January 2024

HIV Treatment Adherence Counseling and Retention Guide

A job aid for cadres supporting caregivers of children and adolescents living with HIV (ages 0-14) in Orphans and Vulnerable Children (OVC) Programs



Acknowledgments

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Purpose and use of this tool

This tool will be used to provide counseling and support to caregivers of children and adolescents living with HIV (CALHIV) ages 0-14, to ensure they support them to adhere to HIV treatment and achieve viral load suppression. The guide is intended for OVC program cadres with caregiver counseling responsibilities, such as case workers, case worker supervisors, and linkage officers/coordinators.

STRUCTURE

The tool has five sections, each focuses on a specific topic and on potential challenges caregivers of CALHIV may encounter in helping their children adhere to treatment.

Section 1. Introduction to HIV Treatment. Introduces caregivers to HIV treatment, drug resistance, and viral load; helps caregivers identify their own reasons/motivations for helping their child start and/or continue treatment; and helps caregivers identify and address challenges their child might face in staying adherent.

Section 2. Removing Obstacles to Adherence. Helps caregivers discuss obstacles to adherence their child has encountered, or may encounter, and formulate a backup plan for each obstacle. Not all slides may be relevant for all caregivers.

Section 3. Multimonth Dispensing (MMD). Helps caregivers understand the benefits of MMD; how to manage a larger supply of medication and less frequent clinical consultations; and how to help their child stay adherent to treatment and healthy between refills.

Section 4. Decentralized Drug Distribution (DDD). Helps caregivers understand the benefits of DDD; where to pick up medications; issues related to privacy, confidentiality, and stigma and discrimination when receiving DDD services; and when and how to reach out to the antiretroviral therapy (ART) clinic, if needed.

Section 5. Return to Care and Special Situations. Guides caregivers on specific situations their child may face after missing doses or stopping treatment, such as unsuppressed viral load, and what to expect when their child returns to treatment.

SAMPLE COUNSELOR'S CARD

Card Topic

The topic is shown on the caregiver's card along with an image (each topic has multiple cards)

KEY MESSAGES

Important information to share with the caregiver



Let's Review

Questions to guide review with caregivers

Assess the caregiver's understanding of what was discussed and provide opportunities to address misunderstandings.

Document

Tells the counselor which forms to use to document

discussions with caregivers

The "Adherence Barriers and Interventions Log" can be used in initial and follow-up sessions to document findings from the discussions (see sample next page). It should be included in the client's case file and updated in each session.

TALKING POINTS

- Notes and questions to prompt and guide discussion
- Suggested steps for follow-up
- Key points are in bold
- Questions to ask caregiver are in italics

is optional; caregivers will get tired if every point is discussed

Each point

Counselor Instructions

Gives the counselor specific instructions for their interactions and conversations with caregivers

Guidance on how to optimize messaging and/or counseling

The flipchart should be positioned on a desk or table so that the caregiver can see the pictures while you see the notes card.

SAMPLE: Adherence Barriers and Interventions Log

Purpose: This register longitudinally documents the barriers and solutions to ART adherence for each OVC caregiver.

Instructions: At each encounter, score the ART adherence (good; poor) based on the national guidelines or, if not available, use the 7-days recalling system (Good = 7/7 doses within last week; Poor = 1+ missed doses within last week). Enter a maximum of three ART adherence barriers per caregiver per assessment. Assist the caregiver to prioritize the most relevant barriers. Keep the log in the caregiver's file.

7000	COUNTRYXXX				PROVINCE/REGION XXX				DISTRICT XXX			
REFERENCE ART CLINIC XXX				REFERENCE ART HEALTH CARE PROVIDER XXX				OVC CASE WORKER XXX				
OVC CLIENT ID	123			ADDRESS	123 First Road, Town			DATE OF BIRTH	01.01.2012			
ART START DATE dd/mm/yyyy	02.01.2023			PHONE	1234567			SEX AT BIRTH	F			
DATE dd/mm/yyyy	ART ADHERENCE	ART ADHERENCE BARRIER		DATE dd/mm/yyyy	ART ADHERENCE	ART ADHERENCE BARRIER	ART ADHERENCE SOLUTION	DATE dd/mm/yyyy	ART ADHERENCE	ART ADHERENCE BARRIER	ART ADHERENCE SOLUTION	
06.01.2023	Poor	Knowledge	education for the caretaker	02.06.2023	Good	None						
13.01.2023	Poor	Forgot dose	change time pill intake	16.06.2023	Good	None						
20.01.2023	Poor	Disclosure	peer support	14.07.2023	Good	None						
27.01.2023	Good	None	successfully disclosed to child									
	_											
03.02.2023	Good	None					Create an Adhere				ons Log	
	Good	None Forgot dose	change time pill intake				Create an Adhere hat suits the nee				ons Log	
03.02.2023 10.02.2023 24.02.2023			change time pill intake take pill with food								ons Log	
10.02.2023	Poor	Forgot dose									ons Log	
10.02.2023	Poor	Forgot dose Illness/ nausea	take pill with food								ons Log	
10.02.2023 24.02.2023 10.03.2023	Poor Poor	Forgot dose Illness/ nausea Forgot dose	take pill with food								ons Log	
10.02.2023 24.02.2023 10.03.2023 24.03.2023	Poor Poor Poor Good	Forgot dose Illness/ nausea Forgot dose None Ran out of	take pill with food create reminder on phone get meds from DDD								ons Log	
10.02.2023 24.02.2023 10.03.2023 24.03.2023 07.04.2023	Poor Poor Good Poor	Forgot dose Illness/ nausea Forgot dose None Ran out of medication	take pill with food create reminder on phone get meds from DDD								ons Log	

Topics by section

	Introduction to the counseling sessions
Section 1	 Introduction to HIV Treatment Starting and understanding treatment (x2) Resistance Viral load: undetectable = non-transmissible (U=U) Why start and stay on treatment? Planning to stay on treatment
Section 2	 Addressing Barriers to Adherence 6. Transportation to the clinic 7. Keeping appointment dates and obtaining medication refills 8. Make a daily medication schedule 9. Storing medications 10. When at school 11. Traveling away from home 12. Coping with side effects 13. Disclosure 14. Violence 15. Substance use 16. Mental health 17. Physical health 18. Healthy lifestyle and ART adherence 19. Nutrition and food security 20. Handling missed doses 21. Psychosocial and peer support 22. Communicating with the treatment team 23. Review and summary of adherence planning

Introduction to the counciling coccions

Section Multimonth Dispensing

- 24. Optimized treatment
 - 25. Multimonth dispensing (MMD)
 - 26. Benefits of multimonth dispensing
 - 27. Challenges of multimonth dispensing

Section

3

Decentralized Drug Distribution

- 28. Decentralized drug distribution (DDD)
- 29. DDD pickup points
- 30. Safety and quality of DDD services

Section

5

Returning to Care and Special Situations

- 31. Follow-up adherence counseling visit
- 32. Returning to care after having missed dose(s) or stopped treatment (x3)
- 33. Tips to improve taking medications (x3)
- 34. Your child's viral load is suppressed
- 35. Your child's viral load is not suppressed
- 36. HIV medications are not working well

Setting the stage for a productive counseling session

Take the following steps to ensure the caregiver is comfortable sharing information, planning, and problem solving with you:

- Choose a quiet, private space to meet.
- Sit face-to-face and make eye contact.
- Speak clearly, respectfully, and in a nonthreatening tone.
- Use language the caregiver can understand.
- Explain the limits of confidentiality. You will not share their information with others unless you are concerned for their child's health and safety or the health and safety of others.
- Don't assume the caregiver lacks knowledge.
 Check what they already know before presenting new information.
- When presenting new information, stop frequently and assess the caregiver's understanding of the information.



Focus on the caregiver's needs and motivations.

Motivational interviewing (MI) and communication skills

Good communication skills are critical for supporting caregivers to help their children initiate and remain on treatment. Use the following techniques, where appropriate, (sample language provided):

- **A. REFLECTIVE LISTENING:** Use "you" statements; interpret nonverbal signs to gather information, guide the conversation, and reinforce the caregiver's motivations for change.
 - You're wondering if it matters if your child takes his/her medications.
 - You are so overwhelmed that your child's health is the least of your problems right now.
 - Let me see if I understand. You want your child to start treatment, but you are worried your child's family, friends, or peers will find out. You would like to disclose your child's status, but this does not feel like the right time. Is that right?
- **B. AFFIRMATION:** Accentuate the positive, recognize the caregiver's worth, support, and encourage.
 - I appreciate you for being honest about the challenges your child is facing taking his/her medications.
 - You are clearly a resourceful person to manage so many challenges.
 - You have worked hard to make sure your child takes the medications despite these challenges.
- **C. QUESTIONING:** Use open-ended questions that seek information and the caregiver's perspective.
 - What makes it difficult for your child to take his/her medication every day?
 - What have you already done to ensure your child takes his/her medication every day?
 - What is likely to happen if your child does not take his/her the medication every day?

Motivational interviewing and communication skills

- **D. ASK-TELL-ASK:** Ask what the caregiver knows; ask permission to offer new information; ask what the caregiver thinks of the new information.
 - I get that question a lot. First, let me ask you, what have you heard about this?
 - I understand you're feeling concerned about how your child's family, friends, or peers might react.
 - Many people have felt the same way when they first encountered this problem.
 - We've found that there are effective ways to talk to your child's family, friends, or peers about this.
 - Would you like to hear more about that?
- **E. RECOGNIZE WHEN CLIENTS TALK ABOUT CHANGE:** When the caregiver expresses the desire, ability, rationale, need, or commitment to change.
- **F. STRENGTHEN WHAT THE CAREGIVER SAYS ABOUT CHANGE:** Reflect, affirm, ask for examples, and summarize.
 - Use the confidence/importance ruler. Ask the caregiver to indicate, on a scale of 0–10, how important change is to them and how confident they are they can achieve it.
 - Ask questions about desires, abilities, needs, or reasons for change. This highlights their motivation, which is a significant factor in the effectiveness of treatment.
 - Prompt discussion about possible barriers to progress. This information can be used to help the caregiver set goals for their child's treatment that are realistic, engaging, and achievable. It can also help highlight issues the caregiver might want to include in the agenda for future sessions.

Communication "traps" to avoid

Avoid these:



- Assuming you know the caregiver better than they know themselves
- Telling the caregiver why they should change or pushing them to agree to change when they are not ready
- Arguing with the caregiver
- Ordering or commanding the caregiver to do something
- Blaming, shaming, or judging the caregiver

Try these instead:

- Use open-ended questions to understand the caregiver's knowledge, experiences, and challenges
- Learn about the caregiver's own reasons for making a change
- Explore reasons for the caregiver's resistance; shift the focus to something else if necessary
- Use simple and double-sided reflection when the caregiver is not sure about a decision
- Involve the caregiver in problem solving
- Emphasize that the caregiver is free to make decisions for themselves



Key considerations for counseling caregivers of CALHIV

- Caregivers often do not accept their child's HIV diagnosis, do not have enough information on HIV care and treatment, and do not understand the health implications of poor adherence to treatment.
- Building caregivers' knowledge and skills can be an important component of care and support to CALHIV, since they can play a critical role in supporting their child's treatment continuity.
- Counselors should develop relationships with both the caregiver and their child by creating a balance between providing appropriate health supervision and listening to the caregiver's and their child's voices regarding their health.
- Counselors must ensure their personal beliefs do not interfere with their ability to provide nonjudgmental person-centered care.
- Counselors should sensitize caregivers on the need to disclose to their child in an age-appropriate way and link them to a counselor in the health center for disclosure counseling and support (in line with country disclosure guidelines).

