

Adolescent HIV Care and Treatment

Module 8:

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



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Module 8 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

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Module 8 Learning Objectives (Continued)

- 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

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Session 8.1

Introduction to Retention and Adherence

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Session 8.1 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

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Overview of Retention and Adherence

Retention:

- **Definition:** Keeping ("retaining") clients in HIV care and treatment
- A goal of all HIV care and treatment programs is to retain clients in care and treatment.
- For ALHIV, supporting retention also means supporting their transition to adult care and treatment.

Adherence:

- **Definition:** How faithfully a person sticks to and participates in his or her HIV prevention, care, and treatment plan
- Includes active participation of the client (and caregiver)
- Includes adherence to both medications and care
- Depends on a shared decision-making process
- Determines the success of HIV programs
- Changes over time

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Adherence to Care Includes:

- Entering into and continuing lifelong care and treatment
- Attending appointments and tests as scheduled
- Taking medicines to prevent and treat OIs
- Participating in ongoing health education and counseling
- Picking up medications when scheduled and before running out
- Recognizing problems and coming to the clinic for care
- Adopting a healthy lifestyle and trying to avoid risky behaviors

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Adherence to Treatment Includes:

- Taking ART correctly, as prescribed, for a person's whole life — even if he or she feels healthy
- Taking other medicines, such as CTX, as prescribed
- Not taking any "treatment breaks"

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.

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Non-Adherence Includes:

- Missing one or many appointments
- 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 medicines at the wrong times
- Taking medicines without following instructions about timing or food intake

Non-adherence to treatment can lead to **drug resistance**, preventing ART from working and causing people to get very sick.

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Discussion Question:

- *Why is excellent adherence to care and treatment important for ALHIV?*



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Why is Excellent Adherence Important?

- To ensure that medicines do their job (increase CD4 count, decrease amount of HIV in the body, prevent OIs, etc.)
- To make sure people get all the benefits of ART (feeling better, not getting sick as often, living longer)
- To reduce the risk of spreading the virus to others ("*altruistic adherence*")
- To help ALHIV grow and develop into healthy adults
- To keep people looking and feeling good so they can get back to "normal" life
- So the virus does not become resistant to certain medicines

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Remember:

- Retention and adherence are closely related.
- Health workers and health systems play an important role in retaining clients in care.
- Adherence support should be ongoing — not one-time events — and the entire multidisciplinary team is responsible for providing these services.
- **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 find ways to resume good adherence as soon as possible.

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Discussion Questions

- *What are the most common retention and adherence issues for ALHIV?*
- *What are the most common factors affecting retention and adherence among younger adolescents?*
- *How about among older adolescents?*



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Health Service Factors Affecting Adherence

- Youth-friendliness of services
- Level of confidentiality
- Provider attitudes
- Existence of drug stock-outs
- Distance/transportation costs
- Convenience of clinic hours
- Patient record and tracking systems
- Number and type of health workers
- Provider language abilities
- Length of waiting times
- Space for private counseling
- Level of staff turnover
- Linkages between services
- Referral systems
- Existence of support groups
- Level of PLHIV involvement
- Cost of health services or medicines

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Individual Factors Affecting Adherence

- Rebellion or risk-taking
- Desire to fit in with peers
- Feeling self-conscious about taking medication
- Forgetting to take one's medicine
- Side effects
- Forgetting to go to the pharmacy/running out of tablets
- Having difficulty accepting one's HIV-status
- Stigma and discrimination
- Disclosure
- Family or social support
- How sick or well person feels
- Migration or relocation affecting continuity of care
- Whether person can take time away from home, school, or work to go to clinic appointments
- Having a mental illness

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Community and Cultural Factors Affecting Adherence

- Family and social support
- Poverty
- Lack of food
- Stigma and discrimination
- Caregiver's availability, health, and understanding of adherence
- Societal discomfort with youth and related issues, such as sexuality
- Extent of disclosure
- Inability to find child care
- Inability to take time off from school or work for clinic visits
- Gender inequality
- Violence
- Distrust of the clinic/hospital
- Use of traditional medicine
- Political instability or war
- Physical environment

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Medication Factors Affecting Adherence

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

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Discussion Question

- *Which of these issues do you think has the greatest impact on an adolescent's retention and adherence? Why?*



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Remember:

- There are many challenges to adherence among ALHIV:
 - They engage in more risk-taking behaviors.
 - They have a desire to “fit in” with peers and appear “normal.”
 - They may not take their medication as a way of demonstrating defiance or because of a need to define their identity.
- We often blame clients for not adhering to care and treatment, but not having access to quality, youth-friendly health services is often one of their biggest barriers to retention and adherence.

