruits and vegetables thoroughly with clean water.
- Cook food well to get rid of germs.
- Boil drinking water to make sure it's clean.
- Eat enough food. PLHIV need more calories to help their bodies fight the virus.

Unhealthy behaviors:

⁵ It is important to note that condoms occasionally break and using condoms correctly and consistently upon every occasion of sexual intercourse can be hard to do. Abstaining from sex until marriage and being faithful to a single partner are good risk reduction behaviors to practice.

Expert Clients should advise patients to avoid practices or behaviors that are not healthy. These include:

- Drinking too much alcohol
- Smoking
- Sharing medicines
- Stopping medicines without talking to the doctor
- Having multiple sexual partners (concurrent relationships)
- Having sex without considering the risks to yourself and the other person and taking appropriate prevention measures
- Avoiding social contact
- Missing appointments at the clinic
- Taking local or traditional treatments that the doctor doesn't advise
- Not eating enough

11.3: SAFER SEX PRACTICES (30 MIN)

What is safer sex?

Safer sex is any kind of sex that reduces the risk of passing STIs or HIV from one person to another. Safer sex should prevent infected fluids from being passed between partners. These fluids include: semen, fluid from the vagina, and blood.

To be safe, these fluids should not enter the vagina, the anus, or the opening of the penis. They should not enter open sores, cuts, or broken skin anywhere on the penis, in the mouth, on the vagina, in the anus, or anywhere else on the body.

Why is safer sex important to living positively?

- It helps prevent the spread of HIV to a person's partner(s).
- It protects the person and his/her partner(s) from STIs.
- It avoids unintended pregnancy.
- It limits exposure to new, more harmful strains of the HIV virus.

Ways to practice safer sex:

- Reduce the number of partners and use condoms all the time.
- Use a condom for all kinds of sex (vaginal, oral or anal).
- Don't put products or herbs in the vagina before sex.
- Do not have sex if you or your partner has a STI, other than HIV, until treatment has been concluded.
- Never force another person to have sex.

Male and female condoms⁶

⁶ It is important to note that condoms occasionally break and using condoms correctly and consistently upon every occasion of sexual intercourse can be hard to do. Abstaining from sex until marriage and being faithful to a single partner are good risk reduction behaviors to practice.

Myths about condoms:

- They always break.
- They actually give someone HIV.
- They are only for sex workers.
- They make sex feel bad.
- You only use condoms with people you don't trust.
- Using condoms means you are not faithful.
- Condoms aren't for married people.
- Sex without condoms means you are in love.
- Condoms are only for sex outside of marriage.

Safer sex using condoms:

Not having sex at all is the only way to be completely safe. But this is not practical or enjoyable for most adults. Using condoms is one reliable way to practice safer sex – see the list above for other ways. There are a lot of myths about condoms, such as that they are only for sex workers or that they make sex feel less good. Many people in Malawi also think that married people don't use condoms because they are only for sex outside of marriage.

A few words about re-infection

Some people think that if both partners are HIV-positive then they don't need to use condoms at all. This isn't true because there are different types of HIV, called strains, which can still be passed from one PLHIV to another. Even if a person takes ARVs with perfect adherence, a sexual partner could transmit a different strain of HIV. This is called **re-infection**. Some strains of HIV are resistant to certain medicines, and it's possible that a person could be re-infected with one of these. This could cause ARVs to stop working well. Using condoms at every sexual encounter helps avoid re-infection and keeps ARVs working in the body.

In summary, part of the expert client's job is to give accurate information about condoms, including failure rates, and help people learn how to use them to protect themselves and their partners from HIV, a new strain of HIV, and STIs. ECs should be able to counsel clients about the safer ways to get pregnant and have a healthy HIV-free child.

The male condom:

These are the basic steps you should know for using, and demonstrating how to use, a male condom. If penis models are not available, you can use a bottle, banana, or corn.

- Only condoms made out of latex protect against HIV.
- Look at the condom package and check the date to make that the condom has not expired and that the package doesn't have any damage.
- Open the packet on one side and take the condom out. Don't 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.
- Condoms only work when the penis is erect (hard). Once the penis is erect (hard), put the condom on the tip of the penis and unroll it down to the bottom of the penis.
- After sex, hold the rim of the condom while the man removes his penis without spilling the semen. The penis must be removed while it's still hard to make sure the condom doesn't fall off.
- Remove the condom and tie it in a knot to avoid spilling. Throw it away in a latrine or bury it. Don't put it in a flush toilet.

- Never re-use condoms - use a new condom every time!

Also, it's important to:

- Use only lubricants made out of water (not oils).
- Store condoms in a cool, dry place, out of the sun. Don't 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.

