

Module 8 Supporting Adolescents' Retention in and Adherence to HIV Care and Treatment

Session 8.1:	Introduction to Retention and Adherence
Session 8.2:	Supporting Retention and Adherence to Care
Session 8.3:	Providing Adherence Preparation Support to ALHIV and Caregivers
Session 8.4:	Assessing Adherence and Providing Ongoing Adherence Support

Learning Objectives

After completing this module, participants will be able to:

- Define retention in and adherence to HIV care and treatment
- Identify common barriers to retention in care and adherence to treatment among adolescent clients
- Discuss ways that health workers and health facilities can support ALHIV's retention in and adherence to care
- Conduct adherence preparation sessions with ALHIV and their caregivers
- Use tools to provide adherence counseling and to help clients and caregivers make a personal adherence plan
- Assess adolescent clients' (and caregivers') adherence
- Provide ongoing, age-appropriate support to improve adolescent clients' (and caregivers') adherence



Session 8.1 Introduction to Retention and Adherence

Session Objectives

After completing this session, participants will be able to:

- Define retention in and adherence to HIV care and treatment
- Identify common barriers to retention in care and adherence to treatment among adolescent clients

Overview of Retention and Adherence

Definition of retention:

- Retention refers to keeping (or “retaining”) clients in the care program, which in this case means that clients continue accessing lifelong HIV care and treatment services.
- A goal of all HIV care and treatment programs is to retain clients in care and treatment. The onus of retention is on health workers and managers, as they are the ones who can offer quality services and set up systems that support the retention of ALHIV.
- For ALHIV, supporting retention also means supporting their transition to adult care and treatment (see Module 13).

Definition of adherence:

Previously, the standard clinical definition of adherence was taking at least 95% of medications the right way, at the right time. Over time, this definition has been broadened to include more factors related to continuous care, such as following a care plan, attending scheduled clinic appointments, picking up medicines on time, and getting regular CD4 tests.

Key concepts of adherence:

- It includes active participation of the client in his or her care plan (and, if applicable, the active participation of caregivers in the client’s care plan)
- It includes adherence to both medicines and care
- It depends on a shared decision-making process between the client (and caregivers) and health workers
- It determines the success of HIV prevention, care, and treatment programs
- Adherence not static — in other words, it changes over time and as ALHIV age and go through different developmental stages and life changes

Adherence

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

Adherence to care includes:

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

Adherence to treatment includes:

- Taking (or giving) ART correctly, as prescribed, for a person's whole life — even if he or she feels healthy (“every pill, every day”)
- Taking (or giving) other medicines, such as CTX, as prescribed
- Not taking any “treatment breaks”

Non-adherence includes:

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

Why is excellent adherence to HIV care and medicines important?

- To ensure that ART and other medicines do their job, which is to increase the client's CD4 cell count and to decrease the amount of HIV in his or her body
- To make sure people get all the benefits that ART has to offer, such as feeling better, not getting sick as often or as badly, living a longer life, etc.
- To reduce the risk of spreading the virus to others, which can be called “*altruistic adherence*”
 - According to recent studies, PLHIV who are taking and adhering to ART are much less likely to pass HIV to their sexual partners than those who are not on ART.
 - Adherence to ART also reduces mother-to-child transmission of HIV.
- To help ALHIV grow and develop into healthy adults
- To keep people looking and feeling good so they can get back to “normal” life, including going to school, working, socializing, and being an active family and community member
- So the virus does not become resistant to certain medicines

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

Factors Affecting ALHIV Retention and Adherence

The following are lists of some of the common factors that can affect adolescents' retention and adherence.

Health service factors:

The following health service factors can affect adolescent clients' adherence to treatment and retention in care:

- Availability of youth-friendly services
- Level of confidentiality
- Provider attitudes
- Existence of drug stock-outs
- Distance to the clinic/transportation costs
- Convenience of clinic hours
- Strength of patient record and tracking systems
- Number and type of health workers
- Provider language
- Length of waiting times
- Availability of space for private counseling
- Level of staff turnover at the clinic
- Strength of linkages between services, including linkages to social and material support in the community and home-based care
- Strength of referral systems
- Existence of support groups
- Level of PLHIV involvement, including ALHIV
- Cost of health services or medicines

Individual factors:

Adolescence often brings with it new issues that can negatively affect adherence to care and medicines. Some adolescents go through rebellious or risk-taking stages, during which they want to define who they are and take more risks. Adolescents also generally have a desire to “fit in” with peers and appear “normal.” In addition, young adolescents who have been managing well with HIV and adhering to their care and treatment (because their parents or caregivers took primary responsibility for their care) often encounter new adherence challenges as they move through adolescence and begin to take on more responsibility for their own care.

Other individual factors that can affect adolescent clients’ adherence to treatment and retention in care include:

- Feeling self-conscious about taking medicines (particularly in the case of older adolescents)
- Forgetting to take their medicine, or forgetting because of alcohol or drug use
- Experiencing side effects:
 - If they feel sick from the medicine, they more likely to stop taking it.
 - If they begin to notice unwanted body changes caused by the medicine (such as lipodystrophy, which are changes in fat distribution on different parts of the body), they may stop taking it.
- Forgetting to go to the pharmacy at the end of the month and running out of tablets
- Having difficulty accepting their HIV-status
- Facing stigma and discrimination from peers, family, and/or others in the community can affect their willingness to take HIV medicines or to go to an HIV clinic because of fear that these behaviors might disclose their HIV-status
- How far along they are in the disclosure process
- Whether or not they have adequate family or social support (i.e. a treatment “buddy” or supporter)
- How sick or well they feel
- If they migrate or relocate, which often disrupts the continuity of their care
- Whether or not they can take time away from home, school, or work to go to clinic appointments
- Having a mental illness, like depression

Community and cultural factors:

The following environmental factors (related to families, communities, culture, etc.) can affect adolescent clients' adherence to treatment and retention in care:

- Lack of family support or help from caregivers with decision-making (particularly in the case of younger adolescents)
- Poverty
- Lack of food
- Stigma and discrimination
- Caregiver's availability, health, and understanding of adherence
- Societal discomfort with youth and issues related to HIV, like sexuality
- Extent of disclosure within the family, at school, and/or at work — for example, non-disclosure resulting in a lack of peer support or if they fear that taking medicines or leaving early to go to the clinic will inadvertently disclose their HIV-status
- Social support at home and in the community, including at school
- Inability to find child care for their younger siblings (if youth-headed household) or for their own children (if a young parent)
- Inability to take time off from school or work to go to clinic appointments
- Gender inequality: In some places, young women are less likely to have access to adequate nutrition to support their treatment, they may depend on men economically, they may sometimes be forced to share their treatment with others, and it may be harder for them to travel to clinics to access treatment.
- Violence
- Distrust of the clinic/hospital
- Use of traditional medicine, which can decrease perceived need for ART or negatively interact with HIV-related medications
- Political instability or war
- Physical environment (for example, if living in a place with mountains, seasonal flooding, etc.)

Medication factors:

The following things about ART and other HIV-related medicines can affect adolescent clients' adherence to treatment and retention in care:

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

Session 8.2 Supporting Retention and Adherence to Care

Session Objective

After completing this session, participants will be able to:

- Discuss ways that health workers and health facilities can support ALHIVs' retention in and adherence to care

Improving Retention in and Adherence to Care

The following are suggestions for health workers to improve retention in and adherence to care among ALHIV:

- Ensure that HIV services are youth-friendly and that adolescent clients are treated respectfully and non-judgmentally by health workers.
- Ensure that services are provided on days and times that are convenient for adolescents.
- Use counseling and education approaches that correspond to adolescents' maturational stage.
- Build a relationship of trust and respect with clients.
- Ensure linkages to Adolescent Peer Educators and adolescent support groups.
- Make time for private counseling and adherence support sessions and ensure confidentiality.
- Ensure that there are appointment systems in place.
- Ensure that all clients are given reminder cards to help them remember upcoming appointments. If possible, send clients appointment reminders via SMS.
- Ensure that there are systems to track adolescent clients who miss clinic appointments or pharmacy refills.
 - When adolescent clients miss an appointment, contact them through phone calls or SMS messaging. If that does not work or if this is not an available option, send an outreach worker to their home to provide counseling and education and to set up an appointment for their next visit.* (see note on next page)
- Check in with clients frequently after they start or change medicines (if not through in-person clinic visits, then through phone or outreach).
- Make sure to review each client's drug regimen to assess whether changes can be made to facilitate adherence (for example, changing the client to a once-daily regimen).
- Use fixed dose combinations of ARVs when possible to reduce clients' pill burden.
- If possible, provide transportation stipends to clients who are unable to pay for their own transportation to the clinic.
- Consider establishing a formal mechanism, such as an adolescent consumer (or client or community) advisory board (CAB), to obtain client feedback. CABs are autonomous bodies that advise the clinic on how to improve the quality of services and on addressing gaps in care. CABs are discussed further in Module 12.

Also refer to *Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services* in Module 2, which is a tool for auditing services that can provide additional suggestions for making a clinic friendlier for adolescents.

***Permission to call or visit clients at home**

During the baseline intake and at key times thereafter (at least annually), make sure personal client information like addresses and phone numbers are updated. Also, request permission to follow up by SMS, phone call, or home visit if clients miss a clinic visit. Clients who have not disclosed their HIV-status to others in the home may give special instructions regarding what to say to caregivers or siblings about the nature of the visit.

Session 8.3

Providing Adherence Preparation Support to ALHIV and Caregivers

Session Objective

After completing this session, participants will be able to:

- Conduct adherence preparation sessions with ALHIV and their caregivers
- Use tools to provide adherence counseling and to help clients and caregivers make a personal adherence plan

Adolescent-Friendly ART Adherence Preparation

Overview of adherence preparation and support for adolescent clients and caregivers:

- In most places, individuals starting ART are required to participate in a series of adherence preparation sessions. These are conducted in groups, as individual sessions, or as a combination of the two. Depending on the program and national guidelines, this may include between 1–4 adherence preparation sessions that take place over a number of days or weeks. Nurses, counselors, or Peer Educators may conduct these adherence preparation sessions. See Table 8.1 for a suggested list of topics to cover during adherence preparation sessions.
- It is important to follow national guidelines for adherence preparation and to always keep in mind that ongoing adherence assessment and support is necessary for adolescents (and caregivers).
- Group education/peer support sessions are useful for giving many people information at one time.
- Individual sessions can be used to find out what the client (and caregiver) learned from any previously attended group education sessions, to identify the areas in which they need extra support, and to develop an individual adherence plan.
- At minimum, ALHIV initiating care and treatment should have time to speak to a counselor, health worker, and/or Adolescent Peer Educator alone and in private in order to discuss their questions and concerns and to get information tailored to their situation, care plan, and developmental stage.
- Individual counseling session(s) should include talking with the client (and caregiver or treatment buddy) about any adherence challenges he or she may face and making an individual adherence plan.

Remember: while providing as much support as possible, the multidisciplinary care team should be flexible when addressing ART readiness. The preparation process should always facilitate ART initiation and should never act as a barrier to it.

What is a treatment buddy?

A **treatment buddy** or **treatment supporter** is someone who is chosen by a client to provide him or her with ongoing support for adherence to care and treatment.

A treatment buddy is usually a client's caregiver, friend, family member, or another ALHIV who is also enrolled in care and who is a trusted person to whom the client can disclose his or her status. Younger adolescents may have one of their primary caregivers as a treatment buddy, while older adolescents may prefer to have a friend or peer as their treatment buddy. This depends on each individual client. **Remember, not having a treatment buddy should not act as a barrier to any client initiating ART.**

It is important for health workers, including Adolescent Peer Educators, to explain the importance of having a treatment buddy to ALHIV and to make sure that treatment buddies have the information and skills needed to support the client's adherence and positive living. All treatment buddies should be encouraged and welcomed to accompany the adolescent client on clinic visits and, to the extent the client wants, to participate in education and counseling sessions.