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Questions or comments on this session?

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Session 8.2

Supporting Retention and Adherence to Care

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Session 8.2: 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

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Brainstorming

- We are not always able to address ALL of a client’s barriers to adherence, but there are many factors that we CAN address to support retention and adherence.
- *What are some of the ways that health workers can minimize barriers to retention and adherence to care?*



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Improving Retention in and Adherence to Care

- Ensure services are youth-friendly and convenient.
- Use a developmental approach to counseling and education.
- Build a relationship of trust and respect with clients.
- Ensure linkages to Adolescent Peer Educators and adolescent support groups.
- Make time for private counseling; ensure confidentiality.
- Ensure that appointment systems are in place and that clients receive reminder cards; send reminders via SMS.
- Ensure that tracking systems are in place (for clients who miss appointments or pharmacy refills).

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Improving Retention in and Adherence to Care (Continued)

- Follow up with clients who miss an appointment (by phone, SMS, or home visit).
- Check in with clients often after they start or change medicines.
- Review each client's drug regimen to assess whether changes can be made to facilitate adherence.
- Use fixed dose combinations of ARVs to reduce clients' pill burden.
- Provide transportation stipends to clients unable to pay (if possible).
- Obtain client feedback, for example, through an adolescent consumer (or client or community) advisory board (CAB).

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Permission to Call or Visit Clients at Home

- During baseline intake and at least annually thereafter, 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.

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Discussion Questions

Thinking about your health facility:

- Which of the areas discussed are lacking at your facility?
- How could these areas be improved to better support ALHIV's retention in care at your facility?
- What are some of the challenges of implementing these actions? What are some of the solutions?



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Remember:



- One of the most important steps to improve retention in care is to ensure that services are youth-friendly.
- Services that are youth-friendly increase the likelihood of client retention and also support perfect or near-perfect adherence to treatment.

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Questions or comments on this session?

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Session 8.3

Providing Adherence Preparation Support to ALHIV and Caregivers

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Session 8.3 Objectives

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

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Pair Work: The Importance of Adherence Preparation

Discuss in pairs:

- *What happens at your clinic now to prepare adolescent clients and caregivers to start ART?*
- *What do you think works well? What are some of the challenges?*
- *What are some considerations for younger adolescents in terms of adherence readiness and preparation?*
- *What is a treatment buddy and how might a treatment buddy help an adolescent client?*

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Overview of Adolescent-Friendly ART Adherence Preparation

- Depending on the program and national guidelines, adherence preparation may include 1-4 group or individual sessions that take place over a number of days or weeks
- Follow national guidelines and remember that ongoing adherence assessment and support is necessary
- Group sessions are useful for giving many people information at one time
- Individual sessions can be used to find out what the client learned from previously attended group sessions, to identify support needs, and to develop an individual adherence plan

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Overview of Adolescent-Friendly ART Adherence Preparation (Continued)

- ALL ALHIV should be given time — AT LEAST one session — to speak to a counselor, health worker, and/or Adolescent Peer Educator in private
- Discuss potential adherence challenges and make an individual adherence plan

Remember:

- Ideally, adherence preparation counseling should begin early in HIV care.
- While providing as much support as possible, the team should be flexible when addressing ART readiness.
- **The preparation process should always facilitate ART initiation and should never act as a barrier.**

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What is a Treatment Buddy?

- Someone chosen by a client to provide him or her with ongoing support for adherence to care and treatment
- 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 a client can disclose his or her status
- HCWs should explain the importance of having a treatment buddy to ALHIV and should make sure treatment buddies have the needed information and skills.
- HCWs should encourage treatment buddies to accompany ALHIV on clinic visits.
- **Remember: not having a treatment buddy should not act as a barrier to any client initiating ART!**

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Adherence Preparation Topics

- Review national adherence preparation guidelines and tools
- Please take a marker and brainstorm answers on the "Adherence Preparation Topics" flip chart:
 - *What are the most important adherence preparation topics to cover with ALHIV and their caregivers?*



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Key Topics for Adherence Preparation Education and Counseling

See Table 8.1.

Remember: It may be helpful to develop an adherence preparation checklist to ensure that adherence preparation sessions are consistent and cover all of the necessary information, no matter who is leading the session.