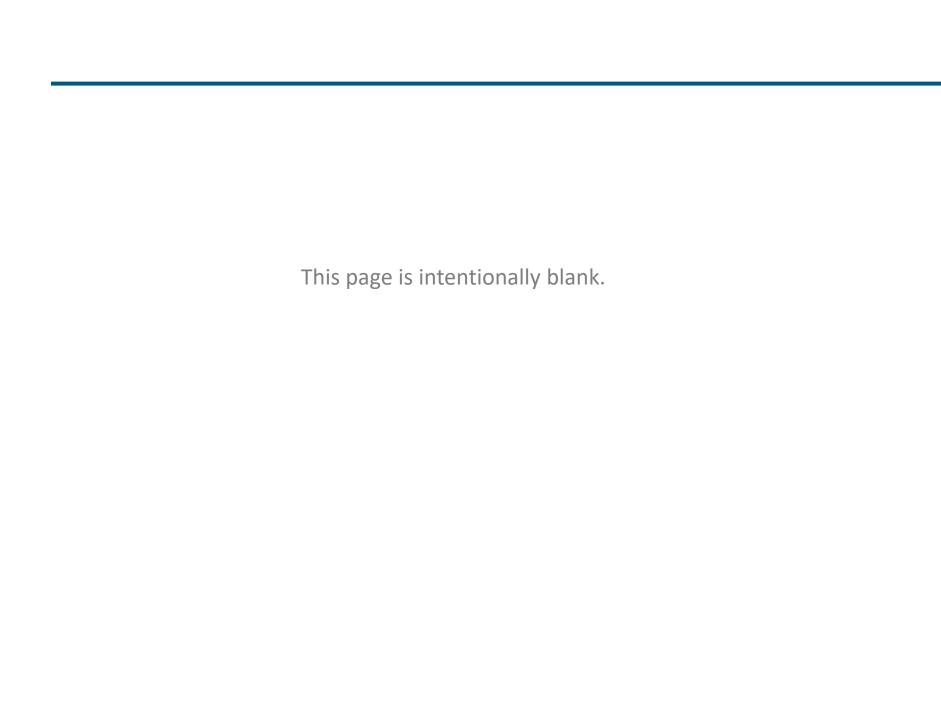
Tips for building rapport with caregivers of CALHIV

- Respect the caregiver
- Do not use judgmental words or body language
- Do not be critical
- Use easy to understand language and educational materials; and use visuals to explain and simplify complex information
- Ensure conversations are private
- Reassure the caregiver about confidentiality and discuss the meaning of confidentiality
- Be open to and allow enough time for questions; be honest when you do not know the answer and obtain the information from another source or cadre
- Empathize with the caregiver's situation and concerns; provide reassurance that the feelings they or their child are experiencing are normal
- Listen carefully and help the caregiver make informed decisions
- Help caregivers recognize and build on their strengths

CALHIV risk segmentation checklist

Child of a key population (e.g., female sex worker)

The following checklist can be used to assess the CLHIV's risks and the need for more frequent and intensive ART adherence monitoring. Intensify monitoring when there is at least one risk factor. HIV stigma (enacted and internalized; community- or school-based) Loss of biological parents (orphanhood) Lack of or unreliable parental/family/school support Out of school Other illnesses (e.g., noncommunicable diseases) Mental health issues (e.g., anxiety, depression) Advanced HIV disease Taking multiple medications; pills burden History of experiencing violence (sexual, physical, emotional) Limited privacy to take medications, (e.g., at school) Lack of disclosure by the caregiver to their child Caregiver/family mobility Misconceptions or false beliefs about ARV medications Feeling healthy Using/injecting drugs or alcohol use



Introduction to the Counseling Sessions



Introduction to the Counseling Sessions



KEY MESSAGES

- We are going to meet regularly during the next few months.
- I will support you with your child's treatment to help him/her live a healthy life.
- When we meet, it's important that you be open to sharing your experiences and your ideas.
- You should also feel free to ask questions at any time. If I don't have the answer to your questions, I will try to find it for you by our next session.

TALKING POINTS

- Thank you for participating in this counseling session. It shows that you are serious about your child's health.
- My name is ______, and I am a __[Title] working with _____[Name of the OVC program implementer] _.
- My role is to support you to ensure your child takes his/her medications as prescribed and to help your child live free from illness and the worry of passing the HIV virus to someone else in the future.
- We are going to meet a few times over the next ____ months to ensure your child's treatment is working and to address any challenges along the way.
- You can contact me anytime you have a question or need support. Here is my phone or whatsApp number (provide number)
- How does that sound to you?
- To begin with, what would you like to get from our discussion today?

SECTION

1

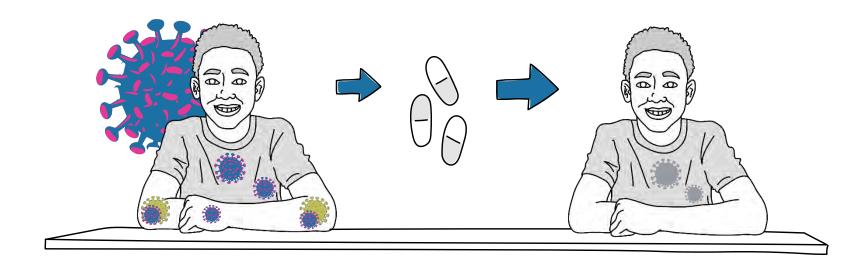
Introduction to HIV Treatment

SECTION

1

Introduction to HIV Treatment

1. Starting and understanding HIV treatment (1)



Children should start treatment as soon as they test positive for HIV.

HIV treatment is also called **antiretroviral therapy (ART)**.

ARVs—antiretrovirals —is the common name for HIV medication.

1. Starting and understanding HIV treatment (1/2)



KEY MESSAGES

- Children should start HIV treatment as soon as they test positive for HIV. If that is not possible, then they should start within 1 week.
- HIV treatment is also called antiretroviral therapy (ART).
- ARVs—antiretrovirals—is the common name for HIV medication.
- Only a qualified clinical provider can prescribe HIV medications, but they can be dispensed by peer outreach workers.
- HIV medications may need to be adjusted as children grow and gain weight.

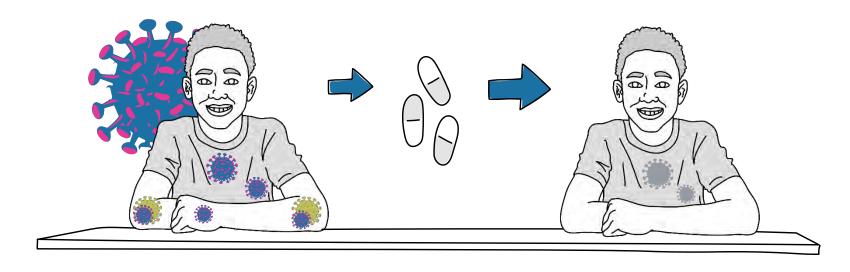
Let's Review

- When should a child who tests HIV positive start HIV treatment?
- In your own words, what are antiretrovirals?
- Who can prescribe and who can distribute antiretrovirals?

TALKING POINTS

- All children with HIV should start treatment as soon as they test HIV positive. If that is not possible, then they should start within 1 week.
- What do you know about HIV treatment?
- HIV treatment, also called antiretroviral therapy (ART), begins
 with the provider choosing an HIV regimen. A regimen is a
 combination of drugs or medications given together.
- ARVs—antiretrovirals—is the common name for HIV medication.
- Only a qualified clinical provider can decide what regimen or combination of drugs/medications to prescribe to a child.
 However, medications can be distributed by a variety of providers, including peer outreach workers.
- As children grow and gain weight, the clinical provider may need to adjust their ARV medications.
- HIV drugs/medications are not the same for everyone. Medicine
 may come in liquid, capsules, or pill/tablet form, depending on
 the child's age, weight, and ability to swallow.

1. Starting and understanding HIV treatment (2)

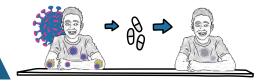


HIV treatment stops the HIV virus from making more copies of itself, allowing your child to stay healthy.

While treatment will not cure HIV, when your child stays on it, the amount of virus in his/her body becomes very low and remains hidden.

It is important for your child to take his/her medication every day exactly as prescribed by the doctor.

1. Starting and understanding HIV treatment (2/2)



KEY MESSAGES

- HIV treatment stops HIV from making more copies of itself, allowing your child to stay healthy.
- While treatment will not cure HIV, the amount of the virus in your child's body becomes very low and remains hidden.
- It is important for your child to adhere to treatment by taking his/her medication every day as prescribed by the doctor.

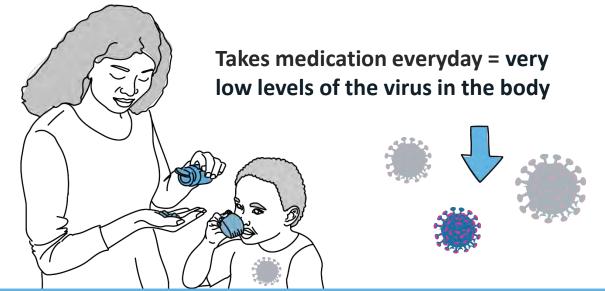
Let's Review

- In your own words, what does treatment do?
- What medications does your child take and when?
- What do you think may prevent your child from taking his/her medications every day?

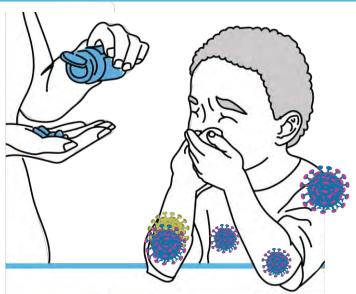
TALKING POINTS

- What do you and your child know about HIV treatment?
- HIV medications stop HIV from making more virus, prevent your child from getting sick, and allow your child to live a healthy life.
- When there is enough medicine in the blood, HIV almost disappears from your child's body, remaining hidden.
- Treatment does not cure HIV, which is why your child must continue taking his/her medication even when feeling well.
- If your child forgets to take his/her medication or runs out of medication, the virus makes more of itself, which can make your child sick.
- They are also more likely to spread HIV to others. This includes adolescents who are having sex, and children when they become older and have sex in the future. The HIV virus can also pass from adolescent girls to their babies during pregnancy, delivery, and breastfeeding.

2. Resistance



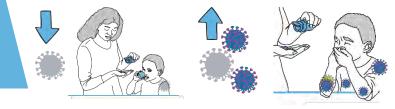
Misses doses = virus produces more copies of itself, and the medication may no longer work as efficiently





It is important for your child to take his/her medication every day as prescribed and avoid missing doses, so s/he can stay healthy and protect loved ones from HIV transmission in the future.

2. Resistance



KEY MESSAGES

- If your child misses too many doses of medication, the virus can change, and the treatment may no longer work.
- This can make it harder for your child to stay healthy and, in the future, protect loved ones from HIV transmission.



Let's Review

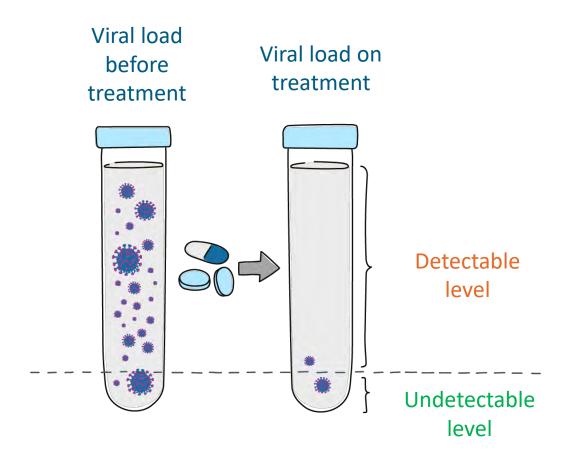
- In your own words, what can happen if your child misses too many doses of his/her medication?
- What can happen to your child if the medication stops working?

TALKING POINTS

- The picture above shows someone who took their medication everyday. The medication stopped the virus from making more copies of itself, and the person has very little virus in their body.
- The picture below shows someone who missed doses. When someone misses doses, the virus can make more copies of itself or change. See how the virus looks different in the pictures?
- If the virus changes, the medicine may no longer work, and your child will become sick and will not be able to live a healthy life. In the future, your child might pass the new virus to someone else, and the medicine would not work for them either.
- This is why it is important to not miss doses.