The 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 don't have to use a male condom. The female condom is becoming more affordable and available to women in Malawi. These are the main steps for using a female condom. If no vaginal model is available to demonstrate its use to people, you can use a box with a round hole cut in it, or your hand.

- Open the packet – do not use 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 the 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 sex, before the woman stands up, squeezes and twists the outer ring to keep the semen inside the pouch and pull the pouch out.
- Put the used condom in a latrine or bury it. Don't put it in a flush toilet.
- Never re-use condoms - use a new condom every time!

Condom negotiation

It's very hard for most people to talk openly about using condoms with their partners. Part of the expert client's job is to teach patients how to use condoms to protect themselves and their partners, as well as to teach patients how to talk to their partners about condoms. Even when a person decides that s/he wants to use condoms, s/he still needs to talk about condoms with the partner, which can be tough.

Expert clients can:

- Promote reduction of sexual partners and faithfulness within relationships
- Discuss condom use for all patients at every sexual encounter. Pregnant women and their partners should also use condoms every time they have sex to protect the woman and the baby from infection.
- Help people practice what they are going to say about condoms to their partners.
- Suggest that the person focus on safety issues instead of trust issues. For example, "it's good for us to use condoms because I don't want to give you HIV. It's not because I don't trust you."
- Use other people practicing safer sex as examples. So, "I know that so and so in the community decided they should use condoms, even though they are faithful to one another."
- Suggest that the person bring their partner to talk with the Expert Client.

11.4: PROMOTING SELF-CARE AS PART OF POSITIVE LIVING (30 MIN)

What is self-care?

Expert clients should always try to leave the patient in charge of his/her own care as much as possible. This is called **self-care**. For example, patients can take responsibility for taking their medications. They can make positive choices about their diet, exercise, and other lifestyle issues that protect their health and help them to live positively.

Patients need to be educated, motivated, and supported in order to take care of themselves. This gives them a better sense of control, makes them feel better about their situation, and helps them be more successful in caring for themselves.

Promoting self care includes developing a good relationship between the care team and the patient. Self care also depends on the support of family, friends, and the community – without stigma and discrimination. It's hard to practice healthy behaviors when these behaviors aren't supported by others (for example a woman who wants to use condoms needs her partner's support).

How can people be more involved in their own care and treatment? Expert Clients should encourage them in several ways.

1. **Be involved:** The patient should be a part of every decision that is made about his/her health.
2. **Think ahead:** When the patient talks to his/her health care providers about a health issue BEFORE problems happen, the patient will get the best possible care.
3. **Ask questions:** If a patient does not understand something that the doctor, nurse or pharmacist said, encourage him/her to always ask questions. If the patient does not understand the answer, he/she should ask the question again. An expert client, family member, a friend or caregiver can also be there with the patient to lend support.
4. **Learn more about health and treatment:** Encourage patients to collect as much information as they can about HIV and their treatment. They should ask their health care workers about the tests and treatments they need, and how to get the treatment. They should also know the risks and side effects of the treatment and what will happen if they do not get the treatment.
5. **Understand which medicines a person is taking:** Advise patients to make lists of all the prescription medicine, traditional medicine, and anything else they are taking or doing for their treatment.
 - Make sure patients write down any allergies to any drugs. Before they take any medicines, encourage patients to ask a health care provider about:
 - How to use the medicine.
 - How a person might feel when he/she is on the medicine (side effects).
 - Which other medicines should NOT be taken when using the medicine.
 - How long the person will need to take the medicine.
6. **Get the results of every test:** Ask for the results of the tests you are taking. Ask what the

results mean for your health and for your treatment.

7. **Ask for more information about referrals:** Ask the doctor, clinical officer, medical assistant, nurse, or expert client:
 - 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 don't have to explain everything?
 - 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?

8. **Understand the treatment plan:** Before leaving the hospital, patients should ask health care workers to explain the treatment plan to be used at home. Also patients should understand the follow-up care plan, and what medicines should be continued. Expert clients should always be available to help!

11.5: INFECTION PREVENTION AND CONTROL FOR EXPERT CLIENTS (30 MIN)

Since expert clients will be providing services within the health care facility, they need to be familiar with standard infection control procedures. This section gives expert clients a detailed understanding of infection prevention and the important steps to take while working in the health facility. Moreover, since all expert clients are also living with HIV, infection prevention skills are important for day-to-day living and are a key part of positive living skills.

