Ministry of Health

Caregiver Guide

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Acronyms

AIDS: Acquired Immunodeficiency Syndrome
ARV: antiretroviral
ART: antiretroviral therapy
FP: family planning
HCW: health care worker
HIV: human immunodeficiency virus
LGBT: lesbian, gay, bisexual, and transgender
PEP: post-exposure prophylaxis
SGBV: sexual and gender-based violence
SRH: sexual and reproductive health
STI: sexually transmitted infection
VL: viral load

Introduction

This curriculum is designed for facilitators of caregiver sessions to use in programs offering guidance to caregivers about how to care for and support infants, children, and teenagers living with human immunodeficiency virus (HIV), including support for lifelong and antiretroviral treatment. This manual guides the implementation by professional and lay workers of educational and informative activities for caregivers. The curriculum is in English, but facilitators and participants can also work in siSwati as needed.

Getting Started

Follow these general recommendations to get started:

1. Find a safe meeting place, preferably at a health care facility. Choose an environment where training and discussions can take place in an undisturbed and peaceful space. It is important to meet in a place where passersby cannot interfere with discussions.
2. Choose a convenient time and manage time efficiently. Start activities as early as possible in the morning so that caregivers can return home timely
3. Establish ground rules for the group meetings. Make sure the rules are reasonable, enforceable, and established before meeting begins.
4. Develop a lesson plan for each session. Before each session, facilitators (facility staff and supporting partners) should meet to review the topic and activities planned for the upcoming session.
5. Register all participating caregivers (preferably before meeting start, but if not, as they come). All caregivers should complete a registration form including their name, address, and phone number.

Key Principles for Facilitators

The following principles are important for success when facilitating caregiver sessions and activities:

1. **Be enthusiastic:** Lead with enthusiasm and create an enjoyable, energetic environment to avoid boredom; know how to reel in energy.
2. **Be creative:** The simplest everyday object can become an interesting teaching aid—with good imagination, the possibilities are endless! Adapt the activities and use materials to suit your context. Bring together teaching methods that will facilitate learning. Think outside the box and integrate ideas and activities that you know older participants will understand and enjoy.
3. **Be encouraging:** Encourage participants throughout every session! Tell them they are doing well, clap and cheer for them, and celebrate what they do no matter how simple the activity.
4. **Be engaging:** Try to engage all the participants at all times. Create activities in which participants are constantly involved and actively participating.
5. **Be responsible:** Be a good role model, and aim to always work in ways that are respectful of participants and their rights. Treat others with respect and create a safe environment for participants.
6. **Be an active listener:** Listen to others and encourage others to listen. Actively try to understand what participants are trying to say. Paraphrase, sum up, or use other active listening techniques to fully grasp and gauge their meaning. Listen to the group as a whole, the individual participants, and yourself.

Lesson Preparation

Lessons should be prepared in advance using the modules in this curriculum.

Module	Estimated Time	Mode of Delivery	Resources
1: Disclosure of HIV Status	1 hour 30 minutes	• Presentation • Discussion • Demonstration • Experience sharing	• Flip charts • Flip chart stand • Marker pens • Notebooks • Pens • Attendance register
2: Antiretroviral Therapy	2 hours		
3: Child and Adolescent Treatment Adherence	1 hour		
4: Stigma and Discrimination	2 hours		
5: Child Abuse and Child Protection	1 hour		

6: Sexual and Reproductive Health and Family Planning	2 hours		• Demonstration materials (e.g., antiretroviral medications)
7: Loss, Grief, and Bereavement	1 hour		
8: Adolescent Transition to Adult Care	1 hour		
9: Adolescent Mental Health 10: Tuberculosis 11: Nurturing Care and Support for Children Living with HIV	3 hours		

Module 1: Disclosure of HIV Status to Children and Adolescents

Disclosure of HIV status to pediatric and adolescent patients and their families and support structures is a critically important component of care and treatment. The process of disclosure is complex, both emotionally and socially. Caregivers frequently experience uncertainty about revealing an HIV-positive status to their children. This can stem from fears of (1) negative consequences from disclosure (such as psychological problems), (2) the child's inability to comprehend and deal with the diagnosis and associated stigma, and (3) unintended disclosure to others.

This module is designed to emphasize the importance of pediatric disclosure, describe the process of disclosure, and explain how caregivers can provide post-disclosure support.

By the end of this module, caregivers will be able to

1. define pediatric disclosure,
2. understand the barriers to disclosure and how to overcome them,
3. list the benefits and possible negative consequences of disclosure, and
4. discuss the key steps in the process of disclosure.

Session 1.1 Pediatric Disclosure and Its Benefits

Disclosure is the process of informing a child of their HIV status. This may also involve the sharing of the caregiver's and other family members' HIV status. Children should learn their HIV status from their parent or caregiver.

Disclosure is a process undertaken according to a child's stage of development. Children can tell from a very young age if something is not right in their home or with their health, and if they are not told what the problem is, they often imagine it is much worse than it really is.

Caregivers should be encouraged to be open about HIV and to communicate about it as an common, chronic illness. It should NOT be treated as a terrible thing that caregivers or parents are secretive about or whisper about. With the help of health care workers (HCWs), caregivers should make sure that children and adolescents know that HIV and Acquired Immunodeficiency Syndrome (AIDS) are treatable with antiretroviral therapy (ART). Even though they are not curable, they are not a death sentence or determining a child's life course/opportunities, etc.

Sharing positive news about HIV with children and adolescents from the radio or television, books or magazines, or even positive role models living with HIV can facilitate these conversations within the family.

Disclosure of HIV status is not a one-time event, but a process involving ongoing discussions about living with HIV as the child or adolescent matures. The main factors used to decide when to provide full disclosure to a child or adolescent living with HIV are the child or adolescent's

- **age and cognitive development (emotional maturity),**
- **need to protect themselves and stay healthy,**
- **adherence to their treatment regimen and ability to take responsibility for their care, and**
- **upcoming beginning of sexual activity and need for sexual and reproductive health education.**

Types of Disclosure

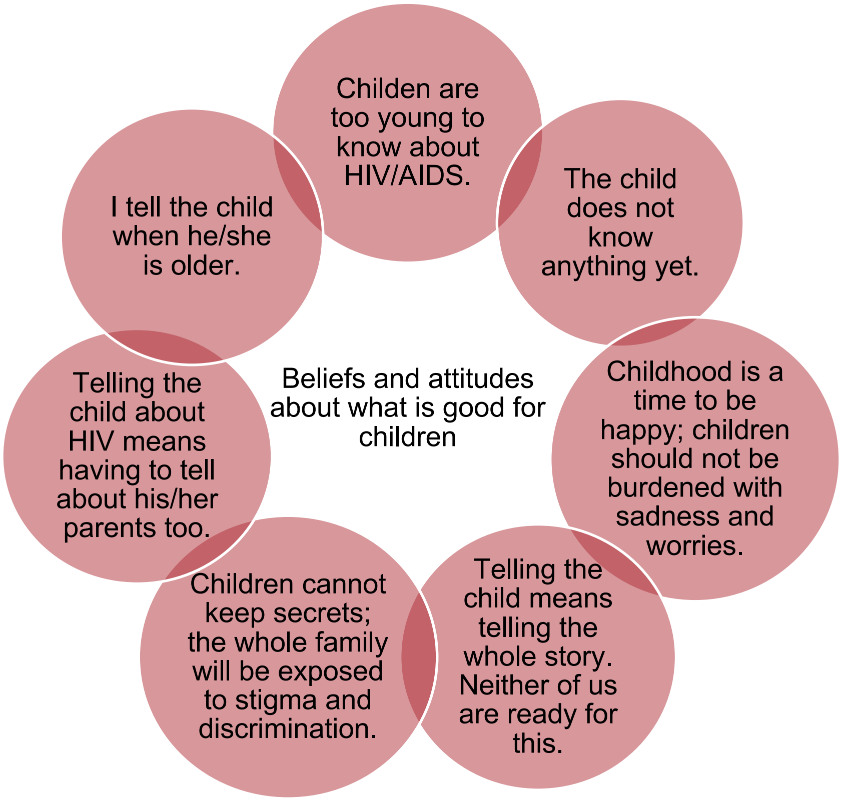
Different types of disclosure include the following:

- **Partial disclosure** is telling the child the truth, but not the whole truth, usually withholding the name of HIV (this can be a step in the full disclosure process).
- **Full disclosure** is providing full information and education about HIV.
- **Post-disclosure** refers to the period following disclosure, commonly divided into early post-disclosure (first three to six months) and late post-disclosure (over six months) periods.
- **Complete nondisclosure** is maintaining complete secrecy around a diagnosis and not telling the truth or not providing any information about the diagnosis.
- **Accidental disclosure** is disclosing HIV status without preparing the child or disclosing by accident. This usually happens unintentionally when an HIV diagnosis is being discussed among adults and a child or adolescent overhears. Accidental disclosure requires HCWs to act on at least partial disclosure of an HIV status to the child or adolescent. A readiness assessment and discussions with the parents or caregiver should be undertaken as soon as feasibly possible.
- **Deception** is ascribing the child's condition to a different illness or linking the child's behavior (e.g., not eating enough) and appearance; this is frequently coupled with nondisclosure.

Session 1.2 Challenges and Barriers to Disclosure

There are many challenges caregivers face when making decisions about disclosure, including beliefs and attitudes about what is good for the child and the caregiver's own fears. It is important for children and adolescents to receive family and social support to address these challenges, and it is important for caregivers to reinforce that HIV is one of many chronic health conditions that can be managed with medication and care. Understanding common barriers to disclosure is the first step.

Beliefs and Attitudes About What Is Good for Children



Caregiver Fears About Disclosure

Caregivers often have their own fears about disclosing HIV status to a child or adolescent, including the following:

- not wanting to hurt the child;
- concern about the child's reaction (e.g., suicidal thoughts or depression);
- fear of inadvertent disclosure of the child's status to other people because the child cannot keep secrets;
- wanting to protect the child from social rejection and stigma;
- guilt about transmission;
- fear about judgment of the parent HIV status being associated with promiscuity or sexual taboos;
- difficulty coping with their own illness or the illnesses of other loved ones;
- difficulty disrupting established family coping strategies including traditional silence about illness and disease, limited communication, or denial;
- concern that the child will not understand anything about HIV infection and antiretroviral therapy;
- discomfort of family members about disclosing an HIV status to the child or adolescent;
- desire to preserve the innocence of childhood;
- belief that the child or adolescent is not ready or is too young;
- concern for the child's emotional or physical health following disclosure;
- fear of adverse consequences (e.g., psychological damage, poor self-esteem, etc.);
- concern about being rejected (especially common among HIV-positive parents);
- belief that the child may not be able to keep the information private and the child or family may be stigmatized; and
- desire to protect the child and family from stigma and rejection.

Session 1.3: Benefits and Possible Negative Consequences of Disclosure

Advantages of Disclosure

There are many ways in which the disclosure of HIV status can positively impact a child or adolescent. Disclosure to the child or adolescent offers the following benefits:

- Provides developmentally appropriate and truthful explanations of the disease
- Clarifies misconceptions about HIV and prepares the child or adolescent to deal with stigma and discrimination
- Enables the child or adolescent to discuss and set their life and HIV treatment goals
- Increases the motivation and willingness of the child or adolescent to adhere to a treatment regimen and reduces frustrations about taking medications
- Improves treatment adherence and thus significantly reduces disease progression and death
- Helps the child or adolescent to better participate in and understand their health care
- May prevent accidental disclosure
- Positively impacts the long-term psychological health of the child or adolescent and enables better self-care and treatment
- Increases acceptance of the diagnosis among the majority of adolescents
- Provides relief after disclosure and feelings that disclosure was important
- May decrease behavior problems by decreasing stress from an unknown source and improve social functioning and school performance by decreasing stress from an unknown source
- Allows for access to health education, sexual and reproductive health (SRH) education, social support, and participation in adolescent peer support groups

Disclosure to a child or adolescent is also beneficial for caregivers. Disclosure offers the caregiver the following advantages:

- Provides relief from the need to maintain secrecy and offers potential for reconciliation or acceptance
- Allows the caregiver to talk openly about their own condition or child condition with the child or adolescent and others and to provide support to the child

- Makes it easier to find ways to normalize the situation due to open and direct communication between the child or adolescent and caregiver
- Builds trust in relationships and improves healthy communication between parents and children when disclosure is family centered
- Allows for easier, more open access of medical care and support services
- Establishes conditions in which safe sex can be discussed Enables families to plan for the future
- Increases the caregiver's ability to get treatment support for the child or adolescent at school and during changes in care (e.g., during holidays and with relatives)
- Potentially reduces behavior problems with the child or adolescent

Possible negative consequences of non-disclosure
Disclosure of an HIV status may lead to stigmatization, discrimination, rejection of, or violence against individuals living with HIV of all ages, as well as their families and partners. The potential negative effects of disclosure may affect both the caregiver and the child or adolescent and may include

- emotional difficulties, such as sadness, anger, or rebellion;
- the child or adolescent blaming parents for infecting them (for those vertically infected);
- distress, fear, worry, and perceived or directly experienced discrimination;
- internalized stigma;
- withdrawal from peers and friends;
- fears of perceived shortened future life and of death; and
- fear about revealing sexual identity and being judged or rejected by family, partners, or community (for those horizontally infected).

Caregivers can minimize these negative effects by getting support from HCWs for the disclosure process and apply the guidance provided in the manual.

Session 1.4 General Guidelines for Disclosure

When a caregiver wants to disclose HIV status to a child, he or she can discuss the timing and method with a HCW. The HCW will assist in developing a *disclosure plan.* The objective of this plan is to outline the various steps that the caregiver will take during the disclosure. It also includes certain factors that must be considered for each child during the disclosure process.

General Guidelines for Disclosure	Individual Factors
• Choose a private location. • Plan the disclosure in advance. • Notify others that the disclosure will take place. • Tell the child who they can talk to about their status and who they should not talk to. • Disclose the information in a progressive manner (rather than all at once). • Provide follow-up support.	• Age • Maturity • Prior knowledge • Personality • Previous illnesses • Treatment status • Health of others in the family • Recent stressors

Who, When, and Where
The disclosure should be made by a person the child trusts and respects, typically the caregiver, parent, or guardian. A HCW can be used as a source of support. When a child is not close to any family member, a trusted health professional should disclose HIV status.

The appropriate timing for disclosure depends on many factors, including age, developmental stage, and family dynamics. Following the pace of the child and using a method of progressive disclosure is ideal. When children or adolescents start asking questions about themselves, their health, or regular clinic visits, explanations should be adapted to the child or adolescent's level of cognitive development and their individual feelings.

