

1Enhanced Adherence Counselling Content Guide for Children and Adolescents

Session 1

Assess the Caregiver's /Adolescent's understanding of 'viral load', 'high viral load' and 'suppressed viral load'. Ask them to explain what each of these terms mean. Provide education if Caregiver and Adolescent requires more explanation

Provide VL result and explanation of result:

"You (your child) have a detectable viral load. There are several possible reasons for this such as problems with adherence, dosing of your medications, interactions with other drugs or foods, or possible drug resistance. It is very important for us to work with you determine which may apply to you."

How do they feel about the result?

Explain the process of enhanced adherence:

"Patients with a high viral load come for at least 3 adherence counselling sessions to discuss what might cause a high viral and to look for solutions on how adherence can be improved. Another viral load test will be done after 3 months of good adherence to see if the ART can be continued or if we need to change treatment."

Check whether the child or adolescent has had previous problems with adherence and/or missed appointments

Ask:

"Why do you think your (your child's) viral load is high?"

Sometimes the adolescent/caregiver may already know why the VL is detectable. Start by giving them a chance to provide their own explanation. Often, they will admit that they are struggling with their adherence. If they really don't know why their VL is high you can say:

"We notice that when people sometimes forget to take their ART everyday it gives the virus a chance to grow. Do you think that you sometimes forget to give your child medication?"

Assess for Possible Barriers to Adherence

Cognitive Barriers (HIV and ART knowledge)

Assess Caregiver or Adolescent's knowledge about HIV and ART; correct any misconceptions

"What is HIV?"

"What is the immune system and CD4 cells?"

"What is ART and how does it work?"

"Why is it important to be adherent? And how?"

"Why do you have to come for follow-up appointments? What should you bring?"

Behavioral Barriers

Review how the caregiver gives medication or adolescent takes drugs

"How does taking medication/giving your child medication fit in your daily routines?"

- Assess with the caregiver or adolescent whether the time is a problem. For example, if the caregiver or adolescent has chosen 9 pm, but they are already asleep by 9 pm, then that is not a good dosing time. The timing should also fit into the child/adolescent's school schedule. If the time is a problem then determine a new, more appropriate time with the patient based on their schedule
- Remind the adolescent/caregiver that a missed dose should be taken as soon as he/she remembers (up to a couple hours before the next scheduled dose). The next dose should be taken at the usual time

"What reminder tools do you use? (e.g., mobile phone alarm)" "What do you do in case of visits, and travel?"

- Travelling is always a risk for poor adherence or default from treatment. Encourage the caregiver/adolescent to plan, to make sure they have enough medication on hand before and to remember to pack it
- Make sure that all relevant information is on the appointment card and explain that if they are ever away from home and they are about to run out of medication that they must go to the closest ART clinic and show their appointment card

"What do you do in case of side effects?"

- Ask the caregiver if the child is experiencing any side effects from the ARVs, and if they sometimes find it difficult to take ARV medication because of the side effects. Ask how s/he manages side effects and if it influences the way s/he takes the drugs. Has the child/adolescent skipped medication due to unpleasant effects of the drug?
- Check for alcohol or drug use for the adolescent or caregiver. Ask the caregiver or adolescent in a casual way (not in an accusing way) if they sometimes use substances; emphasize treatment planning in case they do. Alcohol or substance use can make it difficult for the caregiver to ensure their child's adherence to medication
- *"Taking alcohol or drugs sometimes makes it difficult for us to remember to take treatment. If possible, it is best to limit your use, but if you are planning to take any alcohol or drugs, it is important to plan ahead so that you don't forget to take your treatment"*

"If you feel your alcohol or drug use is affecting your child's adherence, are you ready to be referred to some professionals that may help you to work on that problem?"

Emotional Barriers

- Review the adolescent's/Caregiver's motivation:

"How do you feel about giving your child medication every day?" "What do you want to be when you are done with school?"

You can use motivation cards for this: Ask the adolescent to think of his or her own personal goals/dreams for the future. What are the 3 most important things they still want to achieve? Have them write them in their own words on a notecard. Encourage them to read the notecard every day, preferably right before they take their medication.

¹ Borrowed from NASCOP Care and treatment Guidelines

Assess Disclosure status of the child/adolescent and support appropriately. Is the child/adolescent's disclosure status appropriate for their age?

Mental health screening: Depression is an important reason of non-adherence. All patients with suspected or confirmed treatment failure should be screened for depression using the PHQ-9 tool (Table 4.14)

The adolescent or child may be in any of the five stages of grief (because of their HIV diagnosis or for other reasons): denial and isolation; anger; bargaining; depression, or; acceptance. This needs to be assessed and addressed

Socio-economical Barriers

For the Caregiver: *"Do you have any people in your life who you can talk to about your child's HIV status and ART?"*

- Discuss how the caregiver can enlist the support of their family, friends, and/or co-workers in encouraging and reminding them to give their child medication if they have not already done so
- For the adolescent encourage support from a treatment buddy: if the adolescent came with a treatment buddy, assess their input towards adherence.
- Support in family/community/support group: explore support systems, in addition to the treatment buddy, that the adolescent/caregiver is currently using and other options that they can start using. Discuss the advantages of joining a support group and any reasons the adolescent/caregiver is hesitant to join. Inform the adolescent on the benefits of an OTZ group and encourage them to join
- Profession, income generating resources: review the child's/adolescent's family's sources of income and how well they cover their needs
- Specific barriers to come to health center on regular basis: ask the caregiver/adolescent if they have any challenges getting the clinic on a regular basis. Help the patient develop strategies to overcome those challenges
- Stigma and discrimination
"Are you ever worried about people finding out your (your child's) HIV status accidentally?" "Do you feel like people may treat you (your child) differently when they know your(their) HIV status?"
- Discuss if stigma is making it difficult for them to take their medications on time, or for them to attend clinic appointments.
- Religious beliefs: find out if the caregiver/adolescent has tried faith healing, or if they have ever stopped giving the child medicine because of their religious beliefs

Referrals and Networking

- Review the child/adolescent's file to determine if they have been referred to other services. This includes referrals to social services, support groups, psychology services, nutrition services, medical clinics, etc
- Ask the adolescent/caregiver if they attended the appointments, check in on their experience with the referral services and re-organize referrals as necessary

- Plan for a home visit

Develop Adherence Plan

Go through each of the adherence challenges identified during the session and assist the adolescent/caregiver to develop a plan that addresses each of the issues. It is important to let the patient come up with the solutions so that they own them

Some examples of addressing adherence challenges:

Behavioral barriers: using a reminder tool; using a pill box; using a wrist watch; redefining the medication schedule to fit with their school schedule; keeping an emergency dose of drugs when away from home Refer to clinician in case of side effects

Socio-economical barriers: move on in disclosure process; identify a treatment buddy; join a support group; refer to CBO/NGO to learn about income generating activities .

Emotional barriers: emotional support or refer to clinician for mental health management

Agree on a follow-up date for the next session

Session 2 (usually 2-4 weeks after Session 1, preferably with the same provider)

Review Adherence Plan

- Ask the caregiver/adolescent if he/she thinks adherence has improved since the last visit. Enquire in a friendly way if any doses have been missed
- Review the barriers to adherence documented during the first session and if strategies identified have been taken up. If not, discuss why not

Identify Any New Issues

- Discuss specific reasons why the patient may have missed their pills or a clinic appointment since the last counselling session, and determine if it is a new issue that wasn't addressed during the first session
- Discuss if other issues have come up because of implementing the adherence plan (