2

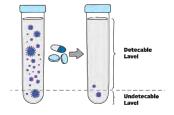
3. Viral load: undetectable = untransmittable (U=U)



- For a child starting treatment, a viral load test will be conducted in six months to see how much virus is in the body.
- If treatment is working, the laboratory may not find virus in your child's blood. This means the virus is undetectable. HIV is still there, but at a very low level.
- If the virus cannot be detected, then your child can no longer pass HIV to others.
- It is important that your child have the viral load test done and to know the results of the test.

Source: Clinicalinfo.HIV.gov [Internet]. HIV/AIDS glossary. Bethesda (MD): Office of AIDS Research, National Institutes of Health. c2023 [cited 2023 Aug 9]. Available from: https://clinicalinfo.hiv.gov/en/glossary/undetectable-viral-load.

3. Viral load: undetectable = untransmittable (U=U)



KEY MESSAGES

- Your child will have a viral load test in six months to see how much HIV is in his/her body.
- If treatment is working, the laboratory may not find the HIV virus in your child's blood. This is called "being undetectable." HIV is still there, but at a very low level.
- If undetectable, then your child will stay healthy and, in the future, will not transmit HIV to others sexually.
- It is important to have viral load tests done and to know your child's viral load test results.

Let's Review

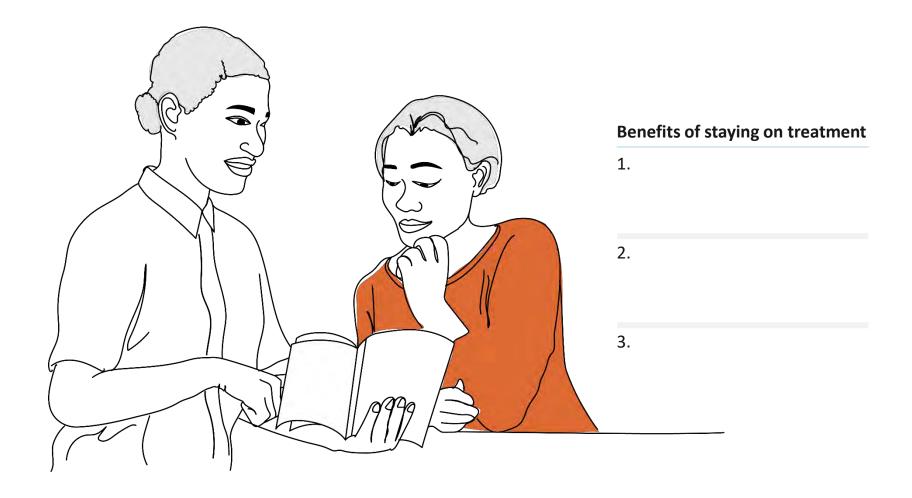
- In your own words, what is a viral load?
- What are the benefits of achieving a low viral load?
- For a child newly initiated on ART, when should s/he have a viral load test?*

*Refer to national guidelines for appropriate timing and algorithms.

TALKING POINTS

- Viral load is the amount of HIV virus in the blood; viral load tests measure the amount of virus in the blood.
- If your child stops his/her medication, HIV will make more copies of itself, and over time, she/he will get very sick. This is called AIDS.
- AIDS can lead to death and increases the risk of passing HIV to someone else.
- However, if your child takes his/her medication exactly as prescribed by the doctor and the treatment is working, the laboratory test may not find HIV in his/her blood. This is called being undetectable. The virus is still there, but at a very low level.
- When your child adheres to his/her medications, his/her viral load test result number will usually be less than 1,000 after six months. The goal is to have a low viral load number (200 ml or lower).
- It is important to have your child's viral load test done and to know the results of the test.
- What are some of the benefits of having a suppressed viral load?
 - Staying healthy and living longer
 - Making fewer hospital visits
 - If undetectable (refer to national guidelines), a person cannot transmit HIV to their sexual partners. However, it is still important to use condoms to protect against other sexually transmitted infections.

4. Why start and stay on treatment?



4. Why start and stay on treatment?



KEY MESSAGES

A simple sticker/notecard system in your home may help you remember why your child needs to stay on his/her medications.



Counselor Instructions

Ask the caregiver what support the child might need and from whom to maintain his/her motivation to stay healthy.



Document

Document the specific barriers in the Adherence Barriers and Interventions Log.

TALKING POINTS

 What are some of the benefits or reasons for your child to start and stay on treatment?

Note for the counselor: Please write them on a notecard.

- Some people use a sticker/notecard system to remember the reasons for staying on treatment.
- You can place a sticker, string, or colored piece of paper somewhere in your home to help your child remember:
 - To take his/her medicine daily and on time
 - Why it is important to take medication and go to clinic appointments
- If a sticker/notecard system would not work for your child, what else might work?

5. Planning to stay on treatment



Taking medications on time can be challenging.

Developing a plan to address possible challenges will make it easier when challenges arise.

We will:

- A. Identify possible challenges
- B. Develop a plan and backup plan to address each potential challenge

5. Planning to stay on treatment

KEY MESSAGES

- Taking medications on time can be challenging.
- Making a plan to address possible challenges will make it easier when challenges arise.



Counselor Instructions

- Use motivational interviewing techniques such as the importance/confidence ruler to gauge the caregiver's readiness and confidence in initiating treatment for their child.
- Based on the challenges identified by the caregiver, proceed to the relevant cue cards in this section.

TALKING POINTS

- On a scale of 1–10 how important is it for your child to start and stay on treatment? (1 = not important; 10 = very important)
 - Why did you provide a ____ [caregiver's number], as opposed to a [insert a lower number]?
- How confident are you that your child could start and stay on treatment, on a scale of 1–10? What can make you more confident?
- What do you see as some potential challenges?
- Based on the challenges you identified; we can discuss some methods to help your child achieve his/her treatment goals.
 - With each one we will create a plan and backup plan.
 - This will help your child stay healthy and live the lifestyle you want him/her to live.
- How does this sound to you?
- Any questions before we talk about those challenges?

SECTION

2

Addressing Barriers to Adherence

SECTION

2

Addressing Barriers to Adherence

6. Transportation to the clinic



6. Transportation to the clinic



KEY MESSAGES

Transportation challenges are common but can be overcome by planning ahead.





- What support might you and your child need to make it to the next appointment?
- How is travelling to the ART clinic impacting your child's adherence to treatment?
- What would you or your child need to resolve the transport issues?



Document

Document the specific barriers you identify in the **Adherence Barriers and Interventions Log.**

TALKING POINTS

- How does your child usually get to his/her medical appointments? (caregiver takes him/her; walking, driving, moto, bus, taxi, friend)
- Does your child usually get to his/her appointments on time?
 If not, what is your goal for achieving this?
- Identify potential barriers:
 - What problems does your child usually experience with transportation? (not enough money for transport, rainy season, transport not available at time of appointment, clinic is too far, child's appointment is not the same day and time as other family members' appointment, etc.)
- What is your plan and backup plan to address these challenges?
 - Child will get to appointments by _____ (walk, bus, taxi, etc.)
 - In case of a problem (e.g., no bus fare, rain, etc.)
 caregiver/child will get to appointment by ______

7. Keeping appointment dates and obtaining medication refills





7. Keeping appointment dates and obtaining medication refills



KEY MESSAGES

Getting ART refills, keeping clinical appointments, and having viral load tests done are key to ensure continuity of treatment.

Counselor Instructions

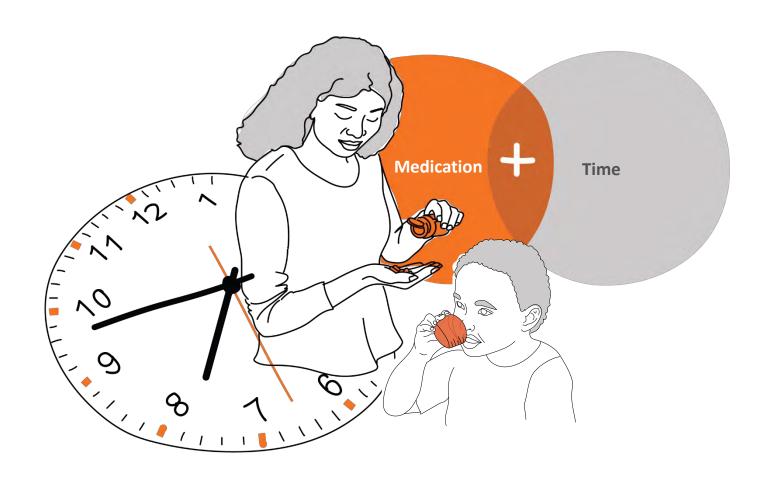
- 1. Ask the caregiver:
 - What support might your child need to ensure he/she remembers their appointments?
 - How can I support you and your child to help disclose his/her status to a family member or loved one?
- 2. Remind the caregiver the days and hours of operation of the ART clinic.

Document

Document the specific barriers you identify in the **Adherence Barriers and Interventions Log.**

- What might cause your child to miss appointments?
 - Caregiver not available, school, stigma and discrimination, lack of HIV status disclosure, illness, etc.
 - Plan to change treatment site/moving soon
- What is your goal to keep appointments and obtain drug refills?
- What can you or I do to make sure that your child keeps the appointment dates and obtains refills?
 - Receive SMS or a phone call appointment reminder from the ART clinic or from the OVC program
 - Have a family member or friend pick up the medication refills
 - Create a physical calendar
 - Set up automatic reminders using a phone

8. Making a daily medication schedule



8. Making a daily medication schedule



KEY MESSAGES

Simple cues at home can help a child remember to take his/her medications regularly. Such strategies have proven to improve adherence.

Counselor Instructions

- Use open-ended questions (for example): What support do you need to ensure your child remembers to take the medications?
- Identify possible solutions based on potential risks



Document

Document the specific barriers in the **Adherence Barriers and Interventions Log.**

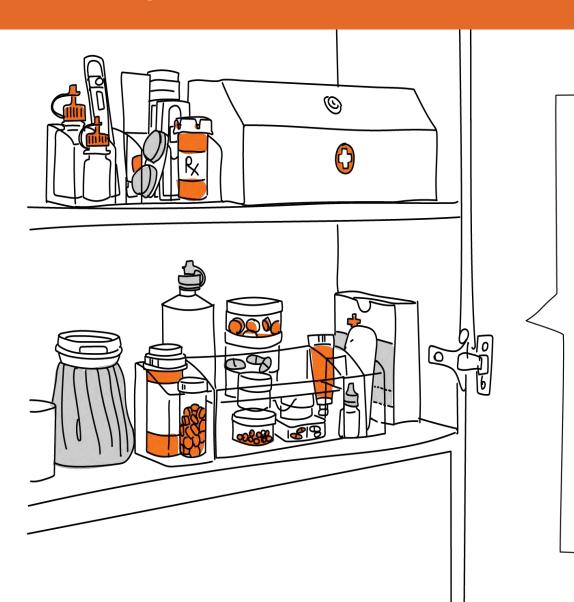
TALKING POINTS

- What happens in your child's typical day from the moment she/he wakes up to when she/he goes to sleep?
- What might prevent him/her from taking his/her medication? When might it be harder for him/her? (identify specific times and situations)
- What activities could your child carry out at the same time as taking her/his medication so that each time she/he does it, she/he will remember to take her/his medication?
- What can your child do to take his/her medications on time?
 We can make a medication schedule together to ensure your child takes his/her drugs on time and keeps their virus level low.

Strategies:

- Put medications somewhere easy to remember, near something your child uses everyday.
- Take them at dinner or during a nightly TV or radio show.
- Place reminders around the house (a piece of tape, a string tied around a door, in the bathroom, etc.).
- Set an alarm on your phone.
- Carry extra medications wherever your child goes.
- Use pillboxes and a calendar to keep track of when your child takes his/her medication.
- Ask for extra medications if your child will not be able to return to the health facility in time for the next refill.
- Work with a treatment buddy; request SMS reminders from counselor.

9. Storing medications



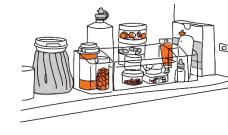
Storage place:

Backup storage place:

Extra supply medication will be carried in:

Extra supply medication will be stored inside:

9. Storing medications



KEY MESSAGES

It may help to have extra medications in a place you can always access them.