Table 8.1: Suggested topics for adherence preparation education and counseling with adolescents and caregivers

Key Topics to Discuss in Group Education and Individual Counseling Sessions with Clients Starting ART (and their Caregivers)
HIV Care and Treatment Basics <ul style="list-style-type: none">• Understanding the diagnosis• How HIV is transmitted and prevented• How HIV affects the immune system• The meaning of CD4 count• Who needs ART• Benefits of ART• Importance of ongoing care and regular clinic visits• Positive living• HIV and sexual initiation, safer sex, dual protection, and prevention and treatment of STIs• OI prophylaxis (especially CTX)• TB prevention and treatment• Importance of disclosure (own disclosure, disclosure to peers, sexual partners)• Family testing and enrollment
Adherence to Care and Treatment <ul style="list-style-type: none">• Beliefs and attitudes about ART• ART = lifetime commitment• Importance of adherence to care plan and to treatment for own health and to prevent HIV transmission to sexual partners• What happens when a person does not adhere• Importance of social support for adherence, including having a treatment buddy and/or directly observed therapy (DOT)• Understanding the treatment plan (explanation of each medicine, the dosing schedule, missed/late doses, adjustments according to school hours, etc.)• How medicines are to be taken (and for young adolescents, how to measure and give medications, tips for children on swallowing pills)• Preventing and managing side effects• Previous adherence experiences (CTX, TB medicines, etc.), strategies, and challenges• Adherence strategies, tips, and tools• Problem-solving around adherence barriers, including the use of tools like medicine diaries, pill boxes, watches, cell phones, etc.• How to make one's care and treatment plan part of one's everyday life and developing an individual adherence plan• What to do if there is a problem or question• Planning 2-week and subsequent follow-up visits• Linkages and referral to support groups and community support services

Adherence Preparation and Planning

Helping clients develop a personal adherence plan

During the individual counseling session, work with clients to develop a personal adherence plan. This plan should address the ARE YOU COMMITTED? question and the WHO, WHAT, WHEN, WHERE, and HOW of the medicines:

- **ARE YOU PLANNING TO TAKE YOUR MEDICINES?** If the response to this question is no, then consider delaying ART initiation.
- **WHO** will help you remember to take your medicine every day at the same time? Is there someone who can help you come to the clinic for appointments?
- **WHAT** medicines are you taking? What is the dose of each and how often will you take each medicine? What will you do when you are about to run out of your medicines? What will you do if you miss a dose of your medicine?
- **WHEN** will you take your medicines? (Establish a routine.)
- **WHERE** will you take your ART (for example, at school, home, work, etc.)? Where will you store your ART?
- **HOW** will you remember to take your medicines at the same time, every day? What about when you are at school or work? When you are away from home? When you are with your family? When you are with your friends? How will you know that you have taken your doses so that you don't miss any or take them twice?

See **Appendix 8A: Adherence Support Tree**, which is a useful tool to help health workers and clients discuss these questions and develop a personal adherence plan. Specific instructions to use the Adherence Support Tree are also included.

Assessing a Client's Readiness for Adherence

Use the plan agreed upon during the WHO, WHAT, WHEN, WHERE, and HOW discussions when completing the “Guide for Assessing Adolescents’/Caregivers’ Readiness for ART” questionnaires in *Appendix 8B: Adherence Preparation and Support Guides*. These assessment guides are standardized tools that can help health workers assess clients’ and caregivers’ readiness for ART. The guides can also:

- Support health workers to increase their clients’ understanding of the importance of lifelong adherence to HIV care and treatment
- Ensure a shared understanding of the client’s care and treatment plan
- Identify potential adherence challenges and help to brainstorm practical solutions

Instructions for administering the guides are also included in *Appendix 8B*.

Note that it may take 1, 2, or even more individual counseling sessions before a client is ready to start ART. Upon completion of the adherence preparation visits and the individual counseling session(s), the client should be ready to initiate ART. If the client is not ready, the multidisciplinary team may advise that the client delay initiation until the next visit or may discuss reservations with the client and/or caregiver and allow them to choose whether to start immediately or to delay temporarily.

Keep in mind that, as with any other one-to-one counseling session, health workers should remind clients that all sessions are confidential. When counseling adolescents, also remind them that the commitment to confidentiality means that health workers will not share any information discussed during individual counseling sessions with their caregiver or partner.

Exercise 1: Conducting an Adherence Readiness Assessment: Case studies in small groups and large group discussion

Purpose	To practice conducting adherence preparation counseling with adolescent clients and caregivers, including using the Adherence Support Tree (<i>Appendix 8A</i>) and the Adherence Preparation and Support Guides (<i>Appendix 8B</i>)
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This exercise consists of 3 parts:

- Part 1: Trainer Demonstration and Role Play
- Part 2: Small Group Work
- Part 3: Large Group Discussion

Refer to *Appendix 8A: Adherence Support Tree* and *Appendix 8B: Adherence Preparation and Support Guides*.

Case Study 1 (for Part 1):

B___ is 11 years old and is supposed to start taking ART today. B___ and her auntie have already gone through the group education sessions and today is B___'s adherence preparation visit. B___'s auntie is her primary caregiver and will be responsible for giving B___ her medicines every day. B___ understands that she has HIV and that she needs to take medicines every day, but her auntie is still worried how she will manage.

- *How would you help B___ and her auntie prepare today for adherence?*
- *What questions would you ask to assess their understanding of adherence and B___'s readiness to start ART?*

Case Study 2:

S___ is 17 years old and lives by himself. He needs to start taking ART and, now that he has attended the group adherence preparation sessions, the doctor asks you to counsel him individually to further prepare him for ART adherence. S___ works during the day as a taxi assistant and you sense that it might be challenging for him to take his medicines the right way since he has not disclosed to anyone and works long hours.