Definition of terms

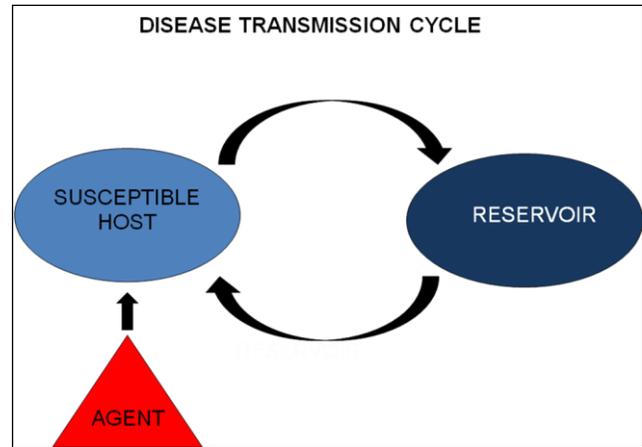
- **Infection prevention** means placing barriers between a susceptible **host** (anything that can become infected) and **micro-organisms** (small germs) to reduce/prevent spread of infection. These barriers prevent the spread of infectious micro-organisms from person to person. It will also prevent spread from equipment, instrument and environmental surfaces to people. **Barriers** can be physical things (like gloves or masks), mechanical (like sterilization), or chemical processes (like bleaching).
- **Micro-organisms** are things that cause infection such as viruses, bacteria, and fungi
- **Asepsis** is the combination of efforts to prevent entry of micro-organisms into any area of the body where they can cause infection
- **Antisepsis** is the prevention of infection by killing/inhibiting growth of micro-organism on skin/body tissue.
- **Decontamination** is the process that makes inanimate objects safer to be handled by people before cleaning (i.e. inactivates hepatitis A virus, hepatitis C virus and HIV. Decontamination reduces, but does not eliminate, the number of other contaminating micro-organisms).

The disease transmission cycle

Micro-organisms are found everywhere in our environment. Humans normally carry them on their skin and in the upper respiratory, intestinal and genital tracts. In addition, micro-organisms live in animals, plants, soil, air and water. Some micro-organisms, however, are more likely to cause disease than others.

Given the right circumstances, all micro-organisms may cause infection.

It's important to note that all humans, not just PLHIV, are susceptible to bacterial infections and also to most viral agents. When organisms come in contact with bare skin, infection risk is quite low. All of us touch materials that contain some organisms every day. When the organisms come in contact with mucous membranes or non-intact skin, infection risk increases. Infection risk increases greatly when micro-organisms come in contact with normally sterile body sites, and that the introduction of only a few micro-organisms may produce disease.



For bacteria, viruses and other infectious agents to successfully survive and spread, certain factors or conditions must exist. There must be an **agent** - something that can cause illness (virus, bacteria, fungi etc). The agent must have a place where it can live such as humans, animals, plants, soil, air or water. We call this a **susceptible host**. Many micro-organisms that cause disease in humans multiply in humans and are transmitted from person to person. The agent must have the right environment outside the host to survive. When it leaves the host, it must have a suitable environment, called a **reservoir**, in which to survive until it infects another person. An agent must have a way to enter the host or a **place of entry**, as well as **place of exit** or way to leave the host to continue spreading.

Method of Transmission

Agents can travel from place to place or from person to person through different ways:

Transmission Method	Description	Example of agent
Airborne	Through the air	Chicken pox, TB, measles
Blood or body fluids	Direct contact with contaminated blood or body fluids, such as sexual contact, sharing a needle, childbirth, etc.	HIV, syphilis, hepatitis
Fecal-oral and food-borne	Humans swallow contaminated food or water	Giardiasis, E coli, toxoplasmosis
Animal or insect-borne	Contact with infected animals or insects through bites scratches, secretions or waste.	Malaria, rabies

Methods of disease prevention

To prevent the spread of infectious agents, we removing one or more of the conditions that the agent needs to move from the host to the reservoir or to the next host by:

- Killing or inhibiting the agent (e.g. applying an antiseptic agent to the skin before surgery).

- Blocking the agent's means of getting from an infected person to a susceptible person (hand washing with soap to remove bacteria or viruses acquired through touching an infected patient or contaminated surface).
- Vaccinating people to boost their immunity.
- Providing community care provider and primary care givers with the appropriate protective equipment to prevent contact with infectious agents (e.g. gloves).

Infection prevention deals primarily with preventing the spread of infectious agents through air, blood or body fluids, and contact, including fecal-oral and food-borne. Because it is not always possible to know in advance whether or not a person may be infected with HIV or another infectious agent, **contaminated instruments, needles and syringes as well as other items from all persons must be handled as if they are contaminated.** This is called **standard or universal precautions.**

Standard precautions

Standard precautions are designed for use in caring for all patients seeking health care in any settings. They apply to blood, all body fluids, secretions and excretions (except sweat), non-intact skin and mucous membranes. Because no one really knows what infection a patient may have at any time, it is essential to note that standard precautions be used at all the time and consider every person as potentially infectious and susceptible to infection.