Counselor Instructions

Use open-ended questions (for example):

- What is a reliable place you or your child can store the medications?
- What challenges might arise if medications are stored in _____?



Document

Document the specific barriers in the Adherence Barriers and Interventions Log.

TALKING POINTS

- How do you plan to store your child's medications safely?
- What might get in the way of storing your child's medications properly?
- What would happen if other people saw your child's medications?
- Are there young children in the house who may open your medication containers?
- If so, what are some private places in your home where you can store your child's medications away from other children?
- Where could you keep some extra medicine just in case?

Possible solutions:

- Store extra medications in a purse/handbag, backpack, jacket, special compartment, sealed container, etc.; a place where it is always with you.
- Put the pill bottle inside an unmarked box (do not re-pack the pills into another container because the pill bottles contain a substance to keep the pills dry and preserve them).
- Use pill boxes rather than bottles when transporting the medications to school or travelling.

10. When at school



10. When at school



KEY MESSAGES

- Children might have limited ability to act toward achieving their personal treatment goals in school because of dependence on teachers and school nurses.
- Children may need to store and take their medication under the supervision of school nurses, which can lead to involuntary disclosure.
- The school can also limit the child's privacy, leading to stigma and discrimination.
- Older children/adolescents need to be accepted and appreciated by their peers, which can result in peer pressure.

Counselor Instructions



Use open-ended questions (for example):

- Does your child take medications exactly as she/he should when in school? If not, why?
- How is the school assisting your child to adhere to the medications?
- Have you or your child disclosed his/her status to anyone within the school?
- Does your child experience any stigma or pressure from peers that negatively impacts his/her adherence to treatment?

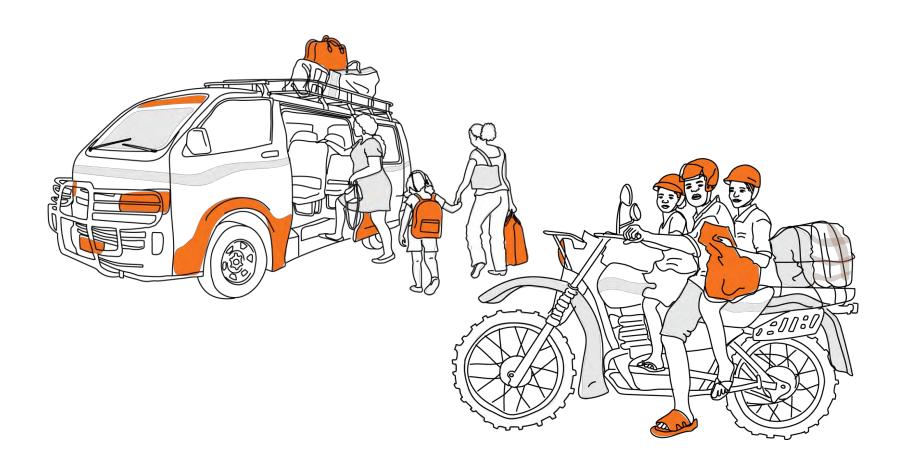
Document



Document the specific barriers on the **Adherence Barriers and Interventions Log.**

- At boarding school, children might feel dependent on teachers or school nurses to achieve their treatmentrelated goals. – Does your child feel this way?
- Children may need to store and take medication under the supervision of a school nurse, which can lead to involuntary disclosure. – Has this happened to your child?
- Disclosing one's HIV (positive) status in school may lead to loss of friends, bullying, social exclusion, and being denied schooling. – Has your child disclosed to anyone there? How did it change your child's life and adherence to the medications?
- Older children/adolescents like being accepted and appreciated by their peers. – Does wanting acceptance and appreciation from peers influence your child's choices and adherence to the medications?
- HIV-related stigma in school environments can be made worse by limited privacy, inadequate systems for supporting students living with HIV, and lack of family support and advocacy on behalf of the child. – Is your child's boarding school supporting your child to stay on treatment and continue being healthy?
- Transitioning out of school may affect treatment continuity.
 - Do you think this might happen to your child as well?

11. Traveling away from home



11. Traveling away from home



KEY MESSAGES

- Your child's traveling might disrupt his/her adherence to treatment.
- Prior to your child's trip obtain sufficient medications from the clinic so your child doesn't run out of pills before returning home.
- It is also important to identify a backup clinic where medications can be obtained in case the child's return home is delayed. I can help you identify a clinic.
- If you are planning to travel away from home, make sure to call your child to remind him/her to take the medication or ask someone you trust to remind him/her.

Counselor Instructions



Assess the child's and caregiver's likelihood of travel:

- Do you plan to travel without your child and need help with caretaking while you are away from home?
- Does your child plan to travel for school or to visit relatives?
- Would you be comfortable letting me know of any trips you or your child plan to make?

Make sure the caregiver has your contact information and the clinic's saved in his/her phone. Obtain a backup number of a family member or friend who knows about the child's status and can help reach him/her if needed.

Document



Document the specific barriers you identify in the **Adherence Barriers and Interventions Log.**

- Does your child ever travel away from home? What might prevent him/her from taking his/her medications while he/she is away? (i.e., running out of medications, having medications stolen, not wanting others to see him/her take the medication)
- What could you do to ensure he/she takes his/her medications while he/she is away?
 - Send your child the medication by bus, or with a family member or friend traveling to that area.
 - Identify another clinic in the area where your child is going, so he/she can get the medications there.
 - Ask a teacher, family member, or friend in the area where your child is to monitor him/her in taking the medication.
- Do you ever travel away from home and leave your child alone? What might prevent him/her from taking his/her medications when you are away? (i.e., forgetting because you are not there to remind him/her)
- What could you do to ensure your child takes his/her medications while you are away?
 - Ask a family member, friend or neighbor to remind your child to take his/her medication.
 - If your child has a phone, call to remind him/her to take the medication.

12. Coping with side effects



12. Coping with side effects





KEY MESSAGES

- Some children experience side effects, many of which will lessen over time. Continuing to take the medication is very important.
- Caregivers should inform the case worker of any side effects and discuss whether a referral to the ART clinic is needed for a review of the medication.

Counselor Instructions

If your child has not begun taking medications, you can discuss potential side effects and develop a plan for addressing them if they arise.

 Who can you contact if your child experiences discomfort or side effects?

Document



Document the specific barriers on the **Adherence Barriers and Interventions Log.**

TALKING POINTS

- What side effects has your child experienced from his/her medications?
 If your child has not experienced any side effects, what have you heard about side effects related to HIV treatment?
 - Common side effects are headache, nausea, and muscle aches.
 - Your child should stay on treatment even if she/he experiences side effects.
- What side effects has your child experienced that made him/her stop medication, or that would make him/her stop if she/he had them?
- What have you done about any side effects your child has experienced? Have you talked to his/her doctor about them?
- What will you do if your child experiences any of the common side effects we have discussed?

Possible solutions:

- Immediately contact your clinical provider to discuss any side effects, and how your child feels about the medications. The provider will determine if there is a need to discontinue or change the treatment regimen.
- Have your child continue taking his/her medication until he/she has been seen by the doctor.
- Have your child take his/her medication with food (to avoid nausea or headache).
- Have your child take his/her medication at night (to avoid drowsiness/mood changes).

13. Disclosure



Tell a trusted family member or friend about your child's HIV status.

13. Disclosure



KEY MESSAGES

- Not knowing their HIV status is one of the most important barriers to adherence among children.
- Knowing their HIV status helps children adhere to treatment.
- Disclosing the child's HIV status to family members or close friends can help the child receive more support for adhering to ART.
- Disclosure should always be voluntary.
- Support for disclosure should be age-appropriate and supported by a trained counselor.

Counselor Instructions

Use open-ended questions (for example):

- Do you think that disclosing your child's HIV status can help improve his/her adherence to ART?
- What do you think about disclosing your child's HIV status to your family and/or people you are close to?
- What support would you like to receive to assist you with disclosure to others?

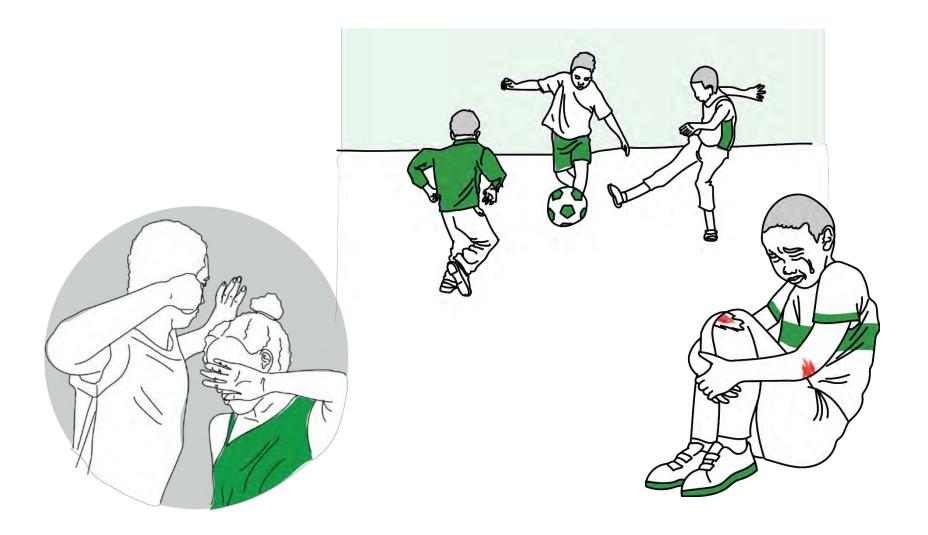
Document



Document any concerns and discuss how they can be mitigated.

- It is important that children living with HIV know their HIV status. This is critical to ensure they adhere to treatment.
- Caregivers should disclose to their children, but this must be done with the support of a counselor.
- Disclosure is a process and must be done in an ageappropriate way.
- Disclosing your child's HIV status to other family members and key people in your child's life (e.g., their teacher) is also important since it can help your child receive more support.
- Disclosure of your child's HIV status is a voluntary decision. You do not have to disclose to anyone, but it may help to have someone close to you know, so they can support your child's treatment plan.
- I can help you disclose to your child [Note for counselor: Say this only if you have been trained on disclosure.] or link you to a trained counselor in the ART clinic that can help.

14. Violence



14. Violence



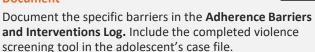
KEY MESSAGES

- Children living with HIV may experience stigma and discrimination due to their HIV-positive status.
- Stigma and discrimination can lead to violence toward children: neglect, and physical, sexual, or emotional violence.
- Violence can negatively affect treatment initiation, adherence, and continuity.
- There are safe, specialized and private services that support survivors of violence.

Counselor Instructions

- Assess the child for violence/risk of violence using the OVC program's violence screening tool.
- Refer the child for support if risk of violence is identified, using the OVC program's service provider directory.
- If violence is identified/disclosed, provide firstline support using the Listen, Inquire, Validate, Enhance, Safety and Support (LIVES) approach and refer to post-violence care services.

Document



- Children living with HIV may experience stigma and discrimination at home, in the community, and in school due to their HIV-positive status. Stigma and discrimination may manifest as neglect or physical, sexual, or emotional violence.
- Examples of stigma and discrimination include exclusion from education, food, health, or other basic support; or physical sexual violence within the community and/or family; as well bullying and teasing by peers in the community and in school.
- Violence, in all forms, can negatively affect treatment initiation, adherence and continuity, so it's important that we discuss any violence that your child has experienced.
- Remember that this is a safe and private space, and that I am here to support you and your child. I will keep all information you share with me confidential.
- Has your child ever experienced any type of violence at home, at school, or in your community you would like to share with me?
 - (If violence has been experienced) Who did you tell about this?
 - (If violence was disclosed) What support did your child receive?
 - (If violence was not disclosed to anyone) Why didn't you tell anyone?
- How did this experience of violence affect your child's initiation or adherence to HIV treatment?
- Specialized confidential services are available to help survivors of violence, as well as safe spaces where survivors can stay to prevent further violence. Would you like me to refer and accompany you and your child to such services?