- *How do you help S___ prepare to start taking ART?*
- *What questions would you ask to assess S___'s readiness for ART?*

Case Study 3:

L___ is 17 years old and lives with her mother and father. She is going to start taking ART and, now that she has attended the group adherence preparation sessions, you have been asked to help prepare her and make an adherence plan. L___ is at the clinic with her older cousin and says that she does not talk much with her mother and father about HIV. Instead, her cousin has agreed to be her treatment supporter.

- *How would you prepare L___ and her cousin for good adherence?*
- *What questions would you ask to assess their readiness and understanding?*

Case Study 4:

J___ is 14 years old and, based on her CD4 results, she is eligible to start ART. She has come to the clinic today with her father for adherence preparation and ART initiation (she has already attended group preparation sessions). Her mother passed away recently, so her father will be her main treatment supporter. While conducting adherence preparation counseling with J___ and her father, her father expresses some concern that ART might be bad for children. He says that his daughter feels fine without medicine, adding that he works long hours so J___ spends a lot of time at home with her older brother.

- *How would you proceed in preparing J___ and her father?*

Case Study 5:

N___ is 16 years old and lives with his mother and 4 younger siblings. N___ is still in school, but only because his mother makes him to go. N___ would prefer to spend his time with his friends, which he does as soon as school ends. He is rarely home before 21.00hrs and he is failing nearly half of his classes. He has not told his mother or siblings about his HIV-status, but he has told his best friend and partner, A___. A___ is 17 and she also has HIV.

- *How do you help N___ prepare to start taking ART (he has already attended group adherence preparation sessions)?*
- *What questions would you ask to assess his readiness for ART?*

Session 8.4

Assessing Adherence and Providing Ongoing Adherence Support

Session Objectives

After completing this session, participants will be able to:

- Assess adolescent clients' (and caregivers') adherence
- Provide ongoing, age-appropriate support to improve adolescent clients' (and caregivers') adherence

Assessing Adherence

Assessing adherence is very challenging and there is no perfect way to do it. We can really only learn about adherence through ongoing, individual adherence assessment and counseling combined with other adherence measures (and review of the client's response to ART over time). It is very important to assess adherence at every visit, but we must also take the next step of offering clients ongoing, individual adherence support.

- The purpose of ongoing adherence monitoring and support is to encourage clients (and caregivers) to express challenges and to be open about any problems they are facing so the multidisciplinary team can provide them with ongoing support.
- **Assess adherence at every visit.**
- All members of the multidisciplinary team should ask questions about adherence (nurses, counselors, pharmacists, doctors, peer educators, etc.).
- If the caregiver or treatment buddy is available, ask him or her about adherence as well.
- Adolescents and caregivers may have different reports and understandings of adherence, so it is important to conduct separate adherence assessment sessions with older adolescent clients and their caregivers.
- In cases where answers to parallel questions differ greatly, discuss these responses with the client and caregiver together to see if they can explain. When asking for an explanation, make sure questions are appropriate and non-accusatory. For example: *“Interestingly, in response to my question, ‘How did the medicines make you feel?,’ you said that the medicine gives you headaches every day. Your mother responded that the medicine has no effect on how you feel. I am sure you’re both being honest, but maybe one of you can explain a bit more about how your responses might seem, on the surface, to be so different?”*
- Do not judge! Make clients feel comfortable and let them know that they will not be punished or judged if they openly discuss adherence challenges.
- Let clients know that everyone has problems taking medicines the right way all the time.
- Build a trusting relationship and encourage clients to be completely honest with you about adherence. Remember: the job of a health worker is to work WITH clients, not against them!
- Refer clients to peer support groups or link them to an Adolescent Peer Educator.
- Talk about clients' adherence at multidisciplinary team meetings.

Adherence Red Flag

For a client on ART, missing pharmacy refills or clinic appointments is a RED FLAG indicating poor adherence that should be addressed immediately.

- Use tools to help assess and improve adherence, such as:
 - Pill counts
 - Review of clinical findings and laboratory tests
 - Review with clients of medicine diaries or calendars

Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. *Appendix 8C: Adherence Assessment Guides* includes two standardized adherence assessment tools. These can be used at every follow-up and refill visit to ensure that the adolescent client (and caregiver) understands the care and medication plan. The assessment questions should be used to identify areas in which the client and/or caregiver may need additional information and support.

Providing Ongoing Adherence Support

When providing adherence support, it is important that health workers build on the trust and rapport they have with the client and caregiver, that they maintain a safe space to discuss any problems, and that they give ongoing encouragement.

If the health worker feels, after discussing adherence with a client, that he or she is adhering well:

- Praise the client (and the caregiver, if present) for good adherence.
- Remind the client to come back if there are any problems.
- Talk about how important it is to be open with health workers and to solve challenges together.

If the health worker or multidisciplinary team has determined that an adolescent client is experiencing challenges with adherence, provide individual counseling and:

- Praise the client for sharing his or her challenges.
- Identify the client's specific challenges and how these challenges affect his or her adherence.
- Help the client resolve each challenge.
- Discuss the importance of adherence.
- Refer the client to an Adolescent Peer Educator, adolescent support group, and other organizations that works with youth in the community.
- Refer difficult cases to a counselor, social worker, or other available mental health worker.
- Plan for next steps, including the clinic return date.
- Record the session on the patient record.
- Follow up at the next visit.
- Share observations with the multidisciplinary team and review the client's clinical status to determine if poor adherence is impacting treatment outcomes.