- Wash hands with soap – This the most important procedure for preventing cross contamination (person to person or contaminated object to person). Wash hands with soap after touching blood, body fluids, secretions, excretion and contaminated items. Wash hands immediately after removing gloves and in between patient contact, before and after each procedure.
- Wear gloves (on both hands) before touching anything wet, broken skin, mucous membranes, blood or other body fluids, or soiled instruments and contaminated waste materials. Wearing gloves does not replace the need for hand washing.
- Use physical barriers (protective gowns, face masks and aprons) if splashes and spills of any body fluids are likely e.g. when cleaning instruments and other items.
- Safely dispose off infectious waste materials to protect those who handle them and prevent injury or spread of infection to the community.
- Process instruments, gloves and other items after use by first decontaminating and thoroughly cleaning them.
- Patient care equipment – Be careful not to let soiled equipment touch skin or mucous membranes and to prevent contamination of clothing or the environment. Clean reusable equipment prior to reuse.
- Linen – Don't touch soiled linen with skin or mucous membranes. Wear gloves.
- Environmental hygiene – Routinely clean patients' environment i.e., dusting and damp mopping to maintain a clean, healthy and pleasing patient and home environment.
- Personal hygiene –Take a bath daily and put on clean clothes.
- Food hygiene – Avoid eating poorly processed and contaminated food.
- Patient placement – Place patients who contaminate the environment or cannot maintain appropriate hygiene in private rooms.

Processing soiled instruments and other items

Decontamination: It is the process that makes inanimate objects safer to be handled by people before cleaning (i.e. inactivates micro organisms and reduces, but does not eliminate, the number of other contaminating micro-organisms). It is the first step in processing soiled instruments, gloves and other items especially if they will be cleaned by hand. Ideally, soiled surgical instruments, gloves and other items should always be handled by people wearing gloves or using forceps. Because this is not always possible, it is safer first to soak these soiled items for 10 minutes in 0.5% chlorine solution, to make them safe to be handled during cleaning especially if it will be done by hand. **Note:** If in a home setting, in the absence of chlorine, use the boiling method of decontamination or consult the Health Surveillance Assistant of your area.

Cleaning: It is the process that physically removes all visible dust, soil, blood or other body fluids from inanimate objects, as well as, removing sufficient number of micro-organisms to reduce risks for those who touch the skin or handle the object. It consists of thoroughly washing with soap or detergent and water, rinsing with clean water and drying. Clean instruments under water. After cleaning instruments or linen, it is also recommended to disinfect them, for example by boiling them.

Boiling: It is the process that eliminates all micro-organisms except some bacterial endospores from inanimate objects. Instruments or linen should be boiled for not less than 10 minutes from the time water has started boiling.



Participant Activity

- Ask a participant to volunteer to demonstrate proper hand washing technique with soap and water.
- Ask observers to highlight any areas for improvement (5 minutes)
- Ask participants to name the five critical times for hand washing during daily life:
 1. After going to the toilet
 2. Before eating
 3. Before feeding a child
 4. Before cooking
 5. After changing a child's nappy
- Ask participants what are the additional times they should wash hands with soap and water when working in a health facility? (5 minutes)
- Mention any key times participants may have missed.

11.6: UNIT SUMMARY

The key points of this Unit include:

- 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.
- Expert Clients play a key role in helping other PLHIV live positively and following the **“recipe for positive living”**
- Expert Clients should know the signs of anxiety and depression and help people overcome them. They should also alert the clinical care team if they think someone is anxious, depressed, or wants to end his/her life.
- Expert clients can help people keep their minds and bodies healthy by practicing safer sex, eating well, staying clean and avoiding infections, and keeping active (among other things).
- Expert Clients should help people stay away from unhealthy things, like alcohol, smoking, unsafe sex, eating sugary and fatty foods, and being isolated from other people.
- PLHIV and their partners should be counseled on risk reduction behaviors and safe pregnancies.
- Safer sex means avoiding passing of semen, vaginal fluids, and blood from one person to another.
- One of the best ways to have safe sex is to think about all possible ways (ABC) to prevent infection and make the decision that is best for you and your partner.
- Expert clients should be comfortable demonstrating how to use male and female condoms.
- Expert clients can help patients develop skills to negotiate condom use with their partners and be safer sex role models.
- Expert clients can help other patients be in charge of their own health care as much as possible and support them to do so.
- Expert Clients can help other patients advocate for themselves, be involved and understand their treatment, ask questions to provides, understand referrals, and other aspects of their care.
- Expert clients need to follow and reinforce guidelines on infection prevention and control when in the health facility.