15. Substance use



15. Substance use



KEY MESSAGES

- If your adolescent child uses substances, it is important to ensure this does not prevent him/her from taking his/her medications every day and on time.
- Substance use can negatively impact your child's treatment adherence and prevent him/her from reaching viral load suppression.
- Specialized services are available to help your child with substance use.



Counselor Instructions

Use the OVC program's service directory to identify a service provider and refer the child to substance use treatment and counseling if desired and available.

Document



Document the specific barriers identified in the **Adherence Barriers and Interventions Log.**

- Substance use among adolescents can negatively impact their treatment adherence and prevent them from reaching viral load suppression.
- If your adolescent child uses drugs/alcohol regularly, we can plan together how she/he can remember to take her/his medications while using.
- What aspects of your child's substance use might make it challenging for him/her to remember to take his/her medications?
 - How often does she/he drink alcohol or use other drugs?
 - How does this interfere with taking his/her medications?
 - Does she/he forget to take medication when using?
- What can your child do to remember to take his/her medicine when using?
 - Who is she/he usually with and where when drinking/using drugs?
 - Is there a friend/family member (e.g., support person) who could bring medicine and encourage him/her you to take it?
 - Would hearing an alarm/seeing stickers help him/her remember?
 - What if the time of the medication changed? Would that help him/her remember?
- Does your child need help or support for stopping substance use? I can refer him/her to specialized services.

16. Mental health



16. Mental health



KEY MESSAGES

- Mental health problems can affect adherence to treatment, particularly among adolescents.
- Psychologists and counselors can help children and adolescents with mental health problems understand and cope better with their negative feelings and emotions.

Counselor Instructions



Ask the following questions:

- How does your child feel today?
- Has your child felt this way before?
- Has your child had any issues within the family, with friends or peers, or within your community?
- Does your child have suicidal thoughts?

If the child is having suicidal thoughts, urgently refer and accompany him/her to a mental health service provider in the health facility.

Document



Document the specific barriers on the **Adherence Barriers and Interventions Log.**

- An HIV-positive diagnosis and the associated stigma and discrimination from family, peers, community members, and health facility staff can lead to mental health issues, particularly among adolescents.
- Children and adolescents with mental health issues are less likely to adhere to treatment and achieve viral load suppression.
- Does your child often experience any of the following emotions or behaviors?
 - Anxiety, sadness, hopelessness, anger
 - Feels life is not worth living/has suicidal thoughts
 - Has lost interest in things she/he used to love
 - Is always fatigued and/or complains about physical problems
- What do you think is making you child feel this way?
- What does your child do to cope with these feelings and emotions?
- A psychologist or counselor can help your child understand and cope better with negative feelings and emotions.
- Would you like me to refer your child to the health facility so he/she can see a psychologist or counselor? Would you like me to accompany you and your child?
- Remember that I am here to support you.

17. Physical health







17. Physical health







KEY MESSAGES

- You should visit your child's ART clinic if he/she constantly has diarrhea, vomiting, headache, rash, fever, or fatigue.
- You can visit your child's ART clinic between appointments, even if your child has received a three- to six-month supply of ARVs.



Counselor Instructions

Use open-ended questions (for example):

• When might your child need to see a health worker between appointments?

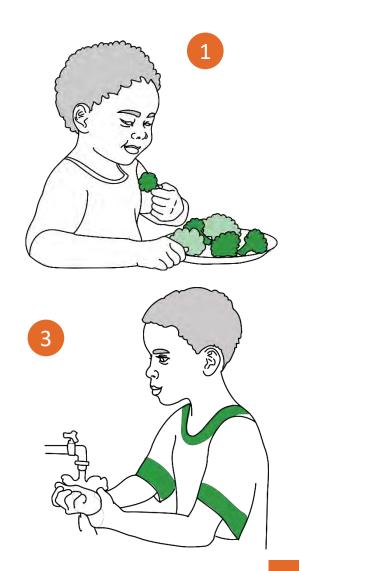


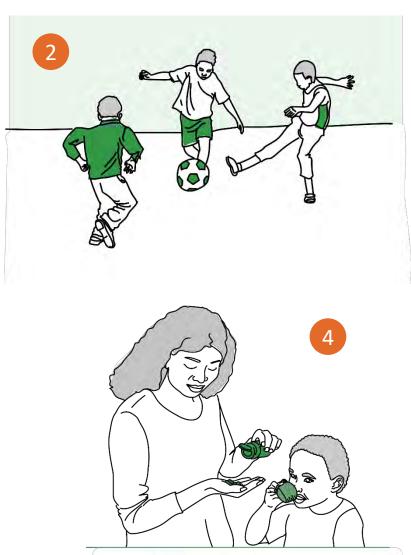
Document

Document any problems or concerns and discuss how they can be mitigated.

- Does your child often have diarrhea, nausea, vomiting, abdominal pain, headache, rash, fever, or fatigue?
- You should take your child to the ART clinic as soon as possible if she/he ever has any of these symptoms, before she/he gets too sick.
- Remember that you can still contact or visit your child's ART clinic between appointments, even if your child has received a three- to six-month supply of medications.
- It's also important to inform me/your case worker whenever your child has a health problem, so that you and your child can receive any support you may need.
- Do you have my/your case worker's telephone number or other contact information?

18. Healthy lifestyle and ART adherence





18. Healthy lifestyle and ART adherence



KEY MESSAGES

- To keep healthy, it is important for your child to take HIV medication as indicated by his/her doctor to maintain viral suppression.
- It's also important for your child to have a healthy lifestyle to prevent illnesses and stay healthy.
- A healthy lifestyle includes eating healthy foods, drinking clean water, practicing good hygiene, and exercising regularly.

Counselor's Instruction



Use open-ended questions for example:

What should your child continue to do to stay healthy?

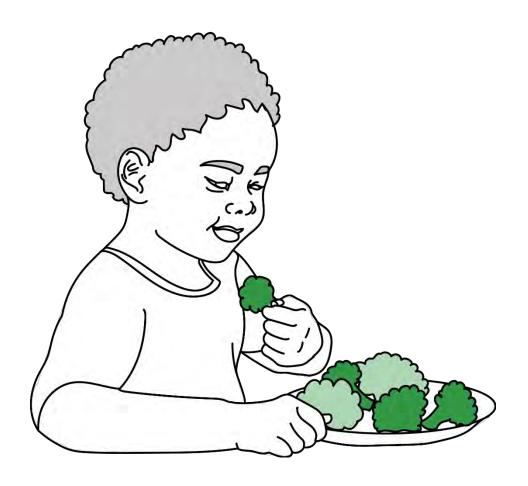
Document



Document any concerns and discuss how they can be mitigated.

- To be healthy and become virally suppressed, your child needs to take his/her medications as prescribed. She/he also needs to have a healthy lifestyle.
- Having a healthy lifestyle means that your child:
 - Has all the vaccines she/he needs for his/her age. Vaccines help prevent infections and diseases.
 - Has proper nutrition by eating healthy foods, such as fruits and vegetables.
 - Drinks clean water.
 - Uses a latrine or toilet.
 - Practices good personal hygiene, including hand washing and menstrual hygiene.
 - Stays active and exercises or plays sports regularly.

19. Nutrition and food security



19. Nutrition and food security



KEY MESSAGES

- Good nutrition means your child has enough nutritious food to eat every day from the three food groups (carbohydrates, protein, fats) to be strong, have energy, and grow.
- Nutritious food (e.g., fruits, vegetables) are especially important for your child since they help protect him/her from diseases and stay healthy.
- Taking food with medication can help your child avoid side effects.

Counselor's Instructions



Use open-ended questions (for example):

What types of foods do you think will help your child have proper nutrition?

Use a job aid to explain and provide examples of the foods in each of the three food groups.

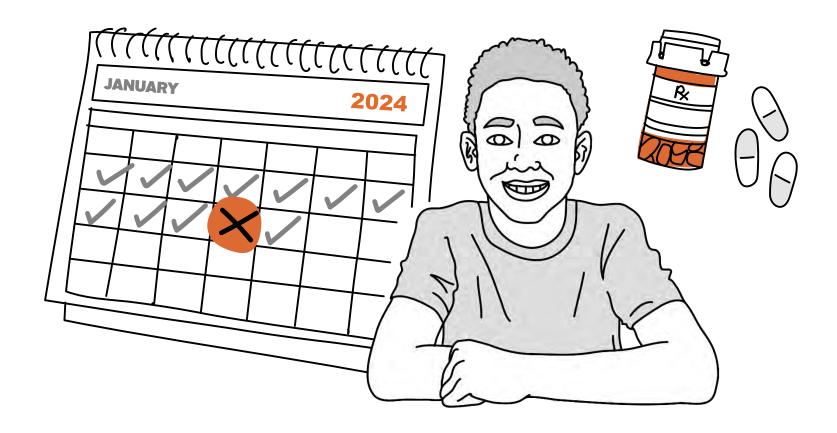
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Document any concerns and discuss how they it can be mitigated.

- Today we will talk about how important it is for your child to have enough nutritious food to eat.
- Good nutrition means your child has the food his/her body needs every day to be strong, have energy, and grow and develop.
- Good nutrition requires a balanced diet that includes proteins, carbohydrates, and fats to obtain essential vitamins and minerals.
- Good nutrition protects your child against diseases, which is especially important for him/her to stay healthy.
- Having enough food also allows your child take her/his HIV medication with food, which helps avoid side effects.
- Eating nutritious food is also important for adolescent girls who are pregnant or new mothers. This can protect her health, as well as her baby's health.

20. Handling missed doses



20. Handling missed doses



KEY MESSAGES

- It's understandable to miss a dose from time to time. However, it is important to get your child back on track as soon as you realize it.
- Your child should never be made to feel foolish for missing one or more doses.
- Identify strategies to help your child avoid missing doses in the future.



Counselor Instructions

Follow up on missed doses with the caregiver in each session.



Document

Document the specific barriers on the **Adherence Barriers and Interventions Log.**

- Make sure your child takes her/his medications as prescribed.
 She/he should not miss any doses.
- Remember, when your child misses doses the virus can make more copies of itself, or change. If the virus changes, your child's medicine may no longer work, and she/he may become very ill.
- Some people forget to take their medications from time to time. The important thing is to learn from the experience so that it doesn't happen again in the future.
- What are some of the reasons that have contributed to your child missing doses?
- What would be the best way for you to respond when your child misses a dose?
- When your child misses a dose, you should keep a positive attitude and try to help him/her return to his/her medication schedule as soon as possible.
- What beliefs may keep your child from restarting his/her medication schedule after missing a dose?

21. Psychosocial and peer support



21. Psychosocial and peer support



KEY MESSAGES

- Psychosocial support (PSS) are activities to support a person's emotional, social, mental, and spiritual needs.
- PSS helps caregivers and children cope better with the challenges of living with HIV and adhere to treatment.
- It's important for you and your child to join a peer support group, so both of you can receive PSS and learn from the experiences of others in your same situation.

Counselor Instructions

Use open-ended questions (for example): What kind of psychosocial or peer support do you think you and your child may need?

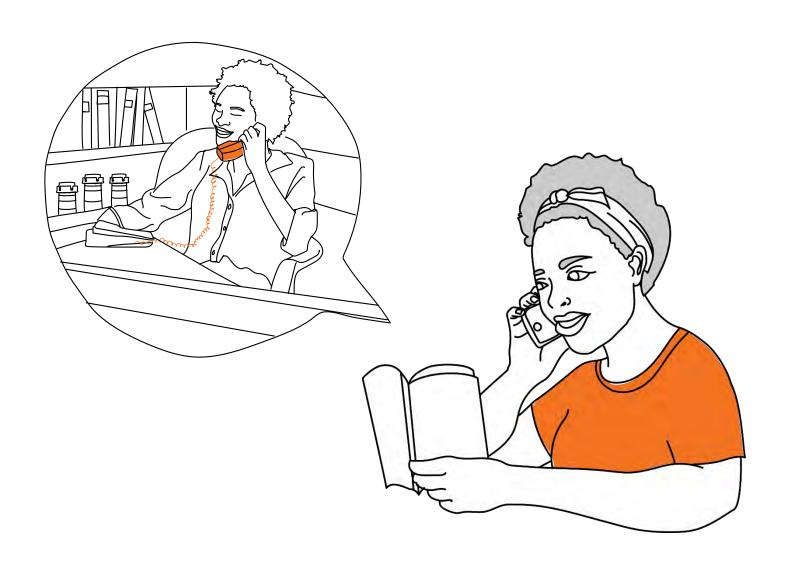


Document

Document any concerns and discuss how they can be mitigated.