Exercise 2: Assessing Adherence and Providing Support: Small group work, role play, and large group discussion

Purpose	To practice conducting adherence assessments with adolescent clients and caregivers and to practice providing ongoing adherence support
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This exercise consists of 3 parts:

- Part 1: Role Play
- Part 2: Small Group Work
- Part 3: Large Group Discussion

For part 1, refer to *Appendix 8C: Adherence Assessment Guides*. For part 2, work in your small groups to answer the following questions:

- A. What are the client's/caregiver's main adherence challenges? What are some possible solutions?*
- B. What are some age-appropriate techniques a health worker could use to build the client's/caregiver's confidence and knowledge about adherence?*
- C. Are there any community-based services that might help the client? What suggestions or referrals would you make?*

Case Study 1: J___ and his uncle

- **The client (J___) introduces himself to the health worker:** I am J___, I am 17 years old, and I have had HIV since I was little. My parents died a long time ago. I live with my uncle and his family. My uncle came with me today.
- **Background:**
 - **J's uncle's says:** J___ is often out all night and comes home drunk. The family is upset with his behavior and is afraid for him. J___ used to be a good student and did well in school. Recently, he has not been taking his ART regularly, and maybe he is not taking it at all. I found medicines thrown away in the outhouse — I am angry with my nephew. I need the clinic staff to scare J___ into taking his medicines. I also have HIV, but J___ does not know.
 - **J___ says:** I think I have taken about half of my ART doses over the past week, mostly because I've been too busy.

Case Study 2: N___ and his mother

- **The client (N___) introduces himself to the health worker:** I am N___, I am 12 years old, and I have been coming to the clinic for a long time. My mother is here with me today.
- **Background:**
 - **N___'s mother says:** N___ always used to cooperate and take his medicines with no problems. But now he is fighting me with every dose — he runs away and spits out his ART. I am planning to tell N___ his diagnosis, but right now he is still too young to know. I haven't used the word "HIV" with him yet.
 - **N___ says:** My mother forces me to take my medicine every morning and every evening. But I don't want to take it anymore — I just want to be normal and not take medicine. My friends don't take medicine, so why do I have to?

Case Study 3: P__

- **The client (P__)** introduces herself to the health worker: I am P__ and I'm 14 years old. I am feeling bad and I want to stop taking ART. My best friend is with me today.
- **Background:**
 - **P__ says:** I've missed about 3 doses of my ART this month, but I think that taking my doses most of the time is good enough. I think the pills are making me look fat. There is a boy in my class that I really like, but I'm sure he thinks I'm ugly. I get teased when I go to school and I only have one friend. She is with me today — in the waiting room.

Case Study 4: M__ and her mother

- **The client (M__)** introduces herself to the health worker: I am M__, I am 16 years old, and I have come in today for my 3-month checkup. As always, my mother is here with me. The doctor told me to give this to you (M__ should hand over her pretend medical record with the results of her last 2 CD4 tests, which show a decrease in her CD4 count).
 - **Background:**
 - **M__'s mother says:** M__ has taken 100% of her medicines on time this month.
- M__ says:** I've taken 100% of my medicines on time this month.



Module 8: Key Points

- Retention and adherence are closely related and are key components of comprehensive adolescent HIV care and treatment.
- Retention refers to keeping (or “retaining”) clients in the care program, which in this case means that clients continue accessing lifelong HIV care and treatment services. In terms of adolescents, this also means transitioning them to adult care and treatment.
- In the context of ART, studies have shown that clients must take over 95% of their necessary doses to achieve the conditions for therapeutic success. Therefore, it is our aim as health workers to support clients to achieve and sustain this rate of adherence to their regimens, both for their own health and to protect their sexual partners (“*altruistic adherence*”).
- Although it is ultimately the responsibility of clients to adhere to their care plans, there are many steps health workers can take to make it easier for clients to adhere to care. One of the most important steps to improve retention is to ensure that services are youth- friendly.
- ART preparation usually includes group education sessions, individual counseling sessions, and an adherence readiness assessment. Follow your national guidelines and adapt them as needed to the unique needs of adolescents.
- Ideally, adherence readiness assessment and counseling should begin early during HIV care, but they should NOT be a reason to delay initiation of ART for most ALHIV.
- Each client should have AT LEAST one individual adherence preparation counseling session with a health worker before starting ART. Caregivers and treatment buddies, when available, should also participate in these preparation sessions.
- In addition, health workers can help the client develop a personal adherence plan by:
 - Asking the ARE YOU COMMITTED? question and then the WHO, WHAT, WHEN, WHERE, and HOW of the medications. Health workers can use the Adherence Support Tree in *Appendix 8A* to help clients and caregivers work through these questions.
 - Administering a standardized assessment tool to help determine a client’s and caregiver’s readiness for ART and to help them develop an adherence plan. Health workers can use the Adherence Preparation and Support Guides in *Appendix 8B*.
- Assessing adherence and providing adherence support to clients and caregivers are important, yet challenging, tasks. The best way is to use several methods, such as a standardized adherence assessment combined with a patient/caregiver self-report, pill count, and review of clinical and laboratory records. Health workers can use the Adherence Assessment Guides in *Appendix 8C* to ask clients and caregivers about adherence at **each clinic visit**.
- Adherence support services should be ongoing — not one-time events — and the entire multidisciplinary team, not just counselors or Peer Educators, is responsible for providing these services.
- Ongoing adherence support is especially important for adolescents because their adherence to care and medications is not static (meaning it will change over time).

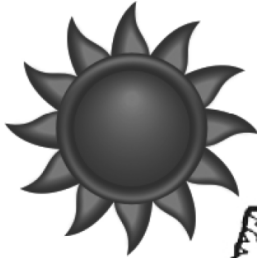
Appendix 8A: Adherence Support Tree¹

Instructions for the Adherence Support Tree:

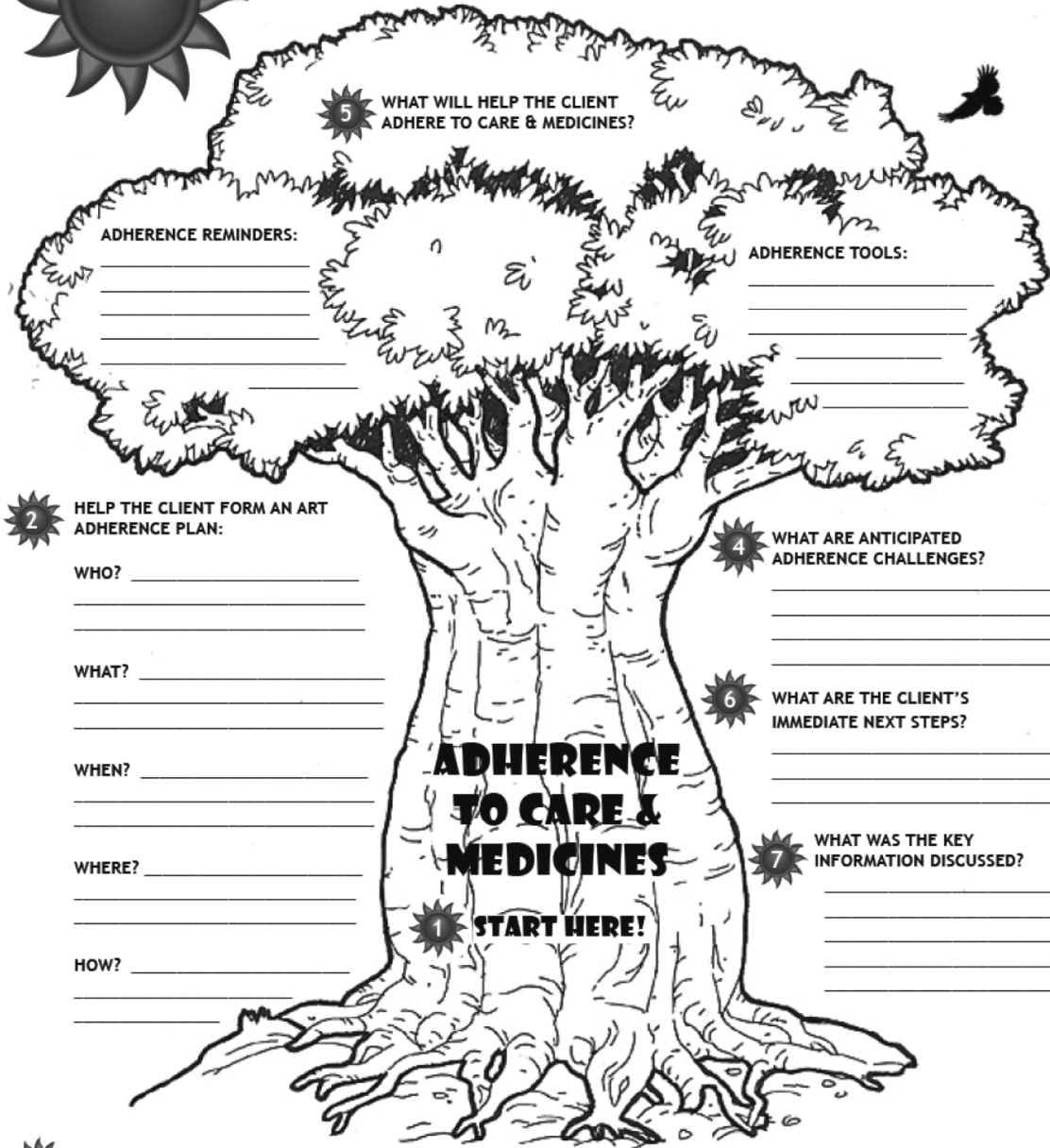
Each instruction below goes with a number on the Adherence Support Tree. The health worker should follow these instructions in order.

1. Start on the trunk. Begin by explaining what we mean by adherence to treatment and why near-perfect adherence is important.
2. Continue by helping the client make an ART adherence plan: address the ARE YOU COMMITTED? question and the WHO, WHAT, WHEN, WHERE, and HOW of the medicines. The lines to the left of the tree are spaces for writing down important information related to the client's adherence plan.
 - ✓ **ARE YOU PLANNING TO TAKE YOUR MEDICINES?** If the response to this question is no, then consider delaying ART initiation.
 - ✓ **WHO** will help you remember to take your medicine every day at the same time? Is there someone who can help you come to the clinic for appointments?
 - ✓ **WHAT** medicines are you taking? What is the dose of each and how often will you take each medicine? What will you do when you are about to run out of your medicines? What will you do if you miss a dose of your medicine?
 - ✓ **WHEN** will you take your medicines? (Establish a routine.)
 - ✓ **WHERE** will you take your ART (e.g. at school, at home, at work, etc.)? Where will you store your ART?
 - ✓ **HOW** will you remember to take your medicines every day and at the same time? When you are at school or work? When you are away from home? When you are with your family? When you are with your friends? How will you know that you have taken your doses so you don't miss any or take them twice?
3. Ask the client to imagine him- or herself as a tree. His or her roots are “where you come from, your home, your family, and your community,” they are “what support and ground you.” Ask the client who will support him or her with the adherence plan and write this under “peers, family, and community” in the roots of the tree. Also write down if the client has a treatment buddy.
4. Discuss the possible challenges to adherence in the client's (and caregiver's) life. Write these under “what are the anticipated adherence challenges?”
5. The branches are the client's adherence strategies. These are things he or she can do to have perfect adherence, like using reminders, having routines, having a treatment buddy, etc. Give the client practical suggestions and help him or her plan ways of remembering to take medicines and to come to the clinic for appointments.
6. Always plan a follow-up session and record any action points under “immediate next steps.” Tell the client that you will always be available to talk more with him or her. Adherence and follow up to the adherence plan should be discussed during every clinic visit.
7. Lastly, summarize the main points that were discussed during the adherence support session, talk about any necessary referrals, and arrange another time to talk (if necessary).

ADHERENCE SUPPORT TREE



DATE: _____
 CLIENT NAME: _____
 NAME: _____
 NAME OF CLINIC: _____



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

ADHERENCE REMINDERS:

ADHERENCE TOOLS:

2 HELP THE CLIENT FORM AN ART ADHERENCE PLAN:

WHO? _____

WHAT? _____

WHEN? _____

WHERE? _____

HOW? _____

4 WHAT ARE ANTICIPATED ADHERENCE CHALLENGES?

6 WHAT ARE THE CLIENT'S IMMEDIATE NEXT STEPS?

7 WHAT WAS THE KEY INFORMATION DISCUSSED?

**ADHERENCE
 TO CARE &
 MEDICINES**

START HERE!