UNIT 12: REFERRALS AND RECORD KEEPING

Time	Specific Objective	Teaching Methods	Learning materials
15 Min	By the end of this Unit, participants shall be able to : Explain the expert clients' role in referring patients from service to service and among hospitals, and health centers.	Discussion	Trainer's manual Projector/LCD Markers Flipchart M&E Forms Referral Forms
15 Min	Explain the importance of record keeping in HIV and expert patient programs.	QA Discussion	
45 Min	List the different M& E tools used in HIV care and treatment services in Malawi and demonstrate how to use them.	Discussion Practical session	

12.1: MAKING REFERRALS (15 MIN)

No one person or organization can provide a person and his/her family with all the comprehensive care and support services they need. That is why it's important to have a strong referral system in place. Making a referral means that you formally send a person to another place in the hospital, another health facility, or another organization for services. Expert clients will be important resource people for referrals and will need to understand the referral system well to help guide patients.

Referrals can be at many different levels, for example:

- From the facility to a community organization for food supplies or support groups
- From a community organization to the health facility for CD4 testing
- From the out-patient department (OPD) to the ART clinic
- From the HCT clinic to the ART clinic
- From the ART clinic to the TB clinic
- From one hospital to another

The "referral network" includes organizations and people in a defined geographical area that provide services and support needed by PLHIV, their caregivers, and their families. Expert Clients play an important role in referrals.

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

Many times a person will need different services at the hospital or health facility on the same visit. This can be very overwhelming for someone who isn't familiar with where things are, how to get from place to place, or if they are not feeling well or have to wait a long time at each place. A key role of the expert client is to help people get from one place to another in the hospital as easily as possible. Therefore it is important for the expert client to be easily identified. They may be given a tag or uniform.

Here are some steps:

- Make sure you know where each service is offered at the hospital and how to get there the fastest way. It's helpful to walk around the hospital alone first and then you will be able to better help patients.
- Make sure you know which days and which hours during the day different services are offered.
- Make sure you know where the patient is 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 do they need?
- Patients usually get the best care if they have a referral form on which the doctor or nurse writes exactly why the person is being referred. Expert Clients should be familiar with any forms used at the hospital.
- Expert Clients should help the patient understand why he/she are being referred and why it's important to get these services. Many times, people don't understand why they are referred and they might just leave.
- WALK WITH THE PATIENT (escorting) to the other part of the hospital and make sure the person has a comfortable place to wait.
- Whenever possible, expert clients should wait with the person at the referral point. This is a good time to provide counseling and support and ask about the needs of other family members.
- Expert Clients should help the patient tell staff that they are waiting and talk with the doctor or

nurse to try and get the patient seen as soon as possible to minimize waiting – especially for pregnant women, children and very sick patients. One of the biggest reasons that people don't get care is because they don't want to wait a long time, many times, during the day. Some facilities give pregnant women "red carpet treatment," meaning they don't have to wait to be seen. This is similar to what happens in banks or on the bus.

- If the person needs other services or gets more referrals, stay with them until they leave the hospital. Continue to explain why each service is important and walk them from place to place.
- If needed, help the person plan follow-up actions and visits to the hospital and provide needed referrals to community-based organizations.

12.2: THE IMPORTANCE OF RECORD KEEPING (15 MIN)

Records are important because they can help us to:

- Remember things
- Plan ahead
- See what we've done
- See what we can do better
- Report to other people (like a supervisor) what we've done
- See what the gaps are and fill them

It's important for Expert Clients to understand the records that are kept in HIV care and treatment programs and to fill in their own reports each month because:

- They will show what you've done in the month (e.g. how many people you've counseled, how many group education sessions you've led, how many pregnant woman you've taken to the ART clinic, etc.)
- They will show your supervisor what you've done.
- They will help plan for the next month.
- They will help follow-up on patients from month-to-month.
- They will help show how effective expert clients can be in helping PLHIV when all of the reports are combined across the country.

12.3: M&E TOOLS IN HIV CARE AND SUPPORT SERVICES AND HOW TO USE THEM (45 MIN)

The MOH has national forms and registers for many services. Each facility should have patient files and registers, but they will differ from place to place. It's important to get to know and understand the forms and registers in the health facility where ECs will be working.

Types of information recorded by ECs each day:

- Number of group sessions held and the number of men and women at each
- Number of one-on-one counseling sessions held, and how many were with men, women, or for pediatric or pregnant patients
- Number of adherence counseling session provided
- Number of health education talks conducted
- Number of couples counseled on HTC

- Number of patients escorted
- Number of HIV positive pregnant women assessed for ART eligibility
- Number of adults and children ART eligibility, and how many were men and women
- Number of mother-infant pairs referred for early infant diagnosis
- Any additional information, such as questions, challenges, successes should be recorded by Expert Clients in their notebook and included in their monthly reports.