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Helping Clients Develop a Personal Adherence Plan

The plan should address:

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

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The Adherence Support Tree

- See Appendix 8A: Adherence Support Tree.
- This is a tool health workers can use to help clients and caregivers prepare for adherence to ART. It can also be used to ask about adherence at follow-up visits.
- Let's practice using the Adherence Support Tree:
 - Work in pairs – one person should play the role of the health worker and the other an adolescent client
 - Use the Adherence Support Tree to discuss the WHO, WHAT, WHEN, WHERE, and HOW of the medications (take about 5 minutes)
 - Next, switch roles and role play again

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Debriefing Discussion

- What do you think of the Adherence Support Tree?
- How could the Adherence Support Tree be used in your clinic setting?



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Discussion Question

- What system do you currently use to assess a clients' readiness to begin ART?



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Assessing Clients' and Caregivers' Readiness for ART

- See Appendix 8B: Adherence Preparation and Support Guides.
- You can use the plan agreed upon during the WHO, WHAT, WHEN, WHERE, and HOW discussions when completing these guides with clients and caregivers
- Standardized readiness assessment tools can:
 - Help health workers assess a client's and caregiver's readiness
 - Help clients understand the importance of lifelong adherence
 - Ensure a shared understanding of the client's care and medications plan
 - Identify potential adherence challenges and help to brainstorm practical solutions

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Assessing Clients' and Caregivers' Readiness for ART (Continued)

- It may take 1, 2, or even more individual counseling sessions before a client is ready to start ART.



Remember: Assessment questions should be used to identify areas where the client may need additional support. It should not be used as a "test" that the client needs to pass before starting ART.

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Discussion Questions

- How could this assessment be modified for adolescents of different ages?
- How do you think you could use these tools in your work/clinic?



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Exercise 1

Developing an Adherence Plan: Trainer demonstration, case studies in small groups, and large group discussion

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Exercise 1: Trainer Demonstration and Role Play - Case Study 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?

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Exercise 1: Small Group Work – 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?

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Exercise 1: Small Group Work – 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?

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Exercise 1: Small Group Work – 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 goes on to say 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?

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Exercise 1: Small Group Work – 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?

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Exercise 1: Large Group Discussion Questions

- How did you decide on an adherence plan with the client or caregiver? What tools did you use? How would you measure the plan's success or outcome?
- Did you have any concerns about the client initiating ART? How would you address these concerns with the client and/or caregiver?
- What advice did you give to the client about adherence to care and medicines? The caregiver?

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Exercise 1: Debriefing

- What did we learn?
- Key points:
 - One of our most important tasks is to provide adherence preparation counseling and support to clients and caregivers.
 - Group sessions are helpful, but individual sessions are required to make an individual adherence plan.
 - Address the ARE YOU COMMITTED, and the WHO, WHAT, WHEN, WHERE, and HOW of the medicines with clients and caregivers. Using the Adherence Support Tree in *Appendix 8A* can help.
 - Using standardized assessment tools (*Appendix 8B*) can help determine a client's and caregiver's readiness for ART and where more counseling and support are needed.

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Questions or comments on this session?

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Session 8.4

Assessing Adherence and Providing Ongoing Adherence Support

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Session 8.4 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

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Discussion Questions

- How do you currently assess adherence with clients at your clinic? With caregivers? What works well? What is challenging?
- What questions would you ask clients and caregivers to assess adherence?
- What other methods (for example, pill count) would you use to assess adherence?



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Assessing Adherence

- ...is challenging, and there is no one perfect way to do it.
- ...requires ongoing, individual adherence assessment and counseling.
- ...can encourage clients to express challenges
- Assess adherence **at every visit!**
- All members of the MDT should ask questions about adherence.
- If available, also ask the caregiver or treatment buddy about adherence.
- Conduct separate sessions with older ALHIV and their caregivers.
- Discuss differing answers with the client and caregiver together.
- **Do not judge!**
- Let clients know that everyone has problems taking medicines the right way all the time.

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Assessing Adherence (Continued)

- Build a trusting relationship and encourage clients to be completely honest.
- Refer clients to peer support groups or link them to an APE.
- Talk about clients' adherence at MDT meetings.
- Use tools to help assess and improve adherence, such as:
 - Pill counts
 - Review of clinical findings and lab tests
 - Review medicine diaries or calendars

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

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Assessing Adherence (Continued)

- See *Appendix 8C: Adherence Assessment Guides*.
 - 1 guide for adolescent clients
 - 1 guide for caregivers
- Always follow national guidelines and use national tools (if they exist).