3 WHAT SUPPORT DOES THE CLIENT HAVE?

FAMILY:

PEERS:

COMMUNITY:

Appendix 8B: Adherence Preparation and Support Guides

How to use these guides:

These adherence preparation and support guides were developed to assist a range of providers (trained counselors, lay counselors, Adolescent Peer Educators, doctors, nurses, pharmacists, community health workers, and others) who work with ALHIV and their caregivers. These guides can help providers work with their clients (and caregivers) to understand the importance of adherence to HIV care and treatment throughout their life; to ensure understanding of the care and medications plan; to identify potential adherence challenges; and to come up with practical solutions. **The adherence guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used, including the age and situation of the individual adolescent client.** It may be helpful to translate the guides into the local language.

Often, adherence preparation is not tailored to the specific needs and concerns of adolescents. In some cases, adolescents are referred to adult ART clinics — which may not be youth-friendly — for adherence counseling and preparation. Many programs stipulate that clients participate in a series of group and individual counseling and preparation sessions before starting ART.

Included here is one adherence preparation and support guide to assess adolescents' readiness for ART and one to assess the readiness of caregivers. The forms should be adapted as needed and used during adherence counseling sessions according to the client's (and caregiver's) needs and situation. Completed adherence assessment forms should be kept in the client's file and referred to during follow-up visits.

Basic information:

Write the client's name and file number at the top of the form. Be sure to sign and date the form at the end of each session and ensure that the form is kept in the client's clinic file.

Questions to ask the client/caregiver:

The questions in this section allow the health worker to discuss specific care, medication, and adherence issues with the adolescent client/caregiver. The questions should be used to identify areas where the client/caregiver may need additional information and support, but should not be used to “score” a client's knowledge and readiness to begin ART. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel comfortable asking questions and expressing potential adherence challenges and they should never be judged or punished. Remember to write down any important information from their responses, as this will help to decide on next steps, to identify important areas for follow up, and to support the client's adherence over the long term.

Client/caregiver requires more counseling and support in these areas:

In this space, write down specific areas in which the adolescent client/caregiver needs ongoing adherence counseling and support. Refer to this section of the form during follow-up counseling appointments and clinic visits. Even if a client has questions about his or her care and medicines, or is facing specific adherence challenges, this is usually not a reason to delay initiation of ART. Instead, these issues should be viewed as important areas for ongoing counseling and support.

Adherence Preparation/Support Guide for Assessing Adolescents' Readiness for ART

Client's Name: _____ Client's Age: _____ Client's File#: _____
 Caregiver and/or Treatment Buddy's Name: _____

Questions to ask the adolescent:	Notes
1. Can you tell me what peer support group or group education sessions you have attended here at the clinic?	
2. Can you explain why you need to take ART?	
3. Who have you spoken to/who knows about your HIV-status?	
4. What do you expect from taking ART?	
5. How do you feel about taking medicines every day for your lifetime?	
6. Can you tell me the names of the medicines you will be taking and when you will take them (how many pills, what times of day)?	
7. Can you tell me some possible side effects of your ART? What will you do if you have side effects?	
8. Can you explain what happens if you do not take all of your ART every day, at the same time?	
9. Who can help you come to the clinic for appointments and help you take your medicines every day? What is his or her name and contact information?	
9a. Has he or she been to the clinic with you?	
9. What might make it difficult for you to come to this clinic for your appointments?	
10. How will you remember to come for your clinic appointments?	
11. How will you remember to take your medicines the right way, at the same time, every day?	
12. Are you taking any medicines other than the ones prescribed to you by the doctor or nurse (including traditional or herbal medicines)?	
13. Where will you store your medicines?	
14. What will you do if you are about to run out of your medicine(s)? What about if you are going to be away from home, like when you are at school?	
15. What will you do if you miss a dose of your medicine?	
16. What questions do you have about the plan for your care and your medicines?	
17. Do you feel ready to start taking these medicines?	

Client requires more counseling and support in these areas (LIST):

Signature of person completing assessment: _____ Date: _____

Adherence Preparation/Support Guide for Assessing Caregivers' Readiness for ART

Client's Name: _____ Client's Age: _____ Client's File#: _____
 Caregiver and/or Treatment Buddy's Name: _____

Questions to ask the caregiver:	Notes
1. Can you tell me what support group or group education sessions you and your child have attended here at the clinic?	
2. Can you explain why your child needs to take ART?	
3. Who knows about your child's HIV-status?	
4. What do you expect from your child taking ART?	
5. How do you feel about your child taking medicines every day for his or her lifetime?	
6. Can you tell me the names of the medicines your child will be taking and when he or she will take them (how many pills, what times of day)?	
7. Can you tell me some possible side effects of your child's ART? What will you do if your child has side effects?	
8. Can you explain what happens if your child does not take all of his or her ART every day, at the same time?	
9. Who will help your child come to the clinic for appointments and help him or her take his or her medicines every day? What is your contact information/other supporters' contact information?	
9a. <i>If someone other than the caregiver:</i> has he or she been to the clinic with your child?	
10. What might make it difficult for your child to come to this clinic for his or her appointments?	
11. How will your child remember to come for his or her clinic appointments?	
12. How will your child remember to take his or her medicines the right way, at the same time, every day?	
13. Is your child taking any medicines — other than the ones prescribed to him or her by the doctor or nurse (including traditional or herbal medicines)?	
14. Where will you store your child's medicines?	
15. What will you do if you are about to run out of medicine(s)? What about if you or your child will be away from each other or away from home, like when he or she is at school?	
16. What will you do if your child misses a dose of the medicine?	
17. What questions do you have about the plan for your child's care and medicines?	
18. Do you feel that you and your child are ready to start taking these medicines?	