- What do you know about psychosocial support (PSS)?
- PSS are activities to support a person's emotional, social, mental, and spiritual needs. These activities help people living with HIV (PLHIV), including children and their caregivers, cope with challenges related to HIV infection, including adherence, disclosure, and stigma and discrimination.
- PSS for children include:
 - Support for establishing trusting relationships with caregivers and/or other adults
 - Basic counseling during home visits or clinic visits
 - Support groups and mentorship programs
 - Activities that nurture feelings of being loved, supported, and safe
- Peer support groups are particularly important for children older than 10 years of age (adolescents) and for caregivers because they receive support and learn from peers who are positive role models.
- Peer support groups are available for your child. Would you like to know more about them? Would you like me to help your child join a group?
- I provide psychosocial support to you and your child during these counseling sessions, but if you would like to receive additional support from someone else, please let me know. I will be happy to put you in touch with them.
 - Who can provide support to your child? Does your child have a family member, teacher, or friend who can support him/her?
 - Why would this be a good person to provide support to your child?
 - Does this person know your child's HIV status? If not, how and when will you disclose to them?
 - If this person is unable to support, who else could you ask? (backup plan)

22. Communicating with the treatment team



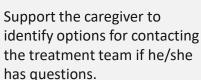
22. Communicating with the treatment team



KEY MESSAGES

The treatment team in the ART clinic includes the HIV clinical providers (doctor, nurse), the peer support group manager, and the OVC linkage coordinator and OVC case worker. They can be contacted anytime with questions, especially if psychosocial issues or unforeseen situations arise that may impact your child's ability to stay on treatment.





Document

Document the specific barriers on the **Adherence Barriers and Interventions Log.**

TALKING POINTS

- It is important for you to communicate with your child's treatment team whenever you have questions or concerns.
- Your child's treatment team includes the HIV clinical providers (doctor, nurse), the peer support group manager, the OVC linkage coordinator and your OVC case worker.
- You can contact the treatment team anytime with questions, especially if issues or situations arise that may impact your child's ability to adhere to treatment. I can give you their telephone numbers if you need them.
- Before you talk to the treatment team it is important to write down any questions or concerns you may have on a piece of paper, so you don't forget them.

Questions for discussion:

- What might prevent you or your child from speaking to the doctor, nurse, counselor, OVC linkage coordinator, or OVC case worker at your child's clinic about any concerns you have?
- Who on your child's treatment team do you feel most comfortable talking to?
 - What can you do to make sure you see this person during your child's visit to the ART clinic?
 - If this person is not at the ART clinic on the day of your visit, who would you speak to about your questions or concerns?

23. Review and summary of adherence planning



23. Review and summary of adherence planning



KEY MESSAGES

Making plans to help your child stay on treatment empowers your him/her to take charge of his/her own health.



Counselor Instructions

Use motivational interviewing techniques to reinforce what the caregivers and children remember from the discussion.

- Provide support for any items that the child may have forgotten.
- Always end on a positive note.
- Affirm that the efforts the child is making demonstrate how dedicated he/she is to protecting their health.



Document

Document the specific barriers on the **Adherence Barriers and Interventions Log.**

- Let's review what we have talked about today:
 - Motivation for starting (or) staying on treatment
 - Potential barriers to staying on treatment
 - Plans and backup plans
- Can you tell me the plans and backup plans we agreed on today?
 - PROBE ON, AND IF NEEDED, SUMMARIZE ANY PLANS
 AND BACKUP PLANS THAT THE CAREGIVER DEVELOPED.
- Do you have any questions or concerns about the plans/backup plans we agreed on today, or anything else?
- Thank you again for taking the time to talk today about why adherence to medication is important, and how you can support your child to stay on treatment.
- I look forward to meeting with you and your child again on
- Would you like to receive a reminder of our next meeting?

SECTION

3

Multimonth Dispensing (MMD)

SECTION

3

Multimonth Dispensing (MMD)

24. Optimized treatment



24. Optimized treatment



KEY MESSAGES

- Current medications are easier to take. They are also safer and more effective because they achieve faster viral suppression with fewer side effects.
- A several-months supply of these medications can be provided to your child [Note for the counselor: MMD is recommended for children ages 2+ years depending on national guidelines.]



Counselor's Instructions

Use open-ended questions (for example):

- How would you rate your child's current medication?
- Do you have any questions about the type of medication your child is taking?

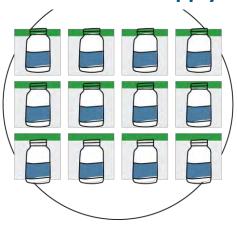
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Document any concerns on the child's medications and discuss how they can be mitigated.

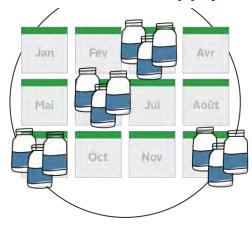
- Current antiretroviral medications are safer and more effective than earlier ones.
- They help children achieve viral suppression faster with fewer side effects and are easier to take.
- Children can take them over a long time, even when they reach adolescence.
- When your child becomes an adult, she/he might not need to change medications if her/his clinical situation has not changed.
- Because the medications are now so much better, HIV clinical providers can provide a several-months supply for your child.

25. Multimonth dispensing (MMD)

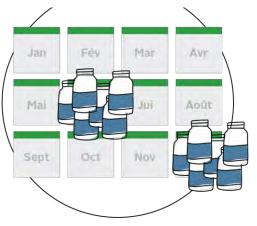
One-month supply



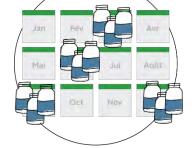
Three-months supply



Six-months supply



25. Multimonth dispensing (MMD)



KEY MESSAGES

Multimonth dispensing refers to receiving a three- to six-month supply of medication, resulting in fewer visits per year to the ART clinic for medication refills.



Counselor's Instructions

Use open-ended questions (for example):

- What have you heard about multimonth dispensing of antiretroviral drugs?
- What do you think about the fact that your child has to go to the ART clinic less times per year?



Document

Document any concern and discuss how it can be mitigated.

- Instead of receiving a one-month supply of medication, your child may receive enough for three to six months. This is called multimonth dispensing.
- This means that you will only need to pick up medications for your child a few times a year.
- The medication your child will receive is the same he/she has been taking. The only thing that changes is the amount of medication they receive at each visit.
- Do not share or sell your child's ARV drugs.
 This will not help anyone and could prevent your child from having enough medication to take.

26. Benefits of multimonth dispensing



26. Benefits of multimonth dispensing



KEY MESSAGES

- Fewer visits to the ART clinic saves you time and money you can use for other personal and family needs, work, and social activities.
- The waiting time for medication refills will be shorter, the time available to speak with the health care provider will be longer, and the risk of exposure to contagious diseases will be lower.



Counselor Instructions

Use open-ended questions (for example):

- In your opinion, what are the advantages or disadvantages for you and your child of going to the ART clinic less often?
- Which of these benefits are you most interested in?
- What will you do with the time and money you save each month?



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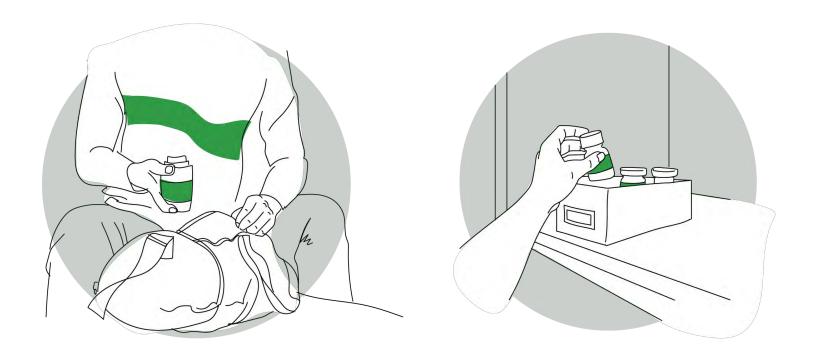
Document any concerns and discuss how they can be mitigated.

TALKING POINTS

Multimonth dispensing has many benefits:

- Your child does not have to visit the ART clinic as often, saving you time and money each month.
- You can use the money you save for other important needs such as food, clothes, or for savings.
- You can use the time you save for other activities, such as doing work at home or at another job or spending more time with your child and family.
- Having more free time also improves your mental health; since it allows you to take better care of your child and your family.
- Your child will spend less time waiting in the ART clinic and will have less risk of exposure to contagious diseases such as the corona virus.
- You and your child will have more time to talk to the clinical providers.
- Your child will not have to miss school as often to go to the ART clinic.

27. Challenges of multimonth dispensing



27. Challenges of multimonth dispensing





KEY MESSAGES

- You can use a discreet bag to carry your child's medications to protect his/her privacy.
- At home, you should keep the medicines in a cool, secure place.
- You can always go back to see your child's clinical provider in between appointments.

Counselor Instructions



Use open-ended questions (for example):

- What are your/your child's concerns about multimonth dispensing?
- How do you think these concerns could be overcome?

Document



Document any concerns and discuss how they can be mitigated.

TALKING POINTS

There are some things you can do to avoid some of the challenges of multimonth dispensing:

- Use a discreet bag to carry your child's supply of medications to protect your child's privacy.
 Some caregivers use double bags for more privacy.
- At home, store the medications in a private, cool, and secure place.
- Some caregivers store the bottles/boxes of medications in different places in the house to avoid storing them all together.
- Other caregivers put the bottles/boxes in another unmarked box to ensure privacy.
- Because refills are less frequent, your child will also see the clinical provider less frequently, but you and your child can always come back to see the provider in between appointments, if needed.

SECTION

4

Decentralized Drug Distribution (DDD)

SECTION

4

Decentralized Drug Distribution (DDD)

28. Decentralized drug distribution (DDD)



28. Decentralized drug distribution (DDD)



KEY MESSAGES

- DDD is possible because today's medications are safer, easier to take, and more effective.
- The medications are the same ones your child has been taking but they can be picked up from a place that suits your needs better.
- DDD also helps reduce overcrowding in ART clinics and avoids exposing your child to the risk of contracting other infections.
- DDD reduces the time and money for traveling to the ART clinic and picking up medications.

Counselor Instructions

Use open-ended questions (for example):

- What do you know about the safety and convenience of the medications your child is taking?
- How much time and money do you spend traveling to the ART clinic to collect your child's medications?
- How long did your child have to wait in the ART clinic the last time you went there to collect the medications?
- If you and your child did not have to pick up the medication at the ART clinic, what would you do with that time and money?

Document

Document any concern and discuss how it can be mitigated.



- Your child can receive the new antiretroviral medications through decentralized drug distribution (DDD).
- This means that you or your child can pick up the medications at another location besides the ART clinic.
- The medications provided through DDD are the same as the ones your child has been taking. Nothing changes except the location where you pick them up.
- DDD will save you time and money since you will not need to travel to the ART clinic as often and wait to receive the medications.

29. DDD pickup points



29. DDD pickup points



KEY MESSAGES

- Medications can be picked up at the location that best suits your needs.
- I can offer you a list of places where you can collect your child's medications besides the ART clinic.
- You can discuss and agree on the pickup point with your clinical provider.

Counselor Instructions



Use open-ended questions (for example):

What do you know about DDD?

Document



Document any concerns and discuss how they can be mitigated.