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Discussion Questions

- Why might it be important to ask adolescent clients and caregivers about adherence separately?
- How could these assessments be modified for young versus older adolescents?
- How do you think you could use these tools in your work/clinic?



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Discussion Questions

- *Why is it important to provide ongoing adherence support?*
- *How do you think we can support long-term adherence to care among younger adolescents? Older adolescents? Caregivers?*



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Providing Ongoing Adherence Support

- When providing adherence support, build on previously established trust and rapport, maintain a safe space to discuss any problems, and give ongoing encouragement.
- **If the client seems to be 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.

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Providing Ongoing Adherence Support (Continued)

If the client seems to be experiencing challenges with adherence, provide individual counseling and:

- Praise the client for sharing his or her challenges
- Identify the client's specific challenges
- Help client resolve each challenge
- Discuss importance of adherence
- Refer client to an APE, adolescent support group, etc.
- Refer difficult cases to a counselor or social worker
- Plan for next steps
- Record the session on the patient record
- Follow up at the next visit
- Share observations with the multidisciplinary team

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Exercise 2

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

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Exercise 2: Case Study 1

J___ and his uncle:

- *What are the client's/caregiver's main adherence challenges? What are some possible solutions?*
- *What are some age-appropriate techniques a health worker could use to build the client's/caregiver's confidence and knowledge about adherence?*
- *Are there any community-based services that might help the client? What suggestions or referrals would you make?*
- *What did the health worker do to address differences between the 2 stories (J___'s and his uncle's)?*

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Exercise 2: Case Study 2

N___ and his mother:

- *What are the client's/caregiver's main adherence challenges? What are some possible solutions?*
- *What are some age-appropriate techniques a health worker could use to build the client's/caregiver's confidence and knowledge about adherence?*
- *Are there any community-based services that might help the client? What suggestions or referrals would you make?*
- *Did the issue of disclosure come up during your counseling session with either N___ or his mother?*

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Exercise 2: Case Study 3

P___:

- *What are the client's/caregiver's main adherence challenges? What are some possible solutions?*
- *What are some age-appropriate techniques a health worker could use to build the client's/caregiver's confidence and knowledge about adherence?*
- *Are there any community-based services that might help the client? What suggestions or referrals would you make?*
- *Did you include P___'s friend in any way? How could she be helpful?*

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Exercise 2: Case Study 4

M___ and her mother:

- *What are the client's/caregiver's main adherence challenges? What are some possible solutions?*
- *What are some age-appropriate techniques a health worker could use to build the client's/caregiver's confidence and knowledge about adherence?*
- *Are there any community-based services that might help the client? What suggestions or referrals would you make?*
- *Do you think M___ was really taking 100% of her medicines?*

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Exercise 2: Large Group Discussion Questions

- *What do you think will be the most challenging aspects of conducting adherence assessments with ALHIV and their caregivers at your clinic?*
- *What approaches should health workers take to make clients and caregivers feel comfortable giving honest answers about adherence?*



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Exercise 2: Debriefing

- *What did we learn?*
- **Key points:**
 - An adolescent's adherence needs change over time and as they age and develop; ask about adherence at every visit.
 - The Adherence Assessment Guides in *Appendix 8C* can be useful tools when asking clients and caregivers about adherence.
 - It is often helpful to ask clients and caregivers about adherence separately.
 - It is important to build a trusting relationship with adolescent clients so they feel comfortable being honest with us about adherence challenges.
 - It is important not to judge clients (or caregivers) if they are non-adherent!

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Questions or comments on this session?

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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.
- Clients must take over 95% of their necessary ART doses to achieve the conditions for therapeutic success. Our aim is 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*").
- One of the most important steps to improve retention in care is to ensure that services are youth-friendly.

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Module 8: Key Points (Continued)

- ART preparation usually includes group education sessions, individual counseling sessions, and an adherence readiness assessment.
- Ideally, adherence readiness assessment and counseling should begin early during HIV care, but they **should not be a reason to delay initiation of ART**.
- 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.

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Module 8: Key Points (Continued)

- Health workers can help the client develop a personal adherence plan by asking the **are you committed?** question and the **who, what, when, where, and how** of the medications. The Adherence Support Tree and Adherence Preparation and Support Guides can be helpful tools.
- The best way to assess adherence is to use several methods. HWs can use the Adherence Assessment Guides to ask clients and caregivers about adherence **at each clinic visit**.
- Adherence support services should be ongoing and the entire MDT is responsible for providing these services.
- Ongoing adherence support is especially important for adolescents because their adherence to care and medications will change over time.

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