Caregiver requires more counseling and support in these areas (LIST):

Signature of person completing assessment: _____ **Date:** _____

Adapted from: ICAP. (2010). Improving retention, adherence, and psychosocial support within PMTCT services: A toolkit for health workers.

Appendix 8C: Adherence Assessment Guides

How to use these guides:

These adherence assessment guides were developed to support a range of providers (trained counselors, lay counselors, Adolescent Peer Educators, doctors, nurses, pharmacists, community health workers, and others) who work with ALHIV and their caregivers. Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. **The adherence assessment guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used and for different ages of adolescent clients.** It may be helpful to translate the guides into the local language.

Included here is one adherence assessment guide to be used with adolescents enrolled in HIV care and treatment and one to be used with caregivers. The guides should be used at every follow-up and refill visit to ensure that the adolescent client and caregiver understand the care and medication plan, and that the client is taking his or her medicines the correct way, every day (and/or that the caregiver is giving the client his or her medicines the correct way, every day). Completed adherence assessment forms should be kept in the client's file and referred to at follow-up visits.

Basic information:

Write the client's name, age, and file number, as well as the caregiver or treatment buddy's name, at the top of the form. Then, tick the box corresponding to the type of visit. Be sure to sign and date the form at the end of each session, and ensure that the form is kept in the client's clinic file.

Questions to ask the client/caregiver:

The questions in this section allow the health worker to discuss and assess adherence. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel comfortable expressing adherence challenges and should never be judged or punished. Remember to write down any important information from their responses, as this will help to decide on next steps, to identify important areas for follow up, and to support the client's adherence over the long term. If possible, the health worker should meet with the client and caregiver separately to identify and address any discrepant responses. Meeting separately is especially important as young clients enter middle and late adolescence.

Other assessment measures and next steps:

This is the section where health workers will make a plan with the adolescent client/caregiver to ensure that the client keeps up good adherence or develops strategies to improve adherence.

- **Other adherence assessment measures:** Depending on standard procedures at the clinic, the health worker may do a pill count and/or review the client's medicine diary or calendar. Record the results in the space provided.
- **Specific adherence challenges identified by the adolescent client, caregiver, and health worker:** Based on the answers to the questions asked in the first section of this form, discuss the specific challenges to adherence that the client is having. Together, discuss possible solutions to each challenge.
- **Referrals made:** If there is an outside organization, such as a youth support group or a home-based care program, that could help support the client (and the caregiver and family) to overcome his or her challenges to adherence, refer the adolescent client (and/or caregiver) to that organization and indicate the name and specific service in this part of the form. In some cases, the client (or caregiver) may need to be referred for other facility-based services, like for an appointment with a trained counselor or for a session with the pharmacist to explain dosing.
- **Next steps and follow-up plan:** Identify which solutions and next steps the client/caregiver thinks are feasible and manageable. For each solution, list the necessary steps the client or health worker will need to take and a timeline for each. Also, make an appointment for a follow-up visit and record the date on the form. This section of the form can be used as a starting point for adherence assessment during follow-up visits.

Adherence Assessment for Adolescents Taking ART

Client's Name: _____ Client's Age: _____ Client's File#: _____
 Caregiver and/or Treatment Buddy's Name: _____

Tick one: 2-week follow up 1-month follow up monthly refill 3-month refill

Questions to ask the adolescent client:	Notes
1. Can you tell me more about how you took your medicines this past month (or 2 weeks)? Do you know the names of the medicines? How many pills do you take? At what time of day?	
2. I would like you to think about the last 7 days. How many pills did you take late in the last 7 days? What were the main reasons you took them late? For twice daily regimens, was it the morning or the evening dose(s) that you took late?	
3. How many pills did you miss in the last 7 days? What were the main reasons you missed them? For twice daily regimens, was it the morning or the evening dose(s) that you missed?	
4. How did the medicines make you feel? For example, did you have any side effects?	
5. Can you tell me about any changes you noticed (such as in your health) or challenges you had with your medicines?	
6. What support or reminders do you have to help you take your medicines at the same time, every day?	
7. What questions do you have about your care or your medicines?	

Other assessment measures and next steps:	Notes
Results of pill count, if applicable:	
Review of medicine diary or calendar, if applicable:	
Specific adherence challenges identified by the adolescent client, caregiver, and health worker: (discuss possible solutions to each)	
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

Notes:

Signature of person completing assessment: _____ Date: _____

Adherence Assessment for Caregivers of Adolescents Taking ART

Client's Name: _____ Client's Age: _____ Client's File#: _____
 Caregiver and/or Treatment Buddy's Name: _____

Tick one: 2-week follow up 1-month follow up monthly refill 3-month refill

Questions to ask the caregiver:	Notes
1. Can you tell me more about how your child took his or her medicines this past month (or 2 weeks)? Do you know the names of the medicines? How many pills does he or she take? At what time of day?	
2. I would like you to think about the last 7 days. How many pills did your child take late in the last 7 days? What were the main reasons he or she took them late? For twice daily regimens, was it the morning or the evening dose(s) that he or she took late?	
3. How many pills did your child miss in the last 7 days? What were the main reasons he or she missed them? For twice daily regimens, was it the morning or the evening dose(s) that he or she missed?	
4. How did the medicines make your child feel? Did your child have any side effects from the medicines? Can you describe them?	
5. Can you tell me about any changes you or your child noticed (such as in your child's health) or challenges your child had with his or her medicines?	
6. What support or reminders does your child have to help him or her take his or her medicines at the same time, every day?	
7. What questions do you have about your child's care or medicines?	

Other assessment measures and next steps:	Notes
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

Notes:

Signature of person completing assessment: _____ **Date:** _____

Adapted from: ICAP. (2010). *Improving retention, adherence, and psychosocial support within PMTCT services: A toolkit for health workers.*

References

¹ Schley, A., Colton, T., Schoeneborn, A., and Abrams, E. (2011). *Positive voices, positive choices: A comprehensive training curriculum for Adolescent Peer Educators, Version 1.0*. ICAP.