Full disclosure should occur between the ages of 6–12 years. Avoid using the words *HIV* and *AIDS* in front of a child under 6 years old. Children under 6 may not be able to understand when it is appropriate to speak about and when it is not and may not be able to keep information confidential.

Disclosure may be done within a health care facility, at home, or another safe location—the caregiver should choose what they feel is best. The caregiver can call a HCW about any urgent questions or needs.

Disclosure Steps

- Always provide information to the child in an age-appropriate manner.
- Directly address silence and secrecy.
- Encourage openness in the disclosure and treatment processes.
- Try to understand the child's perspective about current problems and the child's health. (Ask "What do you think the problem is?")
- Explore what the child knows about HIV, then move from the known to the unknown.
- Assure the child of shared confidentiality.

The following steps should be followed for the disclosure conversation with the child or adolescent:

1. Assess the child or adolescent's perceptions, concerns, and attitudes about their own health.
2. Inform the child or adolescent that they have HIV.
3. Share relevant information about HIV, such as what it does to the body and how to fight it, use age-appropriate resources.
4. Talk to the child or adolescent about the difference between HIV and AIDS.
5. Instruct the child or adolescent on how to live with the virus, what to do, and how to avoid transmitting HIV to others.
6. Discuss how to keep HIV status confidential, who to tell, and what to tell.
7. For adolescents discuss safe sex, the potential for sexual relationships, and reproductive health, including the possibility of a happy life, marriage, a relationship with an HIV-negative partner, and having healthy children.
8. Provide any further information relevant to the age, cognitive ability, and interest of the child or adolescent.
9. Give the child or adolescent time and support to ask any questions. Reassure them that they can ask questions in future.
10. At the end of the conversation, summarize (repeat) the information shared with the child or adolescent.

Post-Disclosure and Follow-Up

Children and adolescents may go through a period of denial, anger, or self-pity following disclosure of their HIV status. Caregivers should support children and adolescents throughout the post-disclosure period in the following ways:

- Assess positive outcomes (such as improved self-confidence or self-awareness) and negative outcomes (such as stigma or depression) in the child or adolescent.
- Review the child or adolescent's understanding of their HIV status.
- Encourage involvement in support groups to reduce stigmatization and victimization.
- Encourage the child or adolescent to draw on inner strength and support from caregivers, community, and friends to help change any negative self-perceptions or outlook on life.
- Educate the child about healthy living practices (e.g., personal hygiene, sexuality, self-awareness, and stress management) to encourage the child to develop a healthy lifestyle.
- Encourage drama, music, and dance, and provide play therapy when appropriate.

- Encourage the child or adolescent to always ask questions and discuss concerns and fears.
- Explore the child's hopes, ambitions, and plans for the future by asking questions and discussing wishes.

Parents, guardians, and caregivers also need support, hope, and opportunities to build self-esteem. They should be encouraged to share the burden with a close friend or treatment supporter or to join a support group or seek ongoing counseling.

Disclosure to Others

Let the child or adolescent decide if they want to tell anyone else about being HIV positive and who they want to tell. Have discussions and help them think about the different factors involved in disclosing to other people, including

- support that is available (e.g., medical, psychological, or practical) from people in the family, HCWs, or teachers;
- consequences of telling others that may not react in a positive way; and
- reactions from others and how to give a person time to take in the information.

Remind the child or adolescent that not everyone knows a lot about HIV and educating others before disclosing their status can help.

Young people who are becoming sexually active must protect others from getting the virus. Talk to the adolescent about disclosing to a potential sexual partner and educate about safer sex.

Module 2: Understanding Antiretroviral Therapy

The purpose of this module is to ensure that caregivers understand antiretroviral therapy (ART), including the different types of antiretroviral (ARV) medications, changes in ARV formulations and dosing for children as they grow, how ARVs work, treatment side effects, and the importance of adherence. Caregivers will also learn about the significance of viral load and the benefits of viral suppression.

By the end of this module, the caregiver should

1. understand ART and how ARVs work;
2. be familiar with the different types of ARV medications, the changes in formulations for children as they grow, and treatment side effects;
3. understand the importance of adherence to ARV medication; and
4. understand viral load, how it is monitored, and the benefits of undetectable viral load.

Session 2.1 ART and Its Benefits

It is important to remember that HIV-positive children do not have to feel sick. While there is not yet a cure for HIV, there are treatments that strengthen children's bodies and make them feel better, have less sickness, and live normal, healthy lives.

The standard treatment for HIV is ART, which consists of a combination of at least three ARV drugs that stop HIV from multiplying or making more copies of the virus inside a person's body. People living with HIV should take these drugs for life (or until a cure for HIV is discovered). They reduce the amount of HIV virus in the blood, referred to as the viral load (VL). Three drugs are used in order to reduce the likelihood of the virus developing resistance.

Many ARV drugs for children are available as a fixed-dose combination (two or three drugs in one tablet) or as a single drug in each tablet. The ARV dosage (the amount of the drug) is adjusted as a child grows and puts on weight. Starting ART in a child or adolescent requires proof of an initial HIV-positive test and another confirmative positive test result prior to initiation.

ART should be started soon as possible after the diagnosis of HIV infection (i.e. the positive HIV test). Taking ARV drugs every day as prescribed has many important benefits for a child or adolescent living with HIV, including the following:

1. Reducing the VL to undetectable levels as quickly and for as long as possible
2. Maintaining higher CD4 cell counts and preventing potential damage to the immune system
3. Maintaining normal physical growth and development
4. Decreasing the risk for HIV-related complications (e.g., diarrhea, tuberculosis, and mental impairment)
5. Decreasing the risk of non-opportunistic conditions (i.e., infections like cancers and heart or renal disease)
6. Minimizing side effects
7. Maintaining the same drug therapy for many years without resistance
8. Improving quality of life

Session 2.2 ARV Medications and Viral Load

HIV is a lifelong infection that requires lifelong treatment with ART. Without ART, HIV multiplies in the body and the amount of HIV (the VL) in the body increases, sometimes to millions of copies or particles. VL is measured through a blood test that estimates the amount of virus in the blood.

An *undetectable* or *lower than detectable* (LDL) measurement means that the VL has reached such a low level that it cannot be detected by standard tests, usually < 20 copies/mL. Reaching and maintaining an undetectable or LDL VL

is a key goal of ART. It is important to remember that even if a child has an undetectable VL, HIV is still present in the body. If the treatment stops, the VL can increase, affecting the child's long-term health.
A *high/unsuppressed viral load*, usually > 1000 copies/mL, could mean that ARVs are not being taken correctly or in the right dose, that doses are being skipped, or that the ARVs used are not working.

CD4 cells are white blood cells that help the body to fight off infections. CD4 cells are like the officers in an army. They fight diseases and they help ensure that other parts of the immune system are working correctly. These are the cells that the HIV virus attacks and kills. For children and adolescents with HIV that are not on ART or not taking ARVs correctly, the total number of CD4 cells gets smaller and smaller, a sign that HIV is killing the cells. Once ART is being taken correctly, the number of CD4 cells increases. The higher the CD4 count, the better the body is able to fight diseases.

Session 2.3 Types of ARV Medications

There are six main types, or *classes*, of ARV drugs. Each class attacks HIV in a different way. ART combines these drugs to ensure a powerful attack on HIV. Different types of ARV drugs work in different ways to destroy HIV and stop it from multiplying in the body, which is why the standard treatment (ART) consists of a combination of at least three ARV drugs that can effectively stop HIV from multiplying or making more copies of the HIV virus inside the body.

It is very important for caregivers to know what treatments their children are taking, including the names and dosage of the medications, how often they must be taken, and the amounts that must be taken every time. This is called the *medicine schedule*. It is also important for caregivers to know the potential side effects of each drug so that they are aware that they may occur and know what to do if they occur.

The life of a child or adolescent with HIV depends on the drugs being taken correctly and regularly, every day. If there is a break in taking the drugs, the HIV may grow resistant and the drugs will no longer work.

Only a HCW can prescribe ARV drugs or change an ART regimen. There are currently three different regimens of ART.

The *first-line regimen* is the first option recommended for treatment for all children starting ART for the first time. These drugs are the most powerful combinations capable of achieving and sustaining durable and maximal virologic suppression over a long period, if taken correctly. First-line treatment regimens are easy to take because there are fewer pills to swallow, they are readily available, and they have fewer side effects. The first-line regimen is available at clinics, hospitals, and health centers.

The *second-line regimen* is the option_recommended when the first-line regimen is not working well. Sometimes, while on a first-line regiment, the child or adolescent's drugs will be changed if VL is persistently unsuppressed and treatment failure is confirmed. The caregiver must commit to adherence as there will be more pills to give and at times, different side effects. The doctor or nurse will make the change to the second-line regimen only if necessary as it means the child will have fewer treatment options in the future. The second-line regimen is available at clinics, hospitals, and health centers.

The *third-line regimen_*is the option recommended when the second-line regimen is not working well (i.e., VL is unsuppressed and treatment failure is confirmed). Third-line treatment regimens are not easy: more pills are required, they are not readily available, they are more expensive for the Ministry of Health to buy, and they have more side effects. This regimen also required special testing to see if they are working and able to control the virus. However, children can still be on third-line treatment regimens for years if they adhere to the medication schedule without missing doses. The doctor or nurse will make this change in the ART drug regimen if necessary. The third-line regimen is only available in hospitals and health centers, and it is the last option available for HIV treatment.

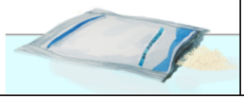
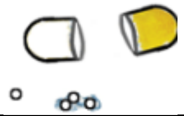
Session 2.4 Formulation Changes as Children Grow

Children may receive different combinations of medicines depending on their individual needs. It is therefore very important that a child take only the specific medicine or ART meant for them and never share with other children or adults.

ART, like other medicines, may come in any of five different forms or formulations: liquids, granules, pellets, tablets, or capsules. The ART formulation recommended is determined according to WHO guidelines and depends on the age of the infant or child and their ability to swallow.

For each ARV in the infant or child's treatment, the caregiver should know the following:

1. What the ARV looks like (i.e., liquid, granule, pellet, tablet, or capsule formulation)
2. How the ARV is given (i.e., method of administration, usually by mouth)
3. How much of the ARV should be given (i.e., volume of liquid or number of packets, tablets, or capsules)
4. How often and when the ARV is given (i.e., how many times a day and at what specific times)

Liquids/suspensions	Granules	Pellets	Tablets	Capsules
				

Liquids

Liquid formulations are an alternative formulation for infants and small children, and they usually contain one drug, which is only part of the standard three-drug regimen they will need to take. For liquid medications, it is important to do the following:

- Draw up the ARV medicine in a clean syringe or measuring cup to measure the proper volume as prescribed. The dose of ARV, and possibly the volume of liquid, depends on the weight of the infant or child and will increase as the child grows.
- Try to give the medicine to the infant or child directly from the syringe or measuring cup.
- Ensure the infant or child takes the entire amount prescribed.
- Ensure the infant or child takes the full standard three-drug regimen, which may involve also taking other liquid formulations or dispersible tablets. **It is important to give all three ARVs to the infant or child at the same time no matter how they are combined.**
- Store syrups in the original container and keep in a cool, dark, dry place (away from the sun).
- Offer the infant or child a good-tasting liquid such as breast milk (for infants) or juice, milk, or soft porridge (for children) right before and after administering the dose as they may not like the taste of the medicine.

Granules and Pellets

These formulations may contain one or two drugs, which are only part of the full ART regimen. In some cases, granules may contain the full standard three-drug ART regimen. For granule and pellet medications, it is important to do the following:

- Prepare the correct number of packets or pellet capsules as prescribed using clean bowls or cups and a small spoon. The dose of ARV, and possibly the number of packets or pellet capsules, depends on the weight of the child and will increase as the child grows.
- Shake each packet to make sure all the granules have settled to the bottom before opening it. Carefully cut or tear open the top of the first packet. Make sure your hands are dry when opening the packets or pellet capsules.
- Empty all of the granules or pellets into an empty bowl or cup. Tap the bottom of the packet or pellet capsule as it is emptied over the bowl to make sure all the granules or pellets come out.
- Pour a small amount of food (expressed breastmilk, formula, juice, soft porridge, yogurt, or soft mashed food) over the granules and put only as much in the cup or bowl that the infant or child will take entirely.

Carefully stir the mixture so the granules combine with the food. The granules will not dissolve, but they will be mixed in.

- Feed the infant or child the entire mixture.
- Ensure the infant or child takes the full standard three-drug regimen, which may involve also taking additional dispersible tablets. **It is important to give all three ARVs to the infant or child at the same time no matter how they are combined.**
- Store granules in the original container and keep in a cool, dark, dry place (away from the sun).
- Keep the medication out of reach of children.

Special Notes for Granules and Pellets

1. If the child misses a dose of LPV/r granules, give the dose as soon as possible. If it has been more than 6 hours, skip the missed dose and just give the next dose at the regular time. **Do not give two doses at the same time to make up for a missed dose**.
2. If you are unsure whether to administer the dose, call your HCW or health care facility.
3. If your child vomits or spits up within 10–15 minutes of taking a dose of LPV/r granules and the granules can be seen in the vomit, readminister a new dose of granules. If more than 10–15 minutes have passed since taking a dose and no granules can be seen, do not readminister the granules.

Tablets

Tablet formulations are recommended for all ages of infants and children and may be in *dispersible tablet* or *solid tablet* form.

Dispersible tablets (dissolve in liquid) are the most common formulation available for children and are used for children weighing as low as 3 kg. Most dispersible tablets are combination medications so that the child can take one pill that contains two or three different medicines.

Solid tablets are typically used for older children, 5 years of age or older. Small children often have difficulty swallowing solid tablets. If the child has difficulty swallowing tablets, ask the doctor, nurse, or pharmacist whether the tablets the child is given can be safely opened, crushed, or split to make swallowing easier.

Capsules

This formulation is found in the alternative first-line drug, Efavirenz. Efavirenz is only used for older children who cannot tolerate other recommended first-line drugs.

Session 2.5 Understanding Viral Load and Viral Load Monitoring

HIV is spread throughout the body and the amount of virus carried in the blood is called the *viral load*. A VL measurement is done with a blood test that measures the amount of HIV in a small amount of blood, which indicates how well ART is working.

VL is checked at regular intervals to ensure that HIV is controlled. In Eswatini, viral loads in children are monitored every 6–12 months and the tests will be scheduled by the HCW at the health care facility. When a person first begins treatment, it usually takes 3–6 months for the VL to become undetectable.