- You can pick up the medicines for your child at the designated DDD points/locations. Pickup points can be:
 - Health posts
 - Community venues (for example, where community ART groups meet)
 - The office of community organizations or nongovernmental organizations
 - Private pharmacies
 - Private clinics
 - Faith-based organization clinics
 - Home delivery
- You can choose the pickup point that best suits you and your child. This may be a location:
 - Closer to your home that saves time and travel costs
 - Not necessarily closer to your residence, but better meets your child's needs for privacy and confidentiality
 - Where you receive other services
 - Your home, in some cases

30. Safety and quality of DDD services





30. Safety and quality of DDD services





KEY MESSAGES

- DDD pickup points are selected based on safety and convenience for clients, and services are offered in accordance with national guidelines.
- The quality of service is controlled, and medications are the same as those at the center.
- Antiretroviral drugs are prepackaged; their name is not visible on the outside.
- Where possible, other medications that a child requires are also provided.

Counselor Instructions

Use open-ended questions (for example):

- What are some of the concerns you have about DDD?
- How do you think you can overcome some of these concerns?



Document

Document any concern and discuss how it can be mitigated.

TALKING POINTS

You may have concerns about DDD, so let's talk more about this:

- The pickup points/locations are selected based on safety and convenience for clients. They meet all confidentiality and privacy standards.
- Medications and services are the same as those offered at the ARFT clinic.
- Services are offered in accordance with national guidelines and standards of care.
- The DDD providers (i.e., community worker, peer outreach worker, pharmacist) are trained on standards of care and national guidelines.
- The quality of service is regularly evaluated by the same team that evaluates this service in ART clinics.
- Medicines are provided to the pickup point by the ART clinic; a system ensures their uninterrupted availability.
- Medications are prepackaged and their name is not visible on the outside, so no one can see what your child is getting. The package does not have a personal ID, only a code that is linked to each child to ensure they receive the correct medications.
- Where possible, a three- to six-month supply is dispensed to avoid having to return too often for refills.
- When needed, other medication will be provided to your child, so you do not have to travel to multiple locations to pick up medications.

SECTION

5

Returning to Care and Special Situations

SECTION

5

Returning to Care and Special Situations

31. Follow-up adherence counseling visit



31. Follow-up adherence counseling visit



KEY MESSAGES

- It's good to see you again!
- Today we will continue to explore challenges you and your child may be having and actions we can take to ensure your child can stay healthy.



Counselor Instructions

- Explore barriers and challenges to the child's adherence.
- Use open-ended questions:
 - Affirm! Avoid having the caregiver and child feel they have failed.
 - Reframe: You are really taking your health seriously despite facing a number of challenges.
 - Note all challenges in the Log.
- Go to the appropriate cue cards in the Adherence Planning section to review plans and adjust as needed.

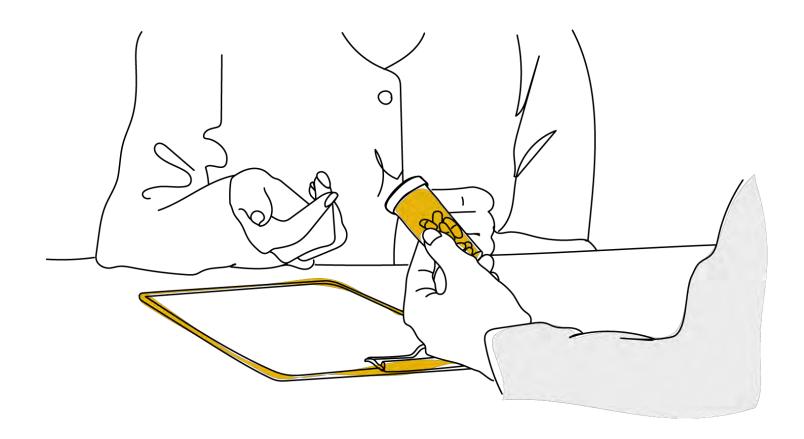


Document

Document the specific barriers in the **Adherence Barriers and Interventions Log.**

- Hello, how are you? Are there any specific issues you would like us to discuss today? (Take note so you can discuss them before the session ends).
- How are things going with the plans we discussed last time?
- Has your child faced any challenges that have affected his/her ability to stay on treatment since we met the last time? If so, what challenges? (Probe for the following challenges):
 - Adherence to treatment medications and schedule (Any issues with taking medications on time, missed doses, or medication side effects?)
 - Keeping appointments (Problems with transportation?, Inflexible school schedules?)
 - Provider-caregiver-child communication (Any privacy or confidentiality issues?)
 - Getting medication refills (Any issues with transport to the pickup point?)
 - Disclosure (Need to disclose to anyone new? Need to disclose to your child? Problems disclosing?)
 - Social support (Any stigma and discrimination issues?)
 - Violence (Any physical, sexual, or verbal violence?, Was it reported? How did it affect adherence?)
 - Substance use or mental health issues (What issues? and How are they affecting adherence?)
 - Travel (Any travel plans? How will medications be obtained?)
- Let's look back at your child's plan. We might have to make some revisions together to the plan. How does that sound to you?

32. Returning to care after having missed dose(s) or stopped treatment (1)



32. Returning to care after having missed dose(s) or stopped treatment (1/3)



KEY MESSAGES

- I'm glad to see you again, and to know that you continue to be committed to protecting your child's health.
- Today we will explore ways to help your child stay on treatment.



Counselor Instructions

Use open-ended questions:

- Affirm! Avoid making the caregiver or the child feel like they have failed.
- Reframe: You made an effort and faced some challenges. Coming in today shows how much you want your child to be healthy.
- Go the appropriate cue cards in the Adherence Planning section to develop or review their plan and adjust as needed.



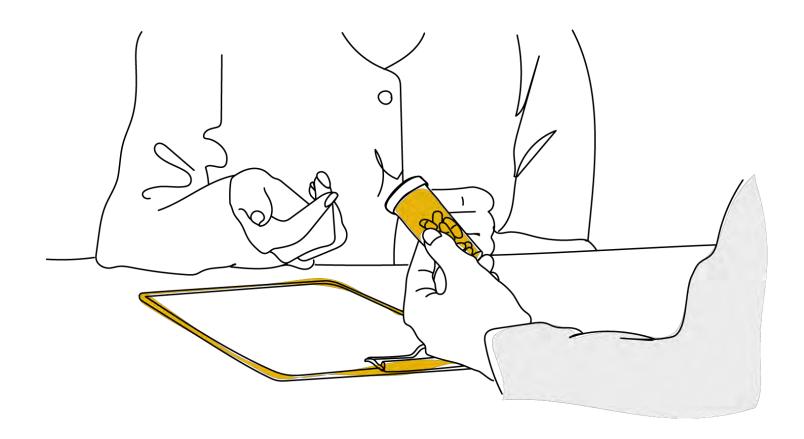
Document

Document the specific barriers on the Adherence Barriers and Interventions Log.

- Tell me about your child's experience taking his/her medications.
 - What medications was your child taking?
 - How was your child taking them?
 - What side effects did she/he have?
 - What were the reasons your child stopped taking them?
 - When did your child stop taking them?
- Let's explore the challenges that affected his/her treatment.

BARRIERS	PROBING QUESTIONS TO ASSESS BARRIERS
Limited knowledge	Can you tell me the names of your child's medications? What is the schedule/plan for your child to take them (e.g., what time of day, how many [if pills])? What is your understanding of the purpose of your child's medications?
Side effects	Have the medications affected the way your child feels? Please describe any problems they have caused (e.g., nausea, diarrhea, sleep disturbance).
Forgot taking dose(s)	Has your child ever or often forgotten to take the medications? Does your child take them at a set time of day? What is your method of reminding your child to take the medications?
Felt better	Does your child take the medications even when she/he is feeling well?
Illness	Has your child had any illnesses that prevented him/her from taking his/her medications?
Mental health	What is your child's mood in general? Has your child been feeling sad or confused? If yes, has this affected your child's ability to take the medications?
Health beliefs	Do you believe that it is good for your child's health to take his/her medications every day? Have you ever tried other remedies to treat your child for HIV? If so, what remedies?

32. Returning to care after having missed dose(s) or stopped treatment (2)



32. Returning to care after having missed dose(s) or stopped treatment (2/3)



KEY MESSAGES

Let's continue to explore ways to help your child stay on treatment and remain healthy.



Counselor Instructions

Summarize what was learned from the child about any specific barriers identified on this card.

A: Affirmations, for example:

- I appreciate that you are honest about the way your child takes the medications.
- You are clearly a resourceful person to manage so many challenges.
- You've worked really hard to ensure your child takes his/her medications despite these challenges.



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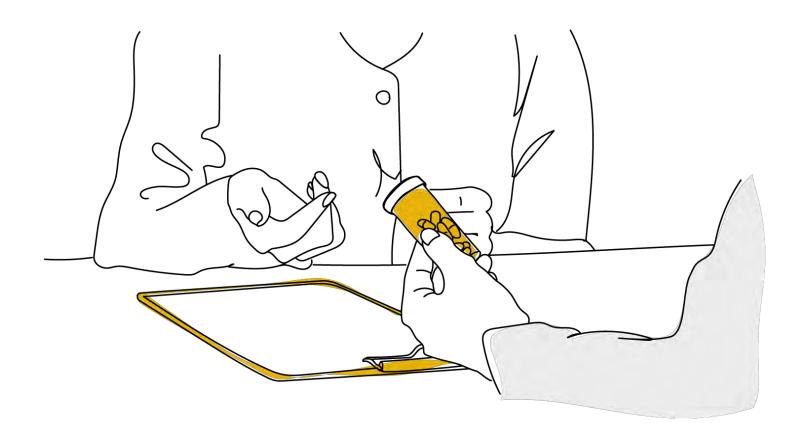
Document the specific barriers on the **Adherence Barriers and Interventions Log.**

TALKING POINTS

Let's continue to explore any challenges your child has faced to stay on treatment.

BARRIERS	QUESTIONS TO ASSESS BARRIERS		
Pill burden	Has the number of pills (pellets, granules, tablets) or amount of liquid been a challenge for your child?		
Lost/ran out of medication	Has your child lost or run out of medications?		
Transportation problems	Have you had any difficulties getting to the ART clinic to pick up your child's medications? If yes, what are the reasons? (e.g., work, long distance, transport expense)		
Scheduling difficulty	Has your child been too busy to take the medications? If yes, what are the reasons? (e.g., working on household chores, studying) Has your child traveled outside of your province/district to visit family/friends or for another reason for long periods of time? Has your child had inflexible school schedules that affected obtaining refills and taking medications daily?		
Sharing meds with others	Have you or your child shared your child's medications with others?		
Fear of disclosure	Have you disclosed your child's HIV status to your child, your family, your child's teacher, or close friends? If not, what are your concerns about disclosure? Are you afraid of potential violence if you disclose your child's status?		
Lack of family, friend/peer support	Have family members, teachers, friends/peers, or sexual partner (if your child is older and has a sexual partner) been non-supportive or kept your child from taking his/her medications? Has your child experienced any form of violence, including physical, sexual, or verbal?		
Inability to pay	Have ART clinic fees, or other fees, kept your child from taking his/her medications?		
Food insecurity	Has lack of food prevented your child from taking his/her medications?		

32. Returning to care after having missed dose(s) or stopped treatment (3)



32. Returning to care after having missed dose(s) or stopped treatment (3/3)



KEY MESSAGES

Let's continue exploring ways to help your child stay on treatment and remain healthy.

Counselor Instructions

Summarize what was learned from the child about any specific barriers identified on this card.

Use reflective listening, for example:

- You're wondering if it matters if your child takes his/her medications.
- So, you said your child feels angry when thinking about taking his/her medications and that makes it really hard.
- What I hear you saying is you and/or your child are so overwhelmed, that your child's health is the least of your problems right now.

Document

Document the specific barriers on the **Enhanced Adherence Plan Tool.**

TALKING POINTS

Let's continue to explore any challenges your child has faced in taking his/her medications.

BARRIERS	QUESTIONS TO ASSESS BARRIERS
Drug stock-out	Have you ever come to the ART clinic and found there were no medications available for your child, or was only given a small supply?
Long wait times	Have you ever left the ART clinic before receiving the medications because of very long wait times?
Stigma and discrimination	Are you afraid that people in your child's family, community, school, or group of friends will find out about your child's HIV status? Does that prevent you or your child from going to the ART clinic? Does that prevent your child from taking his/her HIV medications?
Political crisis/war/natural disaster	Is it ever unsafe for you to go to the ART clinic to pick up your child's medications?