Reporting your work to the immediate supervisor at the clinic:

- Expert Clients should submit their monthly reports to the immediate supervisor at the clinic. Issues needing urgent attention should not wait next month.
- In addition to the numbers and types of patients reached by Expert Clients, the report can also include bullet points about challenges faced, areas that need refresher training, or solutions to problems that may help ECs in other sites.

12.4: UNIT SUMMARY

The key points of this Unit include:

- Referrals are an important part of comprehensive care
- Referrals may be from many different levels and for different purposes, such as from health facility to community support group, from mobile testing center to health facility, etc.
- Many times, patients will be referred from one area of service (like the ANC clinic) to another (like the ART clinic). Expert clients should walk with patients and make sure that patients reach their referral point and get the care needed.
- It's important to use referral forms to make sure that patients get appropriate care.
- Each hospital and clinic will have different slightly referral systems and forms so it's important for Expert Clients to become familiar with these when they return to their assigned facility after the training.
- Expert Clients play a key role in referring patients for services, helping them understand why they are being referred, and taking them to the referral point when possible.
- Monitoring forms will help expert clients keep track of their accomplishments.
- Monitoring forms will also help ECs identify areas for improvement.
- It's important for Expert Clients to keep good records of their work and report every month to their immediate supervisor.

UNIT 13: LINKAGES TO COMMUNITY SUPPORT SERVICES

Time	Specific Objective	Teaching Methods	Learning materials
20 Min	By the end of this Unit, participants shall be able to: Identify what community-based care and support services PLHIV and their families may need.	Question and answer Discussion	Trainer's manual Flip charts Makers Local materials for mapping
30 Min	Explain why PLHIV and their families may need support groups, home based care, access to associations, nutrition, income-generating activities.	Question and answer Discussion	
1 hour	Demonstrate correctly with the multidisciplinary team to map and link with community-based organizations.	Question and answer Discussion	

13.1: IDENTIFY SUPPORT SERVICES NEEDED FOR PLHIV AND FAMILIES (20 MIN)

As discussed in the last unit, truly comprehensive care for PLHIV requires many different service providers.



Participant Activity

- In pairs, ask participants to discuss the different components of comprehensive care for 5 minutes.
- In plenary, ask participants to share some of the ideas discussed, adding new points as each pair presents.
- Move through the rest of this section quickly, only highlighting issues not already mentioned.

Comprehensive HIV care can include:

- Pre- and post-test HIV counseling and testing and follow-up
- Prevention, diagnosis, and treatment of HIV related conditions and other illnesses, such as malaria and TB
- Palliative care, including pain management
- PMTCT, antenatal and reproductive health services
- ART
- Ongoing monitoring of health status (through lab tests and physical exams)
- Hospitalization for those that are very sick
- Counseling on positive living and prevention
- Couples and disclosure counseling
- Referral and follow-up
- Home-based care
- Nutritional support
- Psychological support
- Social and spiritual support
- Economic support
- Care and support for family members, including children

Remember, not any one person or organization can provide all of the services and support PLHIV need. We must all work together to provide a quality continuum of care and support! It's very important for expert clients to have a good understanding of the different kinds of health facility and community support available so that they can help guide patients. Since we've spent most of this training course focusing on the health facility services, we will now review community-based services. As an expert client, it's very important to learn about the community-based services available in your area so that you can refer patients appropriately. Your supervisor can help with this too.

13.2: OVERVIEW OF HBC, SUPPORT GROUPS, NUTRITION AND OTHER SUPPORT SERVICES (30 MIN)

Home-based care (HBC)

HBC programs are for people with chronic illness (those who have been ill for 3 months or longer). HBC involves trained health workers or HBC volunteers visiting people with chronic illness, including PLHIV, in their homes to provide care and support services to the patient and the family.

HBC is needed because:

- Many people prefer to receive ongoing care in their homes, have too many responsibilities at home to visit the facility (children, cooking, farming), or live long distances from health facilities.
- It supports existing, long-standing family and community structures in Malawi, whereby family members take care of each other.
- It ensures a continuum of care to patients with both at the home and health facility levels.
- It can empower PLHIV to take care of each other and themselves when they are trained as HBC providers.
- It provides support and training to caretakers and family members, not just the patient.
- It can promote HIV prevention and can reduce stigma and discrimination in the whole community by bringing HIV out into the open.

PLHIV associations and support groups

There are several PLHIV associations in Malawi like the National Association of People with HIV and AIDS in Malawi (NAPHAM), Malawi Network of People with HIV (MANET+), Malawi Network of Religious Leaders living with HIV (MANERELA), Coalition of Women Living with HIV (COWHLA), Health Workers living positively (HEWCAP), Teachers Living Positively (T'LIPO), and Network of Journalists living with HIV (JONEHA). These establish support groups to promote and advocate for quality care, support and prevention services.

PLHIV associations can offer many services, including:

- Ongoing support through individual or group counseling.
- Support groups for PLHIV and their families.
- Financial or nutritional support to PLHIV and their families.
- Support for children to enroll in or stay in school (formal or non-formal education).
- Income-generating activities or micro-credit schemes for PLHIV and their families.
- Advocacy for PLHIV to receive the services to which they are legally entitled. This can be at the community, regional, national, and international levels.
- Community sensitization and advocacy to reduce stigma and discrimination.
- Sensitization/training for health care providers on providing quality care to PLHIV, drawing on members' own perspectives and experiences.
- Help with legal support when a person is discriminated against because of his/her HIV-status (in the home, at work, in the community).
- Linkages to the national and local PLHIV Associations.

Support groups for PLHIV carry out various activities. Most of the activities are aimed at promoting positive living for the PLHIV. In the initial years of the pandemic, having HIV was seen as the end of the road with more people living a miserable and sickly life and dying. In the course of time with proper counseling and adherence to all principles of positive living and ART, PLHIV have a prolonged and improved quality of life. Among the key activities that promote positive living are:

- Group therapy sessions
- Psychosocial counseling (supportive counseling)
- Income generating activities (to ensure sustainable livelihoods)
- Farming (to ensure food and nutrition security)
- Advocacy – While advocacy does not have direct impact on positive living, it is through advocacy that PLHIV access essential services that have direct impact on their lives and also creation of a conducive environment in which PLHIV live freely without stigma and discrimination.

Moved with passion and love for their fellow humans, PLHIV also carry out other activities that benefit the entire community. Such activities include:

- HIV and AIDS education outreach
- Community Home Based Care (CHBC)
- Care for orphans

During HIV and AIDS education outreach, PLHIV go to schools, religious places, and wider communities to give out messages on various issues related to HIV and AIDS including mobilizing the community members to go for HIV testing and counseling. They share their personal experiences. These activities are done voluntarily. In their CHBC activities, PLHIV are not selective, but they offer the service to any one regardless of HIV status and membership to a support group as long as that person has chronic illness and requires the service.

Sharing personal experiences:

- Encourages community members to go for HTC
- Encourages PLHIV to accept their status and live a positive life
- Helps to deal with stigma and discrimination
- Dispels some of the myths surrounding HIV and AIDS
- Stimulates better support for those who are living with HIV

Expert clients should therefore encourage clients to join a support group for further support as discussed.

Nutrition support

There is a strong relationship between nutrition and HIV. PLHIV need to pay attention to how much they eat, what they eat, and how often they eat. A nutritious diet is essential.

What is a nutritious diet?

It is the diet that provides the body with energy for growth and movement, to build and repair tissue and to protect the body from various infections. A nutritious diet provides the body with all the nutrients that the body needs every day.

In order to ensure that we have eaten a nutritious diet we should make sure that every meal contains food from all the 6 food groups as described in the table below.

FOODS GROUPS AND THEIR FUNCTIONS

Food group	Function
Staple foods include foods high in carbohydrates, like whole grain maize flour (mgaiwa), porridge, irish potatoes, cassava, sweet potato, rice, green bananas, millet, sorghum, yams, coco, and wheat.	Carbohydrates give us energy for living, working, playing, etc.
Animal foods group includes eggs, meat, milk products, fish, ngumbi, mbewa, etc.	The foods in this group contain protein and fat necessary for repairing the body and for growth. These foods also help muscles to stay strong and help the body to build new muscles. They work to build the walls of all structures in our body. Proteins are used to build hair, skin, muscles, etc.
Vegetable group includes dark leafy vegetables (mpiru, bonongwe, chisoso, therere, pumpkin leaves, kholowa, khwanya, chigwada, etc.)	These foods are rich in vitamins, minerals and water. They also contain fibre necessary for proper digestion. Vegetables are immune boosting foods. These are important for protecting our body from germs that are trying to cause disease or sickness in our bodies.
Legumes group includes ground nuts, soya beans, beans, peas, cowpeas, ground beans (nzama), and pigeon peas.	These foods provide protein and carbohydrate. They provide energy for activities as well as protein for body building functions.
Fruit group includes oranges, lemons, and tangerines, bananas, pineapple, pawpaw, mangoes, masau, bwemba, malambe, masuku, peaches, apples, guava, water melon and many others.	Fruits contain carbohydrates, vitamins and water. Fruits have an added benefit of fibre and other medicinal properties.
Fats group includes oil seeds (soybeans, groundnuts, and sunflower seed), avocado (pear), cooking oil, milk and milk products such as butter, margarine, yoghurt, meat, fish, and poultry.	In the body, fats are burned for energy and provide warmth for the body.

Good nutrition is critical for good health! Eating well will:

- Make muscles, skin and bones healthy
- Provide energy
- Protect against infections
- Prevent weight loss
- Improve overall well-being

- Help medicines absorb into the body and prevent side effects from some ARVs

Even if a person does not feel sick, PLHIV need more energy and food than people without HIV. The body needs more energy to fight off the virus and help the person stay healthy. Eating enough nutritious foods can help PLHIV fight off HIV-related conditions and stay healthy longer. Expert clients should help patients understand nutrition. If a patient’s family is food insecure, the EC can link the patient to organizations that can help them get enough healthy foods to eat.

Challenges to good nutrition:

Even though most people know it’s good to eat healthy foods and lots of them, sometimes PLHIV don’t eat enough. This can be because:

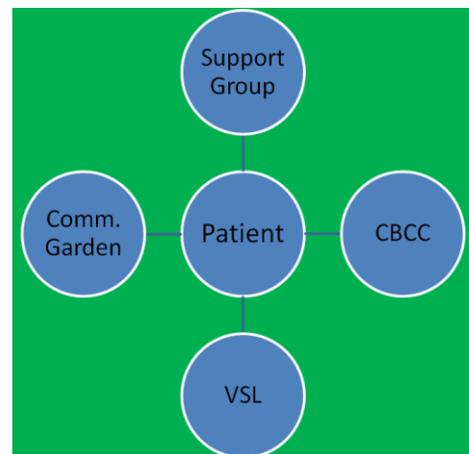
- They lose their appetite or ARVs change the way food tastes.
- They have sores in their mouth or feel nauseated and find it hard to eat.
- They feel tired or depressed and don’t want to eat.
- There is not enough money to buy food or the person is too sick to farm, fish, garden or prepare food.

Expert Clients can work with community-based organizations to help PLHIV and their families get enough good foods to eat:

- Refer patients to community-based nutrition support programs.
- Counsel and educate patients and family members on nutrition, as well as storing and preparing food (like washing hands, keeping food and water covered, and not leaving food out in the sun).
- Help families learn to start community gardens.
- Organize community members to help take care of other people’s gardens when they are ill or need to go to the facility for an appointment.

13.3: MAPPING OTHER SUPPORT SERVICES TO FACILITATE REFERRAL (1 HOUR)

There are many other support services available in communities throughout Malawi including psychosocial support, economic strengthening, legal support, children’s assistance programs, and more. Part of an expert client’s job is to find out which service providers are active in the area and which services they offer. After completing the training, work with your supervisor and community leaders to develop a service directory for your area. This information will complement the services offered at the health facility and will help ensure that patients receive all the services they need to lead healthy and productive lives.



Participant Activity

- Time permitting, ask participants to begin the mapping process in small groups (45 minutes).
- Have them identify different potential referral points within their catchment areas.
- Remind them to think about the many areas of possible support, such as HBC, support groups,

- nutritional support from CBOs, community-based childcare centers, village savings and loans, etc.
- Encourage them to complete this mapping with the multidisciplinary team one they start their placements at the health facilities.

13.4: UNIT SUMMARY

The key points of this Unit include:

- Referrals to community-based services are a key part of the continuum of HIV care and support. No one person or group can provide PLHIV and their families with all the services they need. People must work together.
- There are many community-based services in most places, but often groups don't know about each or make formal plans to work together. Expert clients need to find out what services are available and help encourage cooperation between service providers. Without this collaboration, patients won't be able to access the full continuum of care and support.
- Expert clients provide a vital link for patients to these community-based services through collaboration, referral, and follow-up.
- Expert Clients should assess patients' needs for community-based services and provide referrals and follow-up for:
 - Home-based care and support
 - PLHIV Association membership and links to support groups and income generating activities
 - Nutritional education and food support
 - Other support services
- Once the training is completed, Expert Clients should go back to their sites and work together with other members of the multidisciplinary team to identify and link with community-based organizations.
- Expert Clients should identify and meet regularly with community-based groups in their areas to strengthen the referral systems.
- Meeting regularly with service providers improves the ways facility and community-based groups work together, reduces overlap, and identify gaps in services. Such collaboration leads to better service for patients and families.