Suppressed VL

A VL of less than 1000 copies/mL is called a *suppressed viral load*. A suppressed (or low) VL means that ARVs are being taken as instructed and they are working in destroying the virus and stopping it from multiplying.

Even if the VL is currently suppressed, ARV medications must continue to be administered to keep it suppressed at all times as ARV medications do not cure HIV or eliminate it from the body. If ARVs are stopped, the virus will start multiplying again and the VL will increase.

Maintaining a suppressed VL for many years is possible; some people began taking ARV medication over 20 years ago and continue to do so.

Undetectable VL
An *undetectable* or *lower than detectable* (LDL) *viral load* means there are too few copies of the virus in the blood to be counted or detected with a standard laboratory test, which is a key goal of ART.

It does not mean HIV has been cured. It is important for children and adolescents to achieve and maintain undetectable VL since this indicates that the ARVs are working well and the immune system is working optimally.

High VL
A high or *unsuppressed viral load* of greater than 1000 copies/mL could mean that ARVs are not being taken correctly or that they are not working. In this case, the caregiver and the child will receive additional support to identify and address barriers to adherence, and to support this process, the duration between refills will be reduced to 1 month or less for 3 months.

After 3 months, the VL will be measured again to identify if the adherence support has been effective and the VL suppressed. If adherence was good but the VL was not suppressed, it would indicate that the ARVs were not working (treatment failure) and that the child had developed resistance. The child would be switched to another ART regimen to achieve suppression. Monitoring would continue as scheduled and once a suppressed VL was achieved, the child could be enrolled in a less intensive care model and given a longer duration between refills.

Session 2.6 Possible Challenges of Giving Medicines to Children

Even though ARVs are crucial for treatment, administering the medications to children and adolescents is not always easy. Caregivers should always try to maintain a calm attitude and make sure that taking drugs is presented as part of the everyday routine for the child, just like washing and eating—another way that children can help keep themselves well. Caregivers should provide age-appropriate disclosure, which may be supported by a HCW. Encourage the child from an early age to be a partner in their own health care. Some of the possible challenges caregivers may face include the child or adolescent refusing medication, hiding pills, or experiencing unpleasant side effects.

Refusing Medication
If the child or adolescent is refusing medication, explain why it is important that they take the ARV medicines regularly and do not miss a single dose. Explain that the ARV medicines do not last long in their blood, and that the HIV will start spreading again unless the amount of medicine in their blood is kept strong. The virus will also get a chance to change and become stronger if the medicine is weak.

Seeing other children take medicine is also helpful to many children. HIV support groups for mothers and small children and peer support groups for older children are very useful.

Hiding Pills
Children are very good at hiding pills they do not want to swallow. Caregivers must WATCH the child or adolescent swallow the pills to be sure they were not held in the mouth to be spit out later.

Experiencing Side Effects
Side effects are most common when a person first starts taking ART, but they usually disappear after a short while. Most of the time, side effects only last a week or so and are likely to be mild—Encourage the child or adolescent to persevere!

The most common side effects that occur in children and adolescents may include the following:

- Skin rash
- Nausea and vomiting
- Diarrhea

- Excessive tiredness and muscle pain
- Headache
- Dizziness
- Sleep disturbance or nightmares
- Excessive weight gain

Ask at the clinic or health care facility what will help with any side effects. If the side effects cause a great deal of discomfort or if they continue for more than 2 weeks, take the child back to the clinic—the doctor may decide to change one of the drugs.

Session 2.7 Teaching Children to Swallow Tablets

Different types of tablets are available for children: dispersible tablets and those that must be swallowed whole. Some young children are ready to learn to swallow tablets when they are 4–5 years old, but others are not able to swallow tablets until they are much older. The caregiver will need to observe and assess the child's readiness. Can the child follow simple directions? Can the child easily swallow when eating and drinking without choking or coughing? If the answers are yes, the child is most likely ready to begin to learn to swallow tablets.

Children can be taught to swallow pills using the following method.

1. Explain to the child that learning how to swallow tablets whole means less time taking medicine and more time for playing.
2. Stay calm and reduce stress to help your child learn more quickly. Getting angry or upset with your child while practicing swallowing tablets may make your child resistant to learning. If the child resists, that is OK! Stop practicing and try again later when your child is ready. It is important not to force your child to swallow if they are uncomfortable, upset, or having difficulty as this may cause choking.
3. Start teaching your child before tablets have been prescribed.
    a. Show the child how you swallow your own tablets. The child will gain confidence and motivation when they see how you swallow your tablets.
    b. Give the child a glass of water or a favorite drink such as milk or juice.
    c. Ask the child to take sips and swallow them using different head positions (up, down, left, and right).
    d. Ask which position makes it easier for the child to swallow.
    e. Do this at the start of every practice session.
4. Practice swallowing every day until your child swallows something that is the size of the tablet that will be prescribed.
    a. Start with something small and easy to swallow as a practice tablet, like a papaya seed.
    b. Have the child place the practice tablet under their tongue before taking a sip of water and swallowing. Some children find this an easier way to swallow a small tablet.
    c. Have the child take only a small sip of water. If the child has too much water in their mouth, it is harder to control the practice tablet.
    d. When the child is comfortable swallowing a papaya seed whole, try something just a little bit larger (e.g., a watermelon or maize seed) to slowly increase the size of the practice tablet. Only increase the size of the practice tablet once during each practice session.
    e. Practice just after you have given the child their usual ARVs.

Other methods to consider include the following:

- Play the bird game: Some children may have fun trying to swallow like a bird! Some birds put their heads back and shake them quickly, which helps them to swallow whatever they are holding in their mouths since they don't have teeth. Ask the child to pretend to be a bird by taking the practice tablet with a sip of water, putting their head back, and shaking quickly as they try to swallow.
- Use a straw: Sometimes it is easier for children to swallow tablets if they are drinking from a straw. Have the child place the practice tablet in their mouth, then sip water through the straw. By focusing on the straw, the child may not be thinking about the tablet, which may help it go down more easily.

- Use a dispersible tablet: Dispersible tablets can also be used to practice swallowing. Make sure the child takes only the prescribed number of tablets and takes the complete dose.

Module 3: Child and Adolescent Treatment Adherence

Because HIV can only be suppressed (not cured) with medication, and because ART must be continued for life once it is started, adherence to ART is a very important component of the fight against HIV and AIDS. The purpose of this module is to ensure that caregivers understand ART adherence and the effects of nonadherence.

By the end of this module, caregivers will be able to

1. define adherence,
2. understand why adherence is so important in ART,
3. understand why adherence is so difficult for children and adolescents living with HIV,
4. help teens develop individual adherence plans, and
5. identify strategies to deal with suboptimal adherence.

Session 3.1 Child and Adolescent Adherence

Adherence to ART requires the active participation of caregivers in a child or adolescent's care plan. It includes adherence to both care and treatment, and it depends on a decision-making process shared between the caregivers, child or adolescent, and HCWs. The comprehensive goal of adherence is to ensure the child achieves the **"Triple Zero": zero missed appointments, zero missed does, and zero VL.**

Adherence to Care

Adherence to care means entering into and continuing a lifelong care and treatment plan, including the following:

1. Attending appointments and tests, such as regular VL tests, as scheduled
2. Taking (or giving) medicines to prevent and treat opportunistic infections
3. Participating in ongoing health education and counseling
4. Picking up medicines when scheduled and before running out
5. Recognizing when there is a problem or a change in health and coming to the clinic for care
6. Adopting a healthy lifestyle and trying to avoid risky behaviors as much as possible

Adherence to Treatment

Adherence to treatment means the child or adolescent takes ARVs every day for the rest of their life: (1) at the **right time**, (2) in the **right way**, and (3) in the **right amount** or dosage.

- Some types of ARVs must be taken every 24 hours, or once a day. However, most ARV medicines only work for 12 hours at a time and must be taken twice a day: in the morning and in the evening. They must be taken at the same time every day. The dose schedule is designed so that there is always has a certain amount of medicine in the body.
- If the child does not take the medicine at the correct time, does not take the proper dose, takes some of the medicine but not all, or stops and starts the medicine, the drugs will stop working and the HIV in the body will increase and attack the CD4 cells and increase risk of infections.
- It is very important to take ART as instructed because HIV is a lifelong illness and the virus is constantly trying to outsmart ART.
- Missing just 1–2 doses of medication per month can lead to resistance. A virus that does not respond to a drug is called *drug-resistant*.
- Adherence is important to reduce the risk of development of drug-resistant strains of HIV. When resistance develops, different ART is needed. In most countries, there are a limited number of ART options, so it is important to maintain the effectiveness of the ART medications.
- Being adherent allows ART to work well for many years.

Adherence Counseling

- Adherence counseling provided by HCWs should identify, assess, and address practical barriers to adherence. Interventions to support adherence should be individualized to address specific barriers and HCWs should address any concerns about the need for or the administration of ART. Encourage age-appropriate and family-centered disclosure to help achieve adherence. Ways caregivers can provide support for adherence in children:

- Help children and adolescents understand why taking their medicine is so important.
- Remind them that it is not about not being sick; it is about staying healthy. Even when the child starts to look and feel stronger, they must continue taking their medicines regularly so their body remains strong.
- Regularly review children, adolescent, and caregivers' knowledge, understanding, and concerns about medicines and their benefits.
- Encourage caregivers to allow their children and adolescents to participate in teen clubs and other peer support groups, and encourage caregivers to participate in caregiver support groups.

Non-adherence

Non-adherence includes any failure to follow the care plan, including

1. missing one or more appointments at the hospital or health care center, lab, or pharmacy;
2. missing one or more doses of medicine;
3. taking medicines at the wrong times; and
4. sharing medicines with other people.

When non-adherence is identified, the HCW will discuss challenges and barriers to adherence with the caregiver and child or adolescent, which may include

- possible lack of age-appropriate disclosure,
- stigmatization and discrimination (in the home, school, etc.),
- medicine fatigue,
- socioeconomic issues or lack of finances,
- distance to facility,
- school or work schedules,
- communication barrier between health care provider and patient,
- negative or poor attitude toward care and medication, or
- multiple opportunistic infections (pill burden).

Identify Barriers	**Assess Barriers**	**Address Barriers**
Capacity barrier? Resource barrier?	Caregiver's level of comfort with the medication Caregiver's mental capacity to ensure adherence to treatment Caregiver's awareness of the risks to the child of inadequate adherence	Identify secondary caregiver Offer peer-to-peer support Set reminders Assist with disclosure Have the child share responsibility by asking for their medicine Pack additional medication in preparation for travel/holidays Keep refill appointments to ensure adequate drug supplies

Session 3.2 Adherence Plans

Children and adolescents may live with both parents, have lost at least one parent, or be orphaned. Many live with extended families and face difficulties with disclosure of their HIV-positive status or miss supportive caregivers. It is very important to identify a primary and secondary caregiver and actively involve the child or adolescent and parent or caregiver in the decision-making about the care and treatment plan. The caregiver should be educated about the benefits of ART and long-term optimal adherence and offered support.

A multidisciplinary team (MDT), including doctors, nurses, and counselors, together with the child or adolescent and caregiver, will develop an individual plan to support initiation of and adherence to treatment.

Everyone forgets to take or give medications sometimes, but forgetting to take ARVs can be dangerous. Therefore, it is a good idea for each caregiver to have a plan to ensure that they remember. This could include one or more of the following options:

1. Fitting ART into the child's (or caregiver's) daily schedule
2. Setting reminders or alarms on a cell phone or watch
3. Using daily events as reminders (e.g., meal times, radio or TV programs, the chickens coming out in the morning and going in at night)
4. Identifying someone they can trust (e.g., a family member or a friend) to help remind them
5. Using reminder charts (i.e., checking a box each time the child takes a dose, which also helps keep track of the doses given over time)

Updating Adherence Plans

A child or adolescent's experience taking ART and their needs for support in adherence may change over time. The child's progress will be regularly monitored with an individually tailored appointment schedule. Adherence will be assessed by a discussion with and self-report of the caregiver or child/adolescent at every appointment and will include monitoring of kept appointments, pill counts, and pharmacy records. These will be discussed along with the child's VL results—an indicator of how well the child is taking the medication and how well the ART is working in the body.

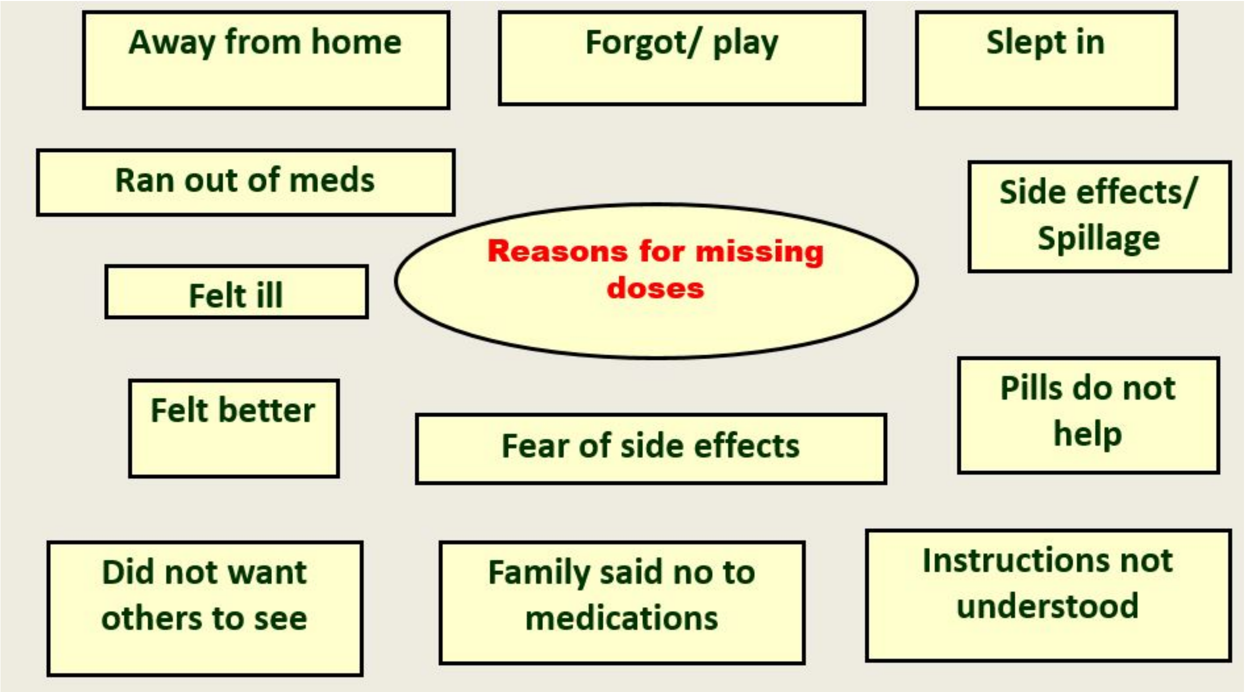
There should be at least one caregiver who is able to supervise the child and make sure that the medicines are being taken in the right way or who will administer the medicines to the child. If possible, there should be another adult or responsible person, preferably living in the same house or close by, to help with the child's ART in case the caregiver falls ill or travels.

Session 3.3 Supporting Adolescent Adherence

Adherence can be very challenging for all people, but especially for adolescents. There are many reasons for this and they are all interconnected. Often, once a child reaches the adolescent years or begins to show physical changes of puberty, they are considered "grown" and able to take care of themselves. Guardians and families often have many responsibilities, and adolescents may be left on their own to remember to take their medications once or twice a day, travel to and from a clinic for appointments, remember the dates of their appointments, and other parts of ensuring adherence. This is a big task for anyone, but even more difficult for adolescents. Caregivers need to watch out for some of these challenges to adherence and support adolescents.

Barrier	Examples	Support Strategies
Timing or forgetting the dose	Being late in the morning and rushing to get to school At a friend's house playing / sleepovers In the fields working	Structured timing of dosing (e.g., put ARVs next to their cup/bed) Establish habit of taking ARVs before eating Set alarms on a cell phone for dose times

		Enlist a treatment supporter to provide reminders
Environments with limited privacy	Social gatherings (e.g., weddings and funerals at home) with relatives unaware of HIV status, shared rooms Boarding school where rooms are shared with many other children Holidays away from home or change of caregivers	Store a few doses with a toothbrush, shower items, or in a pill box and take medicine when there is some privacy Disclosure to a staff member or peer Disclosure to new caregiver
Anger and blame	Disagreement with parents, using nonadherence as retaliation	Counseling support Disclosure and ART literacy
Grief	Poor academic performance Loss of a loved one	Counseling support
Misinformation and religious beliefs	Not taking drugs during religious fasts	Counseling support
Lack of resources	Food, transportation	Referral to a social worker Economic support



Common Reasons Given for Nonadherence

Session 3.4 Improving Child and Adolescent Adherence

Adherence can be improved by involving children and adolescents in their care; even small children can be involved in their care through play. Always begin by telling the truth.

- Tell the child or adolescent that they are going to learn a new skill. Remind them that they have learned many other skills in the past (e.g., dressing, eating, and skipping).
- Ensure that they understand why their medication is so important.
- Make them responsible for their medication with support from an adult.

- Teach them to document when they take their medication (i.e., self-reporting).
- Ensure support from appropriate adults (e.g., school teachers and the school nurse).
- Do not bargain or bribe the child or adolescent to take medication. Bargains or bribes will likely cause the child to take medication to earn a reward rather than because it is a habit, an expected part of growing up, and good for their health.
- Do not hide medications in food or otherwise try to trick the child.
- Do not threaten or punish.

To have good adherence, children and adolescents need to have the correct information about why we take medicines, attend appointments, and monitor VL. All children or adolescents living with HIV should always remember to take their ARV treatments and caregivers must help teach them how to take medications and how to remember what to do.

Module 4: Stigmatization and Discrimination

Stigmatization affects an individual's sense of self-worth and self-esteem, ability to seek emotional and psychosocial support through disclosure to others, confidence to adhere to treatment at school or in the workplace, and willingness to seek health services on a continual basis. Stigmatization can be directed at another person or directed internally through the judgments of others. Understanding and learning how to deal with stigmatization is one of the skills that children and adolescents living with HIV will require as they move into adulthood.

The purpose of this module is to ensure that caregivers understand the meaning of stigmatization and discrimination among people living with HIV (PLHIV) as well as the reasons for, different types of, and effects and impacts of stigmatization among adolescents and young people. Caregivers will also learn how to assist children and adolescents in coping with stigmatization.

By the end of this module, the caregiver should know

1. what stigmatization and discrimination are,
2. why people stigmatize and discriminate against people living with HIV/AIDS,
3. what the different types of stigmatization are,
4. what the potential effects and impacts of stigmatization and discrimination are,
5. how to respond to and reduce stigma and discrimination, and
6. how to assist adolescents in coping with stigmatization and discrimination.

Session 4.1 Understanding Stigmatization and Discrimination

Stigma is a mark of shame or discredit and *stigmatization* is the attitude, belief, or judgment of unfavorable characteristics directed toward someone or something. Stigmatization is an attitude of severe social disapproval of a person or personal characteristics or beliefs that are against cultural norms.

Discrimination is the treatment of an individual or group with partiality or prejudice. Discrimination is the act or behavior of treating or considering a person differently because that person belongs to a certain group, class, or category rather than on individual characteristics (e.g., racial and religious intolerance).

HIV/AIDS-related stigmatization is the judgment, labeling, or categorization of an individual because of their HIV status, either as personally unfavorable or as being part of a group considered socially unacceptable. This kind of stigmatization is often associated with lack of knowledge about HIV.

Session 4.2 Why People Living with HIV/AIDS Are Stigmatized

Individuals with HIV and AIDS are often stigmatized because HIV and AIDS are not well understood by the community or viewed negatively by health care providers. Others often believe their illness to be one or more of the following:

- associated with deviant behavior,
- the fault of the individual,
- the result of immorality (a view often based on religious beliefs) or contracted via immoral behavior and thus a character fault,
- contagious and threatening to the community, or
- likely to result in an undesirable and unpleasant death.

Session 4.3 Types of Stigmatization

Stigmatization can be experienced internally, directed externally, or extended to those associated with people living with HIV/AIDS..

Self-directed or *internal stigmatization* is when people living with HIV experience negative feelings or judgments toward themselves. Internalizing public perceptions about people living with HIV can result in self-hatred, shame, and blame. People living with HIV may also impose their own stigmatizing beliefs on themselves. Self-stigmatizing individuals may practice self-isolating behavior, including hiding any illness, avoiding the company of friends or family, missing work, passing on family gatherings, and avoiding HIV services or support groups they are referred to.

External stigmatization refers to negative attitudes, perceptions, or feelings that people have toward those living HIV, including anger or fear. Believing that HIV-positive people should be isolated or separated from others or deserve poor treatment, exclusion, retribution, or harm and expressing these negative attitudes or beliefs leads to discrimination or *enacted stigmatization*. Enacted stigmatization is any action directed toward people living with HIV including name calling, insulting, gossiping, and rumor mongering. Enacted stigmatization may include exclusion from responsibilities, social gatherings, or family matters; victimization; unfair treatment; refusal to offer treatment, care, or support; HIV testing without consent; and disregard for confidentiality in health care settings.

Associative stigmatization is directed toward the family and friends of people living with HIV. Examples of associative stigmatization include forbidding one's children from visiting or associating with the children of HIV-positive parents; refusing to buy food from vendors perceived as being HIV positive; avoiding sharing cups, clothing, or other items with HIV-positive individuals for fear of getting infected; associating illnesses such as coughs or skin problems with HIV and AIDS; or refusing to visit certain health care facilities known to treat HIV.

Session 4.4 Effects of Stigmatization

Stigmatization has significant effects on individual, interpersonal, and community levels.

Individual Effects

Stigmatization of HIV is often a response to social norms and marginalizes people living with HIV on an individual level. When constantly faced with stigmatization, children and adolescents may lose their self-confidence and fail to develop to their full potential. The effects of stigmatization mean that individuals living with HIV may experience the the following:

- *Fear or discomfort about disclosure:* Children and adolescents may worry that people around them will notice their HIV medications, ask about evident side effects, or see them visiting HIV or sexual health clinics, which may lead to refusal to take medication. Sometimes HIV status is assumed to be related to a stigmatized behavior (e.g., same-sex contact or intravenous drug use), which can add to fear and discomfort about disclosing HIV status (see Module 1).
- *Desire to postpone lifelong identification with HIV:* Many adolescents are reluctant to face their HIV status or fear accessing HIV services and may avoid testing, neglect treatment, or disengage in care. This can have an impact at multiple points of the HIV care continuum.
- *Low self-esteem and depression:* Stigmatization and the stress it causes may lead to feelings of low self-worth and be damaging to the mental health and overall well-being of adolescents. The child or adolescent may refuse to play with others, be reluctant to go to school, or not perform well at school. Deter children and adolescents Living with HIV from adopting risk-reduction practices that may label them as HIV-infected
- *Experiences of discrimination:* Some teachers, medical staff, church leaders, politicians, counselors, guardians, and others who are meant to be leaders in an adolescents's life may show biasness toward adolescents living with HIV or suspected to have HIV. This may result inthem missing opportunities for education, good jobs, or travel, or even be denied basic human rights such as food and shelter.

Interpersonal Effects

Stigmatization may also influence the child's and adolescents' relationships with partners, friends, and family and community members. Stigmatized adolescents may experience the following :

- *Judgment from others related to disclosure or status:* Family, friends, partners and others (e.g., teachers, employers, colleagues, and community members) may express beliefs or use language that is stigmatizing. The bias may be explicit (the person is aware of their judgments) or implicit (the person may not be aware of their bias) but influences their actions.

- *eRejection*: After disclosing their status or discussing HIV with past or potential partners, adolescents may face rejection or other negative reactions. Children may be rejected by play mates or bullied.
- *Inadequate social support networks:* Peers and families may distance themselves from adolescents living or perceived to be living with HIV in order to avoid experiencing associative stigmatization. Adolescents could internalize this abandonment and avoid seeking support.

Community Effects

Stigmatization at the community level can affect children and adolescents through social and cultural influences and in terms of the availability of resources. Associative stigmatization is also directed toward family and friends of PLHIV.

- *Social isolation:* People in the community may forbid their children from visiting or associating with the children of people living with HIV, refuse to buy food from vendors perceived as being HIV positive, and avoid sharing cups, clothing, and other items for fear of getting infected.
- *Internalized cultural norms and traditions*: Social stigmatization can be intensified by attention being further drawn to an adolescent's sexuality, gender identity, ethnicity, class, and culture. Traditional community norms, cultural and social standards, and gender roles can contribute to reinforcing the stigmatization of HIV and contribute to adolescents internalizing it.
- *Limited access to HIV services*: Many schools, businesses, detention facilities, churches, and other community organizations may not integrate discussion of HIV treatment or prevention into their practices, a silence that can contribute to HIV stigmatization. Other organizations may address HIV and sexual health but not offer full services. This can lead to fewer HIV prevention services being made available to youth.

Session 4.5 Reducing and Coping with Stigmatization

Stigmatization and discrimination are real and serious problems. Children, adolescents, and men and women are stigmatized by society in different ways, but caregivers play a key role in fighting stigmatization and discrimination. Caregivers can help support children and adolescents facing any form of stigmatization to deal with and develop ways to cope with it. Disclosure is one of the key strategies in fighting stigmatization and discrimination, along with education and support services.

A number of factors contribute to the development of stigmatization and discrimination, including the following:

- Inadequate knowledge about stigmatization and discrimination across all sectors
- Insufficient access to crisis centers for people living with HIV to find help for suicidal thoughts, depression, and other negative feelings that result from stigmatization and discrimination
- Lack of support from partners and the general population for the disclosure of HIV statuses of parents to children
- Weak follow-up systems for the provision of ongoing counseling
- Limited awareness about HIV and AIDS treatments, support systems, and the importance of wellness for people living with HIV
- Inadequate in-depth knowledge about HIV and AIDS, resulting in the spread of myths and misconceptions about its transmission
- Poor packaging of HIV and AIDS messages, resulting in fear and hopelessness
- No integration of health care services for HIV and AIDS (such as voluntary counseling and testing, ART, and prevention of mother-to-child transmission) into general health services
- Common assumption that an HIV infection means death

Caregivers and others can fight stigmatization and discrimination and support children and adolescents facing them on individual, interpersonal, and community levels.

On an individual level, caregivers should try to do the following for children and adolescents needing support:

1. **Empower** them to understand their rights and actions that violate them.
2. **Educate** them to address fears and change attitudes.

3. **Build self-esteem** by using youth development principles and leadership training focusing on assets and strengths instead of problems.
4. **Show them support** by being engaged, listening to them, and talking to them.
5. **Help them believe in themselves** by creating chances for success in everyday life. Children and adolescents rise to expectations—let them know the expectation is for them to perform to the best of their abilities.
6. **Be attentive and observant** to what they say, notice small changes in their behavior and attitudes or their interactions with other teens that may be a sign of changes in their lives, and point out good things they are doing.
7. **Encourage seeking knowledge and tools** to stay educated about HIV prevention, transmission, and care.
8. **Be honest** and never lie. It is OK to say you do not know the answer to a question and it is important to share with them in a way that makes you comfortable, but adolescents want accurate information and they want to know that you can be trusted.
9. **Be empathetic,** try to understand what it's like to walk in their shoes, and share the thoughts and feelings they might be having.

On an interpersonal level, caregivers and others can do the following:

1. **Foster social support networks** by encouraging children and adolescents to join together to challenge stigma and discrimination. Peer support groups can help protect against stigmatization.
2. **Encourage peer and family acceptance** and promote the use of language regarding HIV that is appropriate, factual, and inoffensive.
3. **Educate** those connected with children and adolescents about HIV transmission, care, and testing. Education is essential to reducing stigmatization. Help children and adolescents living with HIV learn and practice life skills in communication, negotiation, conflict resolution, and decision making, which will empower them to challenge HIV/AIDS-related stigma and discrimination.

At the community level, caregivers and others can do the following:

1. **Increase knowledge** about issues faced by children and adolescents living with HIV, such as domestic violence, which is especially prevalent against newly diagnosed women. Communicate through community leaders that violence against women is inappropriate, immoral, and illegal.
2. **Encourage leaders** to make the schools, churches, workplaces etc HIV-friendly.
3. **Educate the community about HIV interventions** including ART and safer infant-feeding practices, stressing the importance of community and family support in HIV initiatives.
4. **Identify peer leaders** and train them on HIV education, prevention, and support programs.
5. **Secure involvement of community members** with adolescents living with HIV in organizing, developing and delivering HIV education, prevention, and support programs.

Module 5: Child Abuse and Child Protection

All children (persons under the age of 18) have equal rights to protection from harm and everyone has a responsibility to protect children, particularly families and caregivers. Eswatini's Children's Protection and Welfare Act of 2012 protects children from abuse and seeks to promote their welfare with comprehensive protective legislation.

Parents and caregivers offer children love, acceptance, appreciation, encouragement, guidance, and protection as they grow and develop their personalities and identities and as they mature physically, cognitively, emotionally, and socially. Child abuse means inflicting harm or failing to act to prevent harm to a child.

The purpose of this module is to ensure that caregivers understand the importance of child protection and how to prevent and report child abuse.

By the end of this module, caregivers will know

1. the importance of child protection,
2. how to identify violations or abuse of children and how to handle them, and
3. what institutions deal with child protection issues.

Any suspected case of child abuse should be reported as soon as possible to the nearest health care facility, social worker, or the police.

Session 5.1 Child Abuse

What a child sees, hears, thinks, and experiences on a daily basis impacts their personal development and welfare, both physically and emotionally. Protecting children from harm is crucial for proper growth and development.

Individuals and families respond differently to difficult situations, and one environment might become abusive while another does not. Sometimes, economic stresses like unemployment, challenges coping with family responsibilities, or pressures of the workplace create problems with which some individuals and families cannot cope. Lack of social support (especially for women and children) can increase the overall pressure of raising children and lead to inadequate and poor care. On occasion, poor or inadequate care becomes abuse.

Child abuse is inflicting harm or failing to act to prevent harm to a child.

Children may experience abuse in a family, an institution, a community or faith setting, or via social media or the internet. Children may be abused by an adult or adults or another child or children.

Session 5.2 Types of Child Abuse

Any infliction of harm or failure to act to prevent harm constitutes abuse, but there are various types, including physical abuse, sexual abuse, sexual exploitation, neglect or negligent treatment, and commercial exploitation.

- *Physical abuse* is actual or potential physical harm (e.g., hitting, shaking, poisoning, drowning, or burning) perpetrated by another person, adult or child. Physical harm may also be caused when a parent or caregiver pretends or lies about a child having symptoms of an illness or deliberately induces illness in a child.
- *Sexual abuse* involves forcing or enticing a child to take part in sexual activities they do not fully understand or have little or no choice about consenting to, including rape, oral sex, penetration, or non-penetrative acts such as masturbation, kissing, rubbing, or touching. It may also include exposing children to or using them in producing sexual images, watching sexual activities, and being encouraged to behave in sexually inappropriate ways.

- *Emotional Abuse:* persistent emotional maltreatment that impacts on a child's emotional development. Emotionally abusive acts include restriction of movement, degrading, humiliating, bullying (including cyber bullying), and threatening, scaring, discriminating, ridiculing or other non-physical forms of hostile or rejecting treatment.
- *Sexual exploitation* is a form of sexual abuse that involves children being engaged in any sexual activity in exchange for money, gifts, food, accommodation, affection, status, or anything else. It usually involves a child being manipulated or coerced, which may or may not involve the perpetrator befriending, gaining the trust of, or giving the child drugs or alcohol. This form of abuse can be misunderstood by children and adults as consensual but it is not.
- *Neglect or negligent treatment* is a persistent failure to meet a child's basic physical and psychological needs, or both, which is likely to result in the serious impairment of a child's healthy physical, spiritual, moral, and mental development. This can include
  - failure to properly supervise and protect children from harm and provide nutrition, shelter, and safe living or working conditions,
  - maternal neglect during pregnancy as a result of drug or alcohol misuse, and
  - neglect or ill treatment of a disabled child.
- *Commercial exploitation* involves exploiting a child in work or other activities for the benefit of others and to the detriment of the child's physical or mental health, education, moral, or social-emotional development.

Session 5.3 Recognizing Child Abuse

Caregivers should be watchful for any signs of child abuse. Any changes in a child, including a decline in school performance, could be an indicator of abuse. The following are more specific indicators:

- Children who are physically abused may have unexplained bruises, injuries or flinch when approached.
- Children having trouble talking or eating or who are behaving in extreme ways may be experiencing emotional abuse. Young children may exhibit delays in overall development.
- Neglected children are often absent from school due to a lack of adult supervision, sickness, or other reasons; may have poor hygiene; and may often be hungry.
- Children who are sexually abused may have bruising on the genital area or breasts. They may also have sexually transmitted infections or become pregnant. They may walk oddly, behave in a sexually suggestive manner, or overreact to situations.

Session 5.4 Child Protection

Children can protect themselves and each other by doing the following:

- Learning about their rights and about abuse
- Reporting cases of abuse to parents, guardians, older siblings, schoolmates, the police, the chief, relatives, neighbors, school authorities, religious leaders, legal aid organizations, or social workers
- Identifying vulnerable children in their midst and helping them find individuals or institutions that can help
- Attending and participating in forums held to discuss the rights of children (e.g., support groups)

Every caregiver has a responsibility to support the protection and prevent the abuse of children. To do this, caregivers have a responsibility to not engage in or allow any abusive behavior, create good relationships so children feel safe confiding, and teach children

- what abuse is and how to protect themselves,
- the difference between appropriate touch and inappropriate touch,
- what to do if someone tries to abuse them (e.g., scream, run away, kick and bite, etc.), and
- what to do if they have been abused.

In addition, caregivers should remove children from situations in which they are likely to be abused and educate communities on how to intervene with community members who are likely to perpetuate abuse.

Parents and guardians have a duty to ensure children are kept safe from all forms of abuse.

Caregivers have a duty to teach children how to protect themselves from abuse.

Children have a duty to report any abuse perpetrated on them or other children.

Module 6: Sexual and Reproductive Health and Family Planning

The purpose of this module is to ensure that caregivers understand the importance of contraceptive use among adolescents living with HIV and to empower them to provide support to adolescents in issues relating to sexual and reproductive health.

By the end of this module, caregivers will be able to

1. reflect on their own attitudes, values, and beliefs about adolescent sexuality and discuss how these may affect their relationships with adolescents;
2. understand adolescent sexual development and sexuality;
3. define unsafe sex and safer sex and discuss how to empower adolescents to practice safer sex; and
4. encourage adolescents to seek sexual and reproductive health care, including contraception and sexually transmitted infection (STI) screening and treatment.

Session 6.1 Attitudes, Values, and Beliefs About Adolescent Sexuality

Caregivers should reflect on their own attitudes, values, and beliefs about adolescent sexuality and how these may affect their relationships with adolescents. Caregivers should consider some of their own experiences talking about puberty, adolescent sexual and reproductive health (SRH), contraception, and myths regarding contraception.

Caregivers should consider whether they already discuss sexual and reproductive health (e.g., safer sex, contraception, etc.) with adolescents or rely on schools to provide information. The SRH topics for discussion, the reasons they are often avoided, and the importance of integrating SRH services into HIV care and treatment services for adolescents are all important considerations.

Sexuality emerges during adolescence, which is the period when sexual activity typically begins. An important part of adolescent HIV care and treatment is assessing and responding to the SRH needs of adolescents. Caregivers should

- assume that adolescent clients already are sexually active (or will become sexually active at some point in the future);
- be comfortable talking about sexuality and SRH with adolescents living with HIV;
- be able to offer nonjudgmental sexual education and SRH counseling and services; and
- be knowledgeable about the common SRH issues adolescents face and the SRH services and information adolescents need.

Session 6.2 Adolescent Sexuality

It is very important for caregivers to be comfortable talking about sex and reproduction with adolescents; to be knowledgeable about sex, sexuality, sexual orientation, and sexual identity; and to be able to identify potential effects of HIV on sexuality among adolescents.

Sexual Development and Sexuality

Sexuality means more than just sexual acts and sexual feelings—it includes all the feelings, thoughts, and behaviors of a sexual being, including feelings of attraction or being attractive, being in love, and being in relationships that include sexual intimacy and physical sexual activity.

Sexuality is an important part of who we are throughout life and is a component of the total expression of who we are as human beings. Our sexuality emerges in adolescence and is constantly evolving as we grow and develop—there are many different types and expressions of sexuality. It can take time to figure out the sexuality that fits us best. There is no right or wrong, just what is right for each individual.

Sexual Orientation

The physiological attributes that identify a person as male or female (e.g., genital organs, predominant hormones, ability to produce sperm or ova, ability to give birth, etc.) determine a person's *sex*. A person's *gender* refers to either of two divisions, female or male, by which most people are classified on the basis of their reproductive organs and functions. Gender can also refer to widely shared ideas and norms about women and men, including common cultural beliefs about what characteristics and behaviors are feminine or masculine.

Sexual orientation refers to a person's sexual preference or interest and can vary widely. Sexual orientation is often described in one of the following categories:

- **Heterosexual:** a person attracted to people of the opposite sex
- **Homosexual:** a person attracted to people of the same sex
- **Bisexual:** a person attracted to people of both sexes
- **Transgender:** a person who identifies as a gender not aligned with their anatomical sex (for example, an anatomically male person identifying as a female)

Adolescent Sexuality

Adolescence is a time of sexual experimentation and defining one's sexual identity. When approaching and during puberty, adolescents become preoccupied with their developing bodies and body image. They begin to wonder and worry about their level of sexual attractiveness. Adolescents compare their bodies to those of their peers of the same sex and often have an intense need to fit in. Not fitting in can be very traumatic for adolescents, especially when it involves differences in appearance.

Differences in sexual orientation can also be a source of fear and worry. Adolescents who are not heterosexual are particularly vulnerable because they often experience profound isolation and fear of discovery. Caregivers need to be able to accept the sexuality of adolescents and offer nonjudgmental sexual education. Some caregivers have a hard time accepting an adolescent's sexuality, especially if they identify as lesbian, gay, bisexual, or transgender (LGBT). Caregivers need to understand that adolescents who identify as LGBT have an increased risk of depression, anxiety, substance abuse, self-harming, and suicidal thoughts as they come to terms with their sexuality and that they may experience victimization and bullying at school.

Effects of HIV on the Sexuality of Adolescents Living with HIV

HIV affects everyone differently depending on how long a person has been infected, how others respond to their diagnosis, their level of self-esteem, and many other factors. An important part of adolescent HIV care and treatment is assessing and responding to the specific SRH needs of adolescents living with HIV. Adolescents living with HIV may have the following:

- have lower self-esteem than their peers;
- increased anxiety about their sexuality, sexual relationships, and SRH;
- concerns about whether or how they can have sexually intimate relationships;
- fears related to disclosing their status to sexual partners and the possibility of transmitting HIV to them;
- concerns and questions about being able to have safe sexual relationships and, in the future, children;
- delays in puberty or slower growth and development than their HIV-uninfected peers (especially those who were perinatally infected and those who went a long time without HIV treatment);
- illnesses, conditions, and drug side effects that may affect the way they look and their body image and self-esteem (e.g., lipodystrophy, wasting, skin conditions, stunting, and short stature); and

- unresolved issues from trauma related to abuse (if they acquired HIV through sexual abuse).

Session 6.3 Unsafe Sex and Safer Sex

Unsafe Sex

HIV is mainly spread to adolescents and adults through *unsafe sex*. Unsafe sex is any kind of sexual activity that puts a person or a person's sexual partners at risk of getting an STI, including HIV, or having unwanted pregnancy. Adolescents engage in unsafe sex due to ignorance, coercion, fear, embarrassment, peer pressure, misinformation or lack of knowledge about available family planning options, and lack of access to adolescent-friendly contraceptive services.

Some adolescents acquire HIV, or are at risk of acquiring HIV, because of sexual abuse. Although sexual abuse often includes unsafe sex, this is not something that the victim has control over. When discussing sexual abuse with adolescents, the focus of the discussion must be on stopping the abuse, counseling the victim, identifying ways to support healing, possibly punishing the perpetrator and clinical care including STI screening and treatment, pregnancy prevention.

Sexual Abuse and Gender-Based Violence

Sexual abuse and sexual and gender-based violence (SGBV) are problems throughout the world, and many victims are adolescents. When the perpetrator is an adult, it is considered child abuse as well as sexual assault. The most frequent victims of coerced sex are adolescent girls. Sexual abuse can happen inside or outside the home; it can be perpetrated by a partner, family member, family friend, or stranger. It can also include domestic violence.

Caregivers should teach adolescents that it is a basic human right to grow up and live in an environment that is safe and free of physical and sexual violence. Violence should never be considered a normal part of everyday life or a family secret.

Recognizing sexual abuse can be difficult. When adolescents report that they are being or have been sexually abused, there is a high probability that they are telling the truth and caregivers should take this seriously. Following sexual assault, a comprehensive package of SGBV services is needed to address the acute medical needs of the victim. This includes the following:

- HIV testing and post exposure prophylaxis (PEP) following national guidelines (unnecessary if the adolescent is already known to be HIV-infected and on ART)
- A medical examination that includes the collection of forensic evidence and an assessment for STIs
- Medical treatment
- Pregnancy testing and emergency contraception (for females)
- Counseling and support from caregivers and HCWs
- A temporary place to stay, if needed for safety
- Contact with the police for an investigation of the assault

Risky Sexual Behavior

HIV is transmitted from one person to another through four body fluids: semen, vaginal secretions, blood, and breast milk. Sexual activities that present a high risk of transmission are those during which one or more of these body fluids are exchanged. Some of the highest-risk sexual activities are unprotected anal or vaginal sex (i.e., no male or female condom use).

Safer Sex

Honest, factual discussions about sex and sexuality can provide adolescents with the information they need to protect themselves and their partners from STIs and unplanned pregnancy. *Safer sex* refers to a range of methods that protect against HIV (or HIV reinfection), other STIs, and unplanned pregnancy.

Safer sex involves choosing sexual practices and protection methods that prevent body fluids from passing from one person to another. Safer sex reduces the risk of transmitting HIV without reducing intimacy or pleasure. Because ARVs reduce the amount of HIV in body fluids, safer sex includes maintaining excellent adherence to ART.

Dual protection means preventing STIs (including HIV) and unplanned pregnancy at the same time. This practice includes using male or female condoms to protect against STIs and a second method (often a hormonal birth control method) to protect against unplanned pregnancy. Dual protection is a very reliable method.

Caregivers should be comfortable having open conversations with adolescents about family planning and protection methods including

- abstinence;
- barrier methods like male and female condoms;
- hormonal methods like the oral contraceptive pill, emergency contraceptive pill, contraceptive implant, and hormonal contraceptive injections; and
- nonhormonal methods like the nonhormonal intrauterine device.

Session 6.4 Sexual Risk Screening and Risk-Reduction Counseling

Caregivers should start having discussions about sexual risk with adolescents living with HIV before the adolescents become sexually active. A *sexual risk screening* is a discussion that includes respectful questions to help the caregiver assess if the adolescent is sexually active and, if so, with whom and what risks they are taking. Sexual risk screening should build trust with adolescents and caregivers should be sure to

- address sexuality with adolescents before they become sexually active;
- begin discussions with safer topics, such as the physical changes of puberty;
- educate them about what to expect in terms of sexual, physical, emotional, and social development during puberty and adolescence; and
- explain what information can and cannot be kept confidential, emphasizing that HCWs will protect confidentiality unless there is an emergency or a health risk that requires intervention.

Caregivers should be sure to use good communication and counseling skills and focus conversations on sexual behavior, rather than sexual identity. If a discussion is awkward, respect the adolescent’s cues that further talk is unwanted and continue at another time. To increase the effectiveness of the discussion, avoid the following:

- making assumptions about the adolescent, including about their knowledge, behavior, or sexual orientation;
- using any labels not first used by the adolescent; and
- angry, self-righteous, or judgmental outbursts or language.

Risk-reduction counseling focuses on open, nonjudgmental discussions focused on reducing an adolescent’s risk of HIV, other STIs, and unplanned pregnancy by helping them choose a strategy that is right for them. Strategies can include abstinence, delaying sexual activity, reducing the number of sexual partners, and condom and contraceptive use. Caregivers should counsel adolescents about early treatment of STIs and the importance of adherence to ART.

Module 7: Loss, Grief, and Bereavement

From the beginning of their lives, children have the capacity to observe the world around them. They observe many things that they cannot name. They may sense the cycle of life and death but not yet have words for it. They may sense that there are forbidden subjects that are not talked about. As children get older, they begin to realize that they themselves will die. They learn that people grow old and die but they may not know how to acknowledge and deal with their grief and what the loss means to them.

By the end of this module, caregivers will understand

1. loss, grief, and bereavement;
2. how to prepare children and adolescents for the loss of a loved one; and
3. how to help children and adolescents grieve and cope with loss.

Session 7.1 Understanding Loss, Grief, and Bereavement

Loss is the experience of separation from something or someone of personal importance. Separation from loved ones or treasured possessions can create unwanted change in a familiar pattern of existence.

Grief is the normal reaction to a loss. The type of grief relates to the experience of loss, and may be any of the following:

- **Anticipatory:** when death or loss is inevitable and bonds are slowly changed, creating anxiety, dread, and sadness
- **Reactionary:** occurring soon after death or loss or experienced by a seriously ill patient
- **Delayed:** postponed or put off, but later can be triggered by an event or another loss
- **Aborted:** inhibited or stuck

Grief is usually experienced in a series of five stages:

1. **Denial:** “This can’t be happening to me.”
2. **Anger:** “*Why* is this happening? Who is to blame?”
3. **Bargaining:** “Make this not happen, and in return I will …” (bargains often made with God, self, or others)
4. **Depression:** “I’m too sad to do anything.”
5. **Acceptance:** “I’m at peace with what is going to happen or has happened.”

The psychological process (or stages of grief) through which an individual passes on the way to successful adaptation to the loss of a valued object or person is called the process of *mourning*. This period of grief and mourning after a death or loss is called *bereavement*.

Session 7.2 Helping Children and Adolescents with Loss

Many children and adolescents have other family members and friends who are also HIV positive. It is important to talk to the child or adolescent when they are going to lose a loved one and to speak openly about the loved one once they have died. While families and caregivers may not want to express sadness in front of the child or adolescent, it is important to talk about the loss in a manner that makes the child or adolescent feel that they can express their emotions openly.

Caregivers can help support a child or adolescent through the grieving process in the following ways.

- Answer questions honestly about what is happening to an ill loved one.

- Identify support systems early in the process and encourage regular communication with them. Support systems may include friends, teachers, neighbors, or other family members.
- Talk about changes early. If they will experience a change in living situation or a change of their role in the family—such as caring for their siblings—talk about this early in the process to help prepare them.
- Make a memory book together to help them remember the loved one. Health or community care providers can provide a memory book for you to complete.
- Encourage them to express emotions and needs concerning the death or loss, such as speaking with the loved one prior to their passing or helping to plan or attending the funeral.

After a Loss

Important steps for caregivers to take after a loss has occurred including the following:

- Understand that each person expresses and experiences grief differently.
- Understand their own grief and establish healthy coping mechanisms like talking about the loved one who died, attending a support group, and taking good care of themself.
- Return to daily living activities as soon as possible to provide the child or adolescent with a regular routine, including eating meals together.
- Tell the child or adolescent's teachers about the loss so they can make sure the adolescent is adjusting in a healthy manner and be sensitive to their needs while at school.
- Provide reassurance to the adolescent that despite the loss of the loved one, they will still be cared for and that the family will remain together whenever possible.
- Encourage positive living choices whenever possible. This includes finding healthy ways to manage stress, eating well, exercising, and meetings with friends and other loved ones. Ask the child or adolescent's health and community care providers to provide additional information on positive living.
- Encourage the adolescent to participate in activities that he or she enjoys such as sports and other fun events.
- Speak with the child's or adolescent's health and community care providers about counseling services to further assist in managing the adolescent's grief. Consider contacting other community resources for additional support.

Session 7.3 Grief Assessment

It is very important to talk to children and adolescents about changes in their lives. When a loss occurs, assessing grief symptoms will be important to help understand how the adolescent is adjusting to the loss. However, sometimes a child or adolescent may experience the grief more profoundly when questioned, and caregivers must be mindful of the risk of retraumatizing a grieving child or adolescent when assessing grief.

Allow the child or adolescent to guide discussions about any grief they may be experiencing. Caregiver should seek available support including counselling. if they need additional emotional assistance.

Caregivers can ask the following questions in a non confrontational way that facilitates open responses from the child or adolescent. Questions may need to be asked in different ways or reworded to obtain the required information, but should include the following:

- How often do you think about the death of your loved one?
- Do you ever feel angry when you think about their death?
- Is it still hard for you to believe your loved one is really dead (or gone)?
- How has your faith changed since the death of your loved one?
- Have you have lost confidence in people since the death of your loved one?
- Since the death of your loved one, do you ever feel like life is meaningless?

Signs of Loss and Grief

Emotional	Behavioral	Cognitive	Physical
Sadness Helplessness Loneliness Relief Yearning Anxiety Shock Anger Freedom	Social withdrawal Searching and calling out Sleep and appetite disturbances Avoiding reminders of the deceased Dreaming of the deceased Carrying things belonging to the deceased Crying and sighing Wearing clothing belonging to the deceased	Disbelief Preoccupation Confusion Hallucinations Denial Sensing the presence of the deceased	Hollow stomach Lack of energy Chest tightness Dry mouth Breathlessness Oversensitivity to noise Feelings of panic Depersonalization Muscle weakness

Session 7.4 Supporting Grieving Children and Adolescents

During a period of loss, children and adolescents may experience a wide range of emotions including shock, anger, disbelief, depression, hopelessness, and helplessness. The range of possible emotions is broad and not everyone experiences every emotion or stage or grief in the same sequence. Many factors influence the grieving process in children and adolescents, including

- age, cognitive ability, and developmental level;
- personality and emotional maturity;
- gender;
- communication patterns in the family;
- amount and kind of social support available;
- cultural and religious beliefs and practices;
- relationship with the person that died;
- nature of the death; and
- previous life experiences.

It is important for family members or caregivers of children and adolescents to maintain communication with each other and attempt to share feelings with each other and with other members of their support system like pastors, friends, and neighbors. Counseling can be very important during this period.

To best support children and adolescents grieving a loss, a caregiver should always try to do the following:

- **Be a good observer.** A child or adolescent's behavior can be very indicative of their emotions. Communicate with other family members to ensure that everyone understands what the child or adolescent is going through. Monitor how they are progressing.

- **Be a good listener.** What grieving children and adolescents need most is for someone to listen to and understand them—not to talk at them. Instead of worrying about what to say, try to create opportunities for the adolescent to talk about their loss. Listen for underlying feelings that they are expressing. Children may not have the vocabulary to express clearly what they are feeling. Don't rush with explanations—it can be helpful to ask exploratory questions rather than supply set answers.
- **Be patient.** Grief is not always expressed or experienced in typical or obvious ways. Grief may come and go.
- **Be honest.** Use simple and direct language. Share accurate information and correct terminology. For example, death is death, not sleeping. Say "I don't know" when you don't know an answer.
- **Be flexible.** Maintain routines and boundaries, yet provide flexibility around homework, assignments, and responsibilities.
- **Be available.** Children need to know that they can count on the adults in their lives to listen to and support them. When children want to talk, give them your undivided attention. This will let them know that you value what they say and that their grieving is important.
- **Be aware of your own feelings**. Speak to other colleagues and people who can provide support.

Module 8: Adolescent Transition to Adult Care

Transition is the purposeful, planned movement of adolescents and young adults with chronic medical conditions from child-centered to adult-oriented care systems. Transition to adult care typically occurs between 18–24 years of age, but early preparation for transition occurs from 10–19 years of age. The process of transition involves multiple participants and supporters, including the child or adolescent, caregivers, various health care providers, partners, peers, and others. The goal is to ensure the provision of uninterrupted, coordinated, developmentally and age-appropriate comprehensive care before, during, and after the transition to ensure optimal treatment, virological suppression, and retention in care.

By the end of this module, caregivers will understand

1. what adolescent transition to adult care means,
2. the benefits of transition, and
3. how to support adolescents in their transition to adult care.

Session 8.1 Adolescent Experience

For adolescents, transitioning to adult care means that they

- will take more responsibility for their care, treatment, and support;
- must be prepared to become independent and manage their own condition;
- are coming of age and taking responsibility for their own care;
- will be moving from a pediatric clinic to an adult clinic;
- are transitioning to adult HIV treatment; and
- can actively participate in their own health care e.g take increasing responsibility for their own care.

Session 8.2 Benefits of Transition

Just as with other components of becoming an adult, there are a variety of benefits involved in transitioning to adult care for adolescents living with HIV. By taking responsibility for knowing about their medications (e.g., names, purpose, dosage, potential side effects and interactions) and their tests and what the results mean for their ongoing care, adolescents will experience the following benefits:

- A sense of competence and knowledge about managing their condition
- Growth of personal responsibility and self-reliance
- Experience in long-term planning and working to achieve life goals
- Development of meaningful independent living skills and the ability to transfer care anywhere and through any stage of life (e.g., tertiary education, marriage, new jobs)
- Improved self-image
- Enhanced social and emotional development
- Broader systems of interpersonal and social support

Session 8.3 Support and Preparation for Transition

Caregivers can support and prepare adolescents for their transition to adult care by ensuring that adolescents are able to take personal responsibility for

- knowing their medication schedule and adhering to it;
- making their own appointments with the doctor;

- self-reporting their history to providers rather than relying on parents or caregivers or waiting for the provider to ask;
- planning for the future, including how to manage their condition at school, work, and for a future family.

Caregivers must make sure that adolescents understand
- the consequences of not following their medication regimen;
- the impact of their condition on sexual relationships and fertility; and
- the effects of drugs and alcohol and smoking on medication adherence and their condition.

Session 8.4 Readiness Assessment

At the facility, a HCW will provide the adolescent with a checklist to assess their readiness for transition. Caregivers can support children achieve readiness by working with them overtime to get ready for transition.

Readiness Checklist (to be completed by the adolescent)

Age	Knowledge & Responsibilities	Date Completed	Notes on Completing
10–14 years	I can describe my HIV condition.		
	I can name my HIV medications and describe common side effects.		
	I can explain the importance of adherence.		
	I know my viral load results.		
	I know my health care provider’s name.		
	I can make or change a clinic appointment.		
	I am aware that I need to prepare for transition to adult care from age 20–25 years old.		
15–17 years	I know the names and purposes of tests that are done.		
	I know when to come to the clinic between refills.		
	I know my medical history.		
	I understand the risk of non-adherence to ARVs.		
	I understand the impact of illegal drugs and alcohol on condition and treatment.		
	I attend my clinic appointments and pick up ART refills as scheduled.		
	I talk with my parent/caregiver about my HIV care and treatment status.		
	I askmy provider questions when something is unclear or I need more information.		
	I know how HIV is transmitted and how this relates to future sexual activity and family planning.		
18–20 years	I can name the ARVs I am taking.		
	I know the names of past ARVs that I have taken.		
	I can express my health needs to a provider and complete a referral.		
	I know where to find free HIV services and treatment (beyond this clinic).		

	I manage my medical needs outside of the clinic (e.g., at home, school, and work).		
	I book my own appointments, refill my ART, and contact my provider if needed.		
	I carry my health booklet with me and have my transition checklist and plan.		
	I know the benefits of self-managing my HIV care.		

Transition Plan

At the facility, a HCW will ask the child or adolescent some of the following questions prior to completing their transition plan.

1. What treatment successes have you achieved so far?
2. What are your life goals in adulthood?
3. What are your treatment goals?
4. What challenges can you anticipate and how will you overcome them?
5. Who are supportive people and places that can help you on your transition journey?

Session 8.5 Successful Transition

A successful transition to adult care will mean that the adolescent has

- accepted their chronic illness and is oriented toward future goals and hopes, including long-term survival;
- established a good working relationship with HCWs at the pediatric/adolescent site;
- learned the skills needed to negotiate appointments and multiple providers in an adult practice setting;
- achieved personal and medical independence and is able to assume responsibility for their treatment and participate in decision making;
- learned to identify symptoms and describe them;
- learned to arrive to appointments on time and receives uninterrupted comprehensive medical care;
- learned to request prescription refills correctly and allow enough time for refills to be processed before medications run out (not *missing visits*);
- secured entitlements (e.g., home care, housing, and transportation) and is receiving psychosocial support (e.g., peer, family, and facility); and
- learned about SRH and family planning and learned contraception and condom use skills.

By providing the proper support and preparation for transitions, caregivers can help adolescents avoid the consequences of unsuccessful transitioning, which can result in

- poor adherence,
- viral rebound,
- unplanned pregnancies,
- higher rates of loss to follow-up in adolescents and lower retention in care,
- development of weaker immune systems,
- increased morbidity and mortality, and
- higher risk of developing drug resistance.

Module 9: Child/Adolescent Mental Health

Mental health is an important component of the overall health and treatment of children and adolescents living with HIV. Mental health problems may impact a child or adolescent's adherence to ART and retention in care and, consequently, their survival. The adolescent-caregiver relationship is an important potential source of resilience, and improving this relationship can combat common causes of mental illness, including anxiety and depression.

By the end of the session, caregivers should be able to

1. identify their own beliefs and attitudes about mental illness and people living with HIV;
2. understand basic categories of mental illness;
3. discuss the role of caregivers in supporting mental health;
4. recognize when an adolescent may have a mental illness and know what signs must be reported to a health care provider; and
5. understand how to help reduce the stigmatization of mental illness at home and in the community.

Session 9.1 Mental Health and Mental Illness

Caregivers of adolescents living with HIV should be knowledgeable about mental health and mental illness and be able to identify an adolescent struggling with mental health.

Mental health refers to a state of psychosocial well-being and the adoption of adequate strategies to maintain it. *Mental illness* is characterized by the presence of one or both of the following over time: (1) persistent and severe subjective distress or discomfort or (2) moderate to severe impairment of function (e.g., not being able to function in day-to-day activities).

States of mental health and mental illness fall along a broad spectrum ranging from feeling down to experiencing severe depression over a period of time. Temporary states of severe distress and reduced functioning, often in response to stressful life events, are not considered mental illness. Examples might include temporary mood changes, extreme sadness in response to a difficult life event like the loss of a loved one, or not being able to focus in school from time to time.

Most adolescents will experience some type of fluctuation in mood or behavior or problems that affect their emotional and mental functioning. For example, normal adolescent development includes some transient moodiness and challenges to parental authority. It is important to acknowledge these changes and provide a safe space for adolescents to discuss these new feelings with you or someone in their lives.

Session 9.2 Mental Illness in Adolescents

Although the exact cause of most mental illnesses is not known, it is becoming clear through research that many are caused by a combination of factors, including genetic predisposition, injuries to or medical conditions that affect the brain, and the long-term impact of adverse life events. Mental illness not a choice, but a result of a complex interplay of factors.

Mental illness is a broad term that covers a variety of different disorders, many of which can emerge during late childhood and adolescence. Adolescents living with HIV are susceptible to a number of mental illnesses, which can be broadly classified into the following categories:

- **Depression** manifests in feelings of intense sadness—including feeling helpless, hopeless, and worthless—that last for days to weeks and are not explained by bereavement (mourning the death of someone close). If severe and untreated, depression can lead to suicide.
- **Alcohol and substance use disorders** indicate excessive and uncontrollable use or dependence.
- **Anxiety disorders** manifested in persistent fear or worry that is out of proportion to a person's current life circumstances.
- **Behavioral disorders** manifest in violent behavior, aggression, and impulsivity (the tendency to do things without adequate forethought).
- **Severe mental illness** usually refers to schizophrenia or other mental illnesses that have psychotic features (i.e., a loss of contact with reality). These disorders vary in severity and can create barriers to an adolescent achieving self- protection and the expected degree of independence.

SUICIDE

Suicide, or the act of killing oneself, is one of the most severe consequences of mental illness. While severe depression is the mental illness most commonly associated with suicide, psychosis, anxiety disorders, substance use disorders, and other mental illnesses are also associated with an increased risk of suicide.

IF YOU ARE CONCERNED AN ADOLESCENT IS AT RISK, CALL 977 IMMEDIATELY

9.3 Mental Illness and HIV Care

Mental illness can interfere with an adolescent's HIV care, including their retention in care, adherence to ART, positive living, and positive prevention. Primary mental illnesses usually begin in childhood, adolescence, or early adult life. Recognizing possible mental illness as early as possible in a child or adolescent and providing appropriate mental health services is important because of the following:

- Compared to their HIV-negative peers, adolescents living with HIV have an increased risk for mental illness as a result of the direct effect HIV has on the brain, the fact that chronic illnesses are associated with higher rates of mental illness, and the impact of stigmatization and discrimination.
- A person's mental health significantly influences his or her adherence to HIV care and treatment. Adolescents with mental illnesses or substance abuse problems are more likely to forget or choose not to take their medication.
- Mental health status influences the course of HIV disease in various ways. For example, depression can limit the energy needed to stay healthy, and research shows that depression may accelerate progression to AIDS.
- Mental illness can make it more difficult for an adolescent to engage in positive living and positive prevention practices, including practicing safer sex to prevent transmission to sexual partners.
- The presence of one mental illness predisposes a person to the onset of other mental disorders (for example, it is not unusual to see a depressed adolescent also abusing drugs or alcohol).
- People who experience mental health problems or mental illness are more likely to abuse drugs or alcohol and to engage in risky sexual behaviors.
- Untreated mental illness can disrupt adolescent development in a profound way by interfering with the ability to work, attend school, and form social relationships.
- Untreated mental illness can result in suicide.

Studies in adults have found that when depression is treated, clients with HIV are more likely to initiate ART, adhere to ART, and have both higher CD4 cell counts and lower viral loads.

9.4 Recognizing Mental Illness

An adolescent suffering from a mental illness may not be aware that something is wrong or may be too afraid to talk about it. Possible indicators of mental illness might include changes in behavior or somatic symptoms.

Concerns about *changes in behavior* brought about by possible mental illness may be initially expressed by another adult (e.g., teacher or family member) or peer in a child or adolescent's life. A HCW who knows your child well may also notice these changes over time. Be open to discussing any concerns others may have about your child's mental health or any changes they observe, which might include

- dramatic changes in behavior or a major decrease in psychosocial functioning (e.g., used to be friendly, but now only wants to be alone; used to be calm, but now is behaving in a violent way; was a good student, but is now failing in school, etc.), or
- saying things that do not seem plausible (e.g., "my grandmother is trying to poison me," "voices are telling me that I'm a bad person," etc.).

Mental illness, especially depression and anxiety disorders, affect the mind and body and, when severe, are routinely accompanied by physical or *somatic symptoms*, including fatigue, headaches or migraines, abdominal pain or gastrointestinal problems, backaches, difficulty breathing, changes in appetite and weight, changes in sleep patterns, or chest pains.

Caregivers should be observant and report changes in any of the following categories to the adolescent's HCW:

- **Appearance and presentation:** they neglect hygiene and grooming, express themselves as frightening or frightened, smell like alcohol or appear intoxicated, or make no eye contact or cry more easily
- **Attitude and behavior:** they are restless, belligerent, or uncooperative; they make threats, are unwilling or unable to speak, or behave in an odd or unusual way
- **Mood and emotions:** they look or seem to be frightened, sad, or angry
- **Speech, thinking, and perception:** they speak very rapidly or overly loudly or softly, say things that make no sense, say things that are unlikely to be true, or report having hallucinations (hearing or seeing things that are not there)
- **Level of alertness and orientation:** they have trouble staying alert and attentive, are drowsy, or are confused about things like where they are or what time of day it is
- **Social and intellectual skills:** they do not have the verbal, behavioral, or social skills that would be expected of someone their age or are behaving like a younger child

Report any of these behaviors or concerns about them to your HCW immediately.

Session 9.5 Getting Help

Diagnosing a specific mental illness cannot be done at home, but bringing any concerns up with the adolescent's health care provider can be lifesaving! There are a variety of tools available to your adolescent at the health care facility, including screening tools, medications, and psychological support.

If the health care provider is concerned, they may ask the adolescent a few screening questions at the facility to determine the problem. A screening tool called the PHQ-9 is a safe way to identify adolescents with HIV that may benefit from taking medication to help ease the burden of depression or mental illness. Some adolescents may also benefit from support from a clinical psychologist. If you have questions about the screening tool or psychological support, ask the health care provider.

Caregiver support for mental health treatment is an important way to support the overall health of adolescents living with HIV. Talk about mental health openly with adolescents—removing stigma is a powerful tool to reduce suffering from mental illness among young people. Be respectful of and listen to the adolescent's beliefs about the origin and treatment of mental illnesses and be aware of personal biases. Beliefs concerning the treatment of mental health conditions vary among members of different communities and cultural groups. If the decision is made to treat your adolescent's mental illness with psychological support or medication or both, be supportive and address stigmatization head-on.

To further support mental health, develop positive communication habits and show care by helping supervise ART administration, acts that can directly affect the adolescent's feelings of self-worth. Discourage the use of alcohol and drugs, but do so in a way that allows them to talk with you as they are exposed to peers experimenting with these substances. Creating an open, supportive home environment and relationship with your adolescent can decrease the risk of anxiety and depression.

Module 10: Tuberculosis

Tuberculosis (TB) is one of the world's oldest illnesses and affects people all over the world. Childhood TB is prevalent wherever there are high rates of adult TB. TB is very infectious, which means it is spread very easily from one person to another. Many deaths related to childhood TB can be prevented through better education about childhood TB, which results in better prevention and earlier diagnoses.

Eswatini is one of the countries in the world where TB is highly prevalent. All patients must be screened for TB at every visit to a health care facility. Screening enables HCWs to make an early diagnosis of TB, treat TB disease, and identify children and families eligible for preventive therapy. Caregivers are made aware of the symptoms of TB HCWs screen for and can be attentive to these symptoms.

The purpose of this module is to ensure that caregivers understand the importance of screening, preventing, and treating TB.

By the end of this module, caregivers will know

1. what TB is and how it spreads,
2. the risk factors for contracting TB,
3. the difference between latent TB infection and active TB disease, and
4. how TB is diagnosed, treated, and prevented.

Session 10.1 TB in Children and Adults

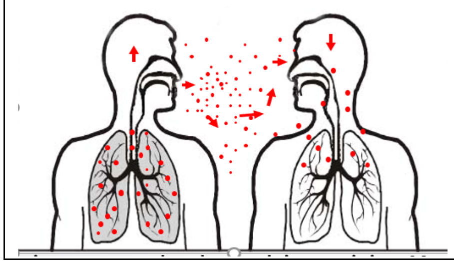
TB is caused by bacteria called *Mycobacterium tuberculosis*. Bacteria are really tiny organisms that you can't see, but can cause illnesses and disease in people. TB in children can look very different from TB in adults.

Adults and adolescents often have symptoms such as a cough that lasts for more than two weeks and may produce sputum, fever, and night sweats. They might also cough up blood. Sometimes they don't feel like eating and they lose a lot of weight.

Children also experience TB symptoms most commonly in the lungs and will also have cough and other unspecific symptoms (e.g., reduced activity, weight loss, fever, and night sweats). Infected children usually have been in contact with an adult with a chronic cough that is possibly a symptom of TB. Children's immune systems are still growing, so less bacteria can still make them sick.

The bacteria can sometimes even spread outside of the lungs and infect other parts of the body, including the lymph nodes, brain, spine, bones, or kidneys. This type of TB is more common in children than in adults, and is called *extrapulmonary TB*.

Session 10.2 TB Transmission

	▪ When someone with active TB coughs, talks, or sneezes, bacteria within tiny droplets are dispersed into the air. ▪ A close contact (e.g., someone in the family) can breathe in these droplets and become infected. ▪ TB bacteria are very easily spread through the air, but only through the air. ▪ It is very important for people to cover their mouths when they cough to avoid spreading TB to others.

Transmission of TB bacteria occurs only in the air—TB bacteria become inactive as soon as they touch a surface and therefore are not spread on surfaces such as cups or spoons. Being exposed to the bacteria does not necessarily make you sick, but there are certain risk factors that make you more susceptible to getting infected or developing TB disease.

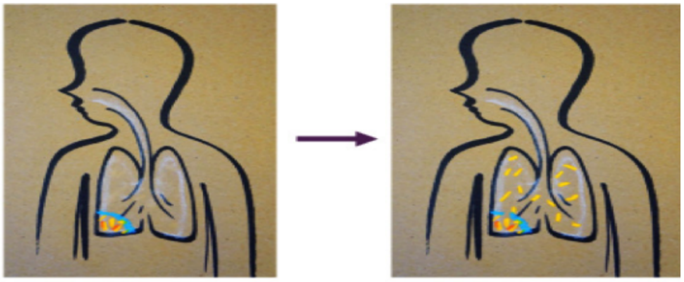
Session 10.3 Risk Factors for TB Infection

There are several factors that increase a person's risk of TB infection, including the following:

- Previous TB infection: Previous infections increase the risk of reinfection.
- Being in enclosed areas with very little airflow or in enclosed crowded areas. The lack of airflow in these spaces increases the risk because bacteria stay trapped in the air.
- Age: Age affects the body's ability to fight bacteria. Children, especially those less than 5 years old, are still developing and their immune systems may not be able to fight the bacteria as well. This puts them more at risk for getting TB. In children, recent exposures to or infections from TB (especially within 2 years) and lack of the vaccination to prevent severe forms of TB put them much more at risk of TB disease. Elderly clients are also more at risk for getting TB.
- Having other diseases: People with other illnesses, such as HIV, are at a much higher risk for getting TB because their bodies are already fighting another illness and their immune systems are weakened. HIV increases the risk of developing active tuberculosis from a 10% lifetime risk to 10% risk per year. HIV increases the severity of TB illness and increases the likelihood of death due to TB. TB also promotes an increase in HIV viral load. Malnutrition and other conditions like diabetes also increase the risk of TB infection.
- Lack of TB preventive therapy (TPT): TPT reduces the risk of TB infection.

Session 10.4 Latent TB Infection and Active TB Disease, Importance of TPT

Having TB bacteria in your body does not always make you sick, but it does mean you are infected. Your body will try to fight the TB bacteria and keep you healthy.



TB Infection TB Disease

Sometimes, your immune system can create a barrier around the TB bacteria so they can't grow anymore. These bacteria can "sleep" inside of you, or remain inactive, for a very long time. This form of TB is called *latent TB*. When TB bacteria are inactive, they do not grow, and cannot be transmitted to other people. A person with latent TB won't experience any symptoms. But these inactive bacteria can "wake up" and become active at some point.

This is why it is important to treat latent TB with TB preventive therapy (TPT). TPT is a course of an antibiotic given to treat latent TB infection so that it does not develop into active TB. There are several options available for TPT. A HCW will discuss with the caregiver and child/adolescent the options and offer the best one for those eligible. It is important that the child/adolescent completes the TPT.

Active TB disease occurs when the bacteria “wake up” and break out of the barrier the body built around them. The bacteria start to grow and spread in the lungs, which causes the person to feel sick. A person with active TB can transmit TB bacteria to others. Active TB is still curable if treatments are taken properly.

Session 10.5 Diagnosing TB

There are several ways to diagnose TB, but the infected person must go to a clinic and be examined and tested by a HCW to be diagnosed. Diagnosing younger children can be different than diagnosing older children, adolescents, and adults. Older children, adolescents, and adults can cough up a substance called *sputum*. Sputum is a combination of mucus and saliva that is coughed up from the lungs. A HCW can take a sample of this sputum and do other tests in the laboratory to confirm whether or not there is TB. Young children often do not produce or cough up sputum, so HCWs must conduct procedures to get sputum or other samples (e.g., urine) and do additional tests to diagnose TB.

Contact Tracing

TB bacteria are transmitted very easily from one person to another. Because of this, it is really important for someone who has TB disease to think about everyone they come in contact with often, especially in their home. *Contact tracing* is a really important way to diagnose people early so they can get treatment earlier. It is also a way to identify all those that are healthy but at risk for TB and need preventive treatment, especially children under 5 and HIV-positive people. Contact tracing works for both children and adults. Often, a child gets TB from a parent who may not have been diagnosed. If a child is diagnosed with TB, it is very important the family and other close contacts get tested for TB.

Session 10.6 TB Treatment

TB is curable with proper treatment. The duration of TB treatment is long because TB bacteria are very complicated, but it must be completed to cure TB. Some of the bacteria grow very slowly and are much harder to get rid of. Current treatments consist of several different drugs that target the bacteria, but it does take a while to get rid of all of them, which must be done so that they do not start growing again.

Dosages for TB treatment are calculated according to weight, not age.

Adherence to all medication instructions and keeping clinical appointments is very important for maintaining progress in treatment.

At each follow-up visit, medicine dosages must be adjusted according to weight. Weight gain during the treatment of TB is an important indicator of improvement.

Side Effects

Common side effects of TB medication include nausea, fever, or stomachache. These common side effects should be reported to the HCW but treatment should be continued. These side effects are much less common in children than adults. The person may also start to feel better—a sign that the medicine is working—but still must finish the treatment. Finishing the entire treatment is so important because if it is not completed, some of the TB bacteria can remain and cause sickness again. Sometimes a form of TB can develop called multi-drug resistant TB in which the bacteria do not respond to the medication and is harder to treat so different medications must be used.

Infectiousness

For the first 2 weeks after a diagnosis, an infected person must avoid crowded places such as buses, not go to school or work, make sure the windows in the home are open, and sleep in their own bed. There is a certain point in treatment after which a person can no longer transmit TB to others, usually after about two weeks. The TB bacteria has been inactivated, so transmission is not possible. At this time, regular daily activities can be resumed as long as treatment is still followed until completion.

Module 11: Nurturing Care and Support for Children Living with HIV

For children to reach their full potential, they need good health, adequate nutrition, safety and security, responsive caregiving, and opportunities for early learning. This begins in pregnancy and continues throughout childhood. Routine services for maternal, newborn, and child health, nutrition, and HIV prevention and care can help caregivers achieve these goals for children. Services that provide treatment and care for caregivers living with HIV help ensure that caregivers have the strength to care for their children. Identifying, protecting, and supporting families and caregivers better enables them to provide children with nurturing care.

The purpose of this module is to ensure that caregivers understand how to provide nurturing care and support in optimal early childhood development.

By the end of this session, caregivers will
1. understand the importance of nurturing care and support for children,
2. understand the importance of good nutrition for children living with HIV,
3. know why is undernutrition common in children with HIV,
4. be able to identify their role as caregivers to improve nutrition, and
5. have better knowledge about the growth and development of children.

Session 11.1 Nurturing Care and Nutrition

Nurturing care focuses on both good health and good nutrition. *Good health* refers to the health and well-being of children and their caregivers. This is important because the physical and mental health of caregivers can affect their ability to care for the child. *Good nutrition* includes both the mother and child because the nutritional status of the mother during pregnancy affects her health and well-being and that of her unborn child. After birth, the mother's nutritional status affects her ability to breastfeed and provide adequate care.

Good nutrition is a very important part of managing the health of children living with HIV. This is because nutrition plays an important role in helping to maintain the normal function of the immune system. Malnutrition weakens the immune system and puts them at greater risk of opportunistic infections.

Session 11.2 Nutrition for Children Living with HIV

It is important that caregivers are aware of and have knowledge about good nutrition. Children living with HIV are more likely to experience problems with nutrition because of their HIV status.

Malnutrition occurs when food intake doesn't match the body's needs. A malnourished person can be experiencing either undernutrition or over nutrition. *Undernutrition* is the result of a lack of nutrients caused by an inadequate diet or disease, or both. Children who are ill commonly have a poor nutritional intake due to poor appetite, sores in the mouth, or inadequate feeding or supervision of feeding at home. Children who are ill may also be undernourished because of nutritional losses (e.g., chronic diarrhea). Increased energy needs during infections like TB also contribute to poor weight gain or weight loss. *Over nutrition* is the result of taking in more nutrients than the body needs over time. This can lead obesity and conditions like type 2 diabetes.

Children and caregivers should eat a variety of foods and include foods from all of the food groups to get the nutrients the body needs, including
- carbohydrates for energy (e.g., cereals, porridge, samp, mealies, rice, potatoes, etc.);
- protein for body building (e.g., beans, peanuts, eggs, meat, poultry, fish, milk, yogurt, emasi, cheese, etc.);

- vitamins and minerals for protection (e.g., fruits like bananas, oranges, mangoes, guavas, apples, and green leafy vegetables like spinach, etc.); and
- sugar, honey, fats, and oils for extra energy.

Children and caregivers should focus on the following critical health and nutrition actions:

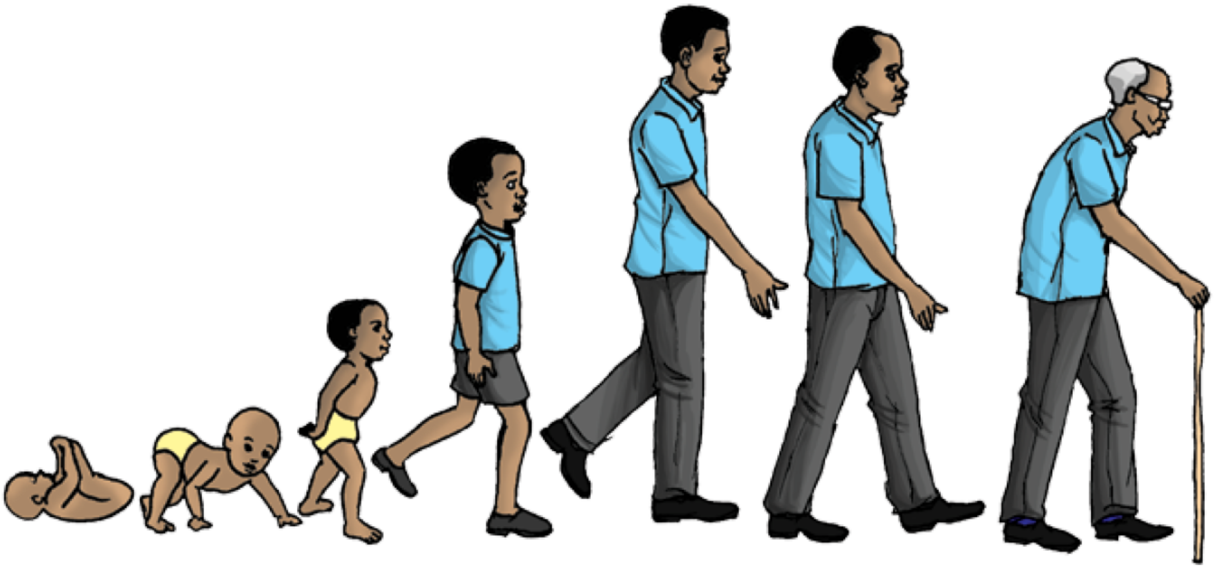
1. Eat a variety of nutritious foods.
2. Drink plenty of safe water (i.e., boiled or treated).
3. Maintain good hygiene and sanitation.
4. Make sure the children play, are active and are outdoors as often as possible.
5. Take all medications as directed by your doctor.
6. Attend scheduled follow-up visits for weight monitoring and early screening, identification, and treatment of infections.

Routine high-quality child health services including immunization, vitamin A supplementation, deworming, growth monitoring and counseling, TB screening, and preventing and managing acute illnesses all help to secure good health and adequate nutrition for children affected by HIV.

Good weight gain on the road to health card is the best indicator that a child is well nourished.

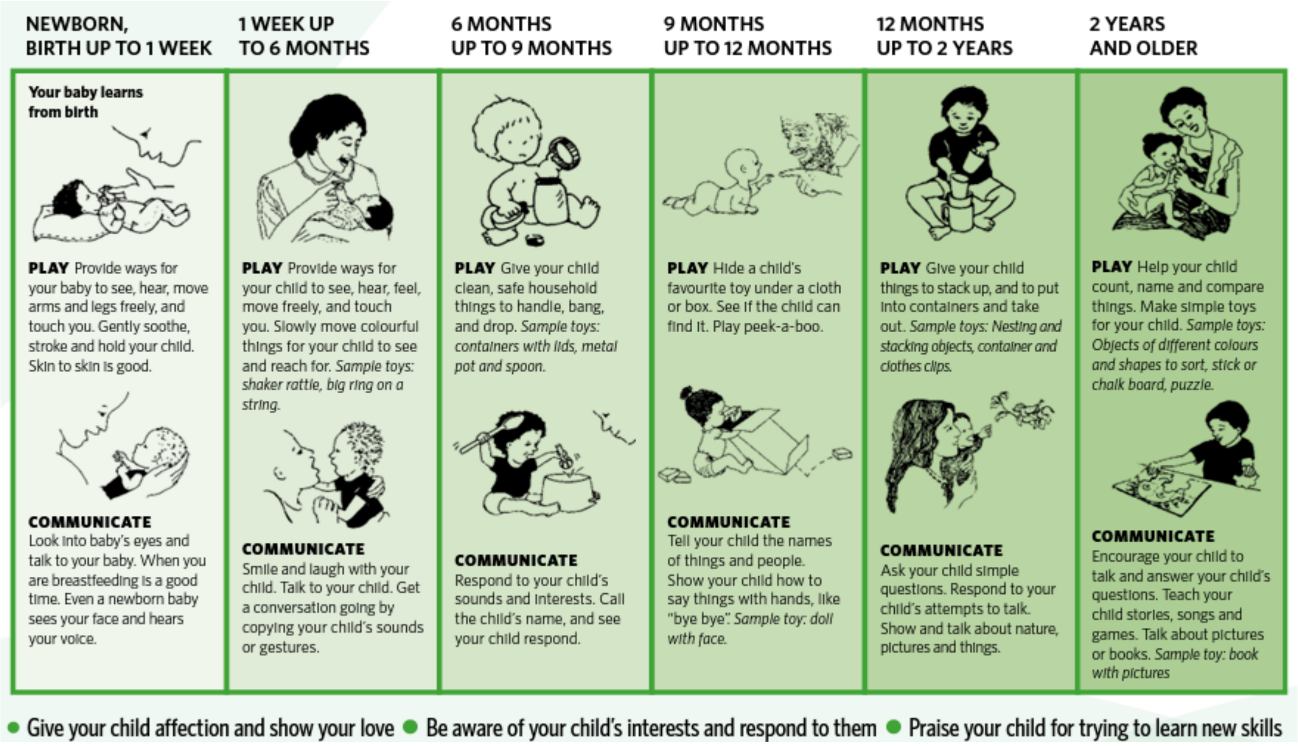
Session 11.3 Child Growth and Development

Child growth and development refer to the progression of life from birth to adulthood. Infants and very young children are completely dependent on their caregivers to recognize and respond to their needs. These needs are not only for nutrition and safety, but also for social engagement, cognitive stimulation, and play.



Child Growth and Child Development

Child Growth	Child Development
physical growth of a child's body based on biological events measured in terms of height, size, and weight considered just one part of development (i.e., physical development)	cognitive, emotional, and social progress of a child influenced by the psychosocial environment in which a child lives (e.g., the attention and encouragement received, the stimulation available, and the love and care received from caregivers measured by general "milestones" that most children achieve at a certain level of their life cycle that relate to skills, capacities, and abilities



NEWBORN, BIRTH UP TO 1 WEEK	1 WEEK UP TO 6 MONTHS	6 MONTHS UP TO 9 MONTHS	9 MONTHS UP TO 12 MONTHS	12 MONTHS UP TO 2 YEARS	2 YEARS AND OLDER
Your baby learns from birth **PLAY** Provide ways for your baby to see, hear, move arms and legs freely, and touch you. Gently soothe, stroke and hold your child. Skin to skin is good.	**PLAY** Provide ways for your child to see, hear, feel, move freely, and touch you. Slowly move colourful things for your child to see and reach for. *Sample toys: shaker rattle, big ring on a string.*	**PLAY** Give your child clean, safe household things to handle, bang, and drop. *Sample toys: containers with lids, metal pot and spoon.*	**PLAY** Hide a child's favourite toy under a cloth or box. See if the child can find it. Play peek-a-boo.	**PLAY** Give your child things to stack up, and to put into containers and take out. *Sample toys: Nesting and stacking objects, container and clothes clips.*	**PLAY** Help your child count, name and compare things. Make simple toys for your child. *Sample toys: Objects of different colours and shapes to sort, stick or chalk board, puzzle.*
COMMUNICATE Look into baby's eyes and talk to your baby. When you are breastfeeding is a good time. Even a newborn baby sees your face and hears your voice.	**COMMUNICATE** Smile and laugh with your child. Talk to your child. Get a conversation going by copying your child's sounds or gestures.	**COMMUNICATE** Respond to your child's sounds and interests. Call the child's name, and see your child respond.	**COMMUNICATE** Tell your child the names of things and people. Show your child how to say things with hands, like "bye bye". *Sample toy: doll with face.*	**COMMUNICATE** Ask your child simple questions. Respond to your child's attempts to talk. Show and talk about nature, pictures and things.	**COMMUNICATE** Encourage your child to talk and answer your child's questions. Teach your child stories, songs and games. Talk about pictures or books. *Sample toy: book with pictures*

- Give your child affection and show your love
- Be aware of your child's interests and respond to them
- Praise your child for trying to learn new skills

Recommendations for Care to Support Child Development *(WHO. 2020. "Nurturing Care for Children Affected by HIV: Early Childhood Development and Children Affected by HIV." WHO Policy Brief)*

Play and Communication

Playing and communicating helps children learn new skills. Play is critical to the healthy developmen of children and contributes to social, emotional, physical, and mental development.

Learning	Healing	Fun
Play is one of the primary ways children find out what effects they can have on their environment and what effects the environment is likely to have on them.	Play has a powerful healing value for children coping with traumatic life experiences.	Play is fun for children and (and adults too)!

Play provides a safe way to explore curiosity and learn about the environment.	Play offers space for expressing emotions (joy, loss, hurt, and failure) and for self-discovery.	Play can be a good way to distract from problems, relax, and enjoy yourself.
Play is an active learning method that strengthens a child's sense of self-worth and helps develop social competencies.		Play and fun provide renewed energy for dealing with challenges in life.
Individual play and play with others facilitates neurological growth, develops physical strength and coordination, provides relaxation, encourages planning, and allows practice of life skills.		

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