Use summary statements (for example):

- Let me see if I understand so far. You are struggling to support your child to take his/her medications. You want your child to be well and healthy, but you also have other problems in your life that make it difficult to focus on your child's health.
- Here's what I heard you say, let me know if it is right. Your child feels fine when he/she misses a dose, and you are unsure about whether the medications are necessary to keep your child healthy.

33. Tips to improve taking medications (1)



Together we will find ways to make it easier for your child to take his/her medications.

33. Tips to improve taking medications (1/3)



KEY MESSAGES

Together we will find ways to make it easier for your child to take his/her medications.



Counselor Instructions

After giving a tip, ask if it seems helpful or if there are questions:

- How likely is it that this will help your child?
- How likely is it that your child will try...?
- What questions do you have about...?



Document

Document the specific barriers on the Adherence Barriers and Interventions Log.

- You are taking *your* child's health seriously by talking about the challenges she/he has faced in taking his/her medications [summarize main challenges and barriers].
- What do you think could happen if your child regularly missed doses? [Use ASK-TELL-ASK if the caregiver does not provide accurate information].
- Let's explore things that could make it easier for your child to take his/her medications. How could you address some of the challenges you raised? [Use caregivers' ideas and the tables on next three cue cards, or the Adherence Planning cue cards to develop solutions.]

BARRIERS	INTERVENTIONS TO ADDRESS BAR	RIERS AND IMPROVE ADI	HERENCE
Knowledge deficit	 Individual counseling for basic of HIV and ARV education 	Group counseling/ peer support group	Written instructions
Side effects	take meds with food (refer to	 Diarrhea → refer to physician Fatigue → refer to physician 	 Anxiety/depression take meds before bed; refer to physician if persists
Forgetting	 Medication organizer (i.e., pillbox) Treatment buddy or supporter Supervision of meds intake 	Visual schedule (calendar, journal)Announced pill count at next session	 Reminders (e.g., through phone call, SMS, alarm) Taking pills late; do not skip dose
Felt better	Basic HIV and ARV education		
Illness	Refer to physician	Supervision of medication intake	 Treatment buddy, peer supporter

33. Tips to improve taking medications (2)



Together we will find ways to make it easier for your child to take the medications.

33. Tips to improve taking medications (2/3)



KEY MESSAGES

Together we will find ways to make it easier for your child to take his/her medications.



Counselor Instructions

Collaborate to develop solutions, for example:

- What has your child already tried?
- You have thought a lot about this; what are other ways to solve this challenge?



Document

Document the specific barriers on the Adherence Barriers and Interventions Log.

TALKING POINTS

Let's continue to explore ways in which we can make it easier for your child to take the medications.

BARRIERS	INTERVENTIONS TO ADDRESS BARRIERS AND IMPROVE ADHERENCE
Mental health	 Refer to professional Individual counseling Peer support group Treatment buddy, peer supporter
Administration challenges	 Mix with palatable food Play a game when administering Give rewards to the child
Pill burden	Refer to physician Change to fixed-dose combination, if available
Lost/ran out of pills	 Extra supply of pills Community caregiver/ children group (to pick up and support taking medications) Educate to alert facility if it occurs
Transportation problems	 Community adherence group (to pick up and support taking medications) Multimonth dispensation (3- to 6-month supply when feasible) Treatment buddy who can pick up drugs when feasible)
Health beliefs	 Individual counseling
Scheduling difficulty	 Education (combine with daily routine such as bedtime or brushing teeth) Reminders through phone calls, SMS, alarm) ART group Treatment buddy, peer supporter Keep a few doses in different locations for easy access

33. Tips to improve taking medications (3)



Together we will find ways to make it easier for your child to take his/her medications.

33. Tips to improve taking medications (3/3)



KEY MESSAGES

Together we will find ways to make it easier for your child to take the medications.



Counselor Instructions

- Offer suggestions to overcome specific barriers that have been identified.
- Summarize the plans.
- Ask the caregiver if they have any questions.
- Discuss the date of the next follow-up session and its purpose.



Document

Document interventions and any needed referrals on the Adherence Barriers and Interventions Log.

TALKING POINTS

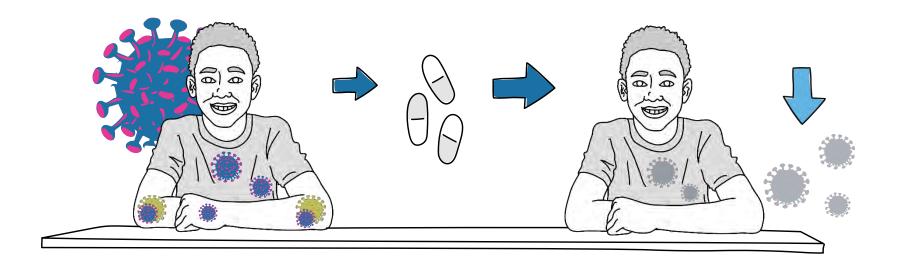
Let's continue to explore ways in which we can make it easier for your child to take the medications.

Sharing meds with others - Individual counseling for basic HIV and ARV education - Individual counseling for basic HIV and ARV education - Individual counseling enable for basic HIV and ARV education - Individual counseling enable for basic HIV and ARV education - Individual counseling enable for basic HIV and ARV education - Individual counseling enable for basic HIV and ARV education - Individual counseling enable for basic HIV and ARV education - Individual counseling enable for basic HIV and ARV education - Individual counseling enable for basic HIV and ARV enable for basic HIV and ARV education - Individual counseling enable for basic HIV and ARV enable enable for basic HIV and ARV enable for basic HIV and HIV		
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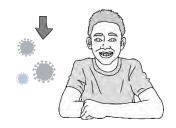
34. Your child's viral load is suppressed

A suppressed viral load means that your child is adhering to his/her medications and that these medications are working. This does not mean that these medications can be stopped.

Your child should continue to take his/her medications every day to keep their viral load suppressed; this will keep your child from getting sick.



34. Your child's viral load is suppressed



KEY MESSAGES

- A suppressed viral load means your child is taking his/her medications as prescribed and they are working.
- This does not mean that the medications can be stopped.
- Your child should continue to take his/her medications every day.



Let's Review

- What medicines does your child take and when?
- Why is it important for your child to continue taking the medications every day?
- What does a suppressed viral load mean?
- When will the next viral load test occur?

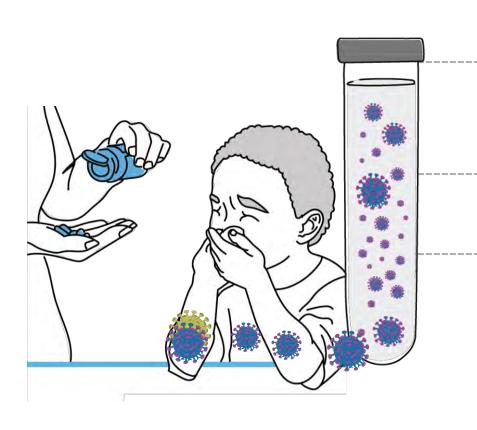
TALKING POINTS

- Your child's viral load is .
- A suppressed viral load (refer to national cut-off) means your child is taking his/her medications as prescribed and they are working. It does not mean that she/he can stop taking the medications.
- Until your child's viral load is suppressed, it is still possible that she/he may become sick.
- A late dose is better than a missed dose.
- Has your child experienced any challenges in taking the medications?
 What has helped your child remember to take them?

A few reminders:

- It's important to keep all of your child's appointments.
- If you notice that your child's medications are running low, go to the ART clinic even if your child does not have an appointment.
- Clinical providers will check your child's viral load again in ____ [six months for newly initiated children and if this is first viral load result, or in one year for those with more than one low viral load test result].
- Please let your child's clinical provider know if your child has any problems taking his/her medications in the future, so the provider can help your child address them.
- Your child's next appointment is ______. It is important for your child to go to the appointment, even if she/he still has medications left.

35. Your child's viral load is NOT suppressed



HIV is making more virus and harming your child's body.

Your child may be missing doses of the medications

Or...

....the virus may have changed, and the medications are no longer working.

35. Your child's viral load is NOT suppressed



KEY MESSAGES

- An unsuppressed viral load means that HIV is making more virus and harming your child's body.
- Your child may be missing doses of his/her medications.
- The virus may be resistant, meaning it has changed, and your child's medications are no longer working.

Counselor Instructions



Remember to use nonjudgmental and respectful language. Do not blame or criticize. For example:

"I am glad you got your child's viral load results.
 Now we can help your child achieve a low viral load."

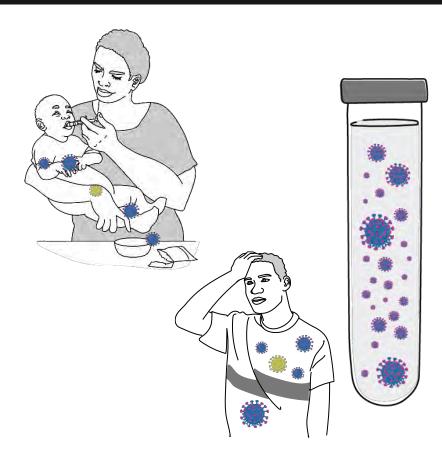
Let's Review



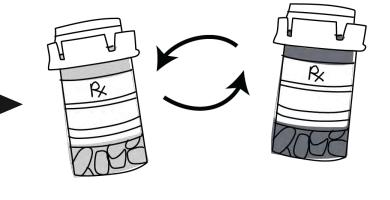
- What are possible reasons for an unsuppressed viral load?
- What can happen when your child's viral load is not suppressed?
- What is beneficial about having a suppressed viral load? How important is your child's long-term health?
- What do you think happens if your child does not take the medications regularly?

- Your child's viral load is ______, which means that she/he is unsuppressed.
- The goal is to keep your child's viral load undetectable, below 200 ml.
- Unsuppressed means that HIV is making more virus in the body.
- This may be because your child is not taking the medications as instructed, or because the medicine is not effective for the form of the virus your child has.
- With this much virus in your child's blood, the immune (defense) system becomes weaker. This can affect your child's brain, heart, liver, and kidneys, and make your child sick.
- If your child does not take his/her medications properly, the virus can change and become "resistant" to the medications, meaning that even if the medications are taken properly, they will no longer work.
- What is the worst thing that could happen if your child continues missing doses?
- What would happen if your child took the medications every day?

36. HIV medications are not working well

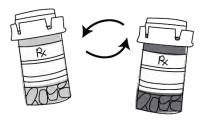


It is likely that the virus has changed, and your child's medications are no longer working.



Changing your child's medication is recommended.

36. HIV medications are not working well



KEY MESSAGES

- It is likely that the virus is resistant, meaning that it has changed, and your child's medications are no longer working.
- Switching your child's medication is recommended.

Let's Review

- Can you please tell me why your child's doctor changed his/her medication?
- In your own words, what does resistance mean?
- What are the new medications your child is taking, and how is she/he taking them?
- What has helped your child take his/her medications?
- When is your child's next appointment?
- I will check your child's viral load again in _____ months to see how the new medications are working.
- Do you have any questions?

TALKING POINTS

- If your child is taking his/her medications every day and his/her viral load result is still high, it is likely that the medications are not working well (the medication is not stopping HIV from making copies).
- If your child's clinical provider has changed your child's medication, discuss possible side effects and how to avoid or manage them.
- The new medication should reduce your child's viral load and keep him/her well.
- It is important that your child take the new medications properly.
- Please let your clinical provider know if your child has any problems, so you can get assistance. (Note for counselor: If the caregiver agrees, you can inform the clinical provider and help with referrals to other services, as appropriate).
- If your child starts any other medications, such as for tuberculosis, please let your child's provider know right away.
- Your child's next appointment is ______

Provider Instructions

Use relevant cards for adherence assessments and counseling, and explanation of viral load results.

Document



Document new ARVs on the **Enhanced Adherence Plan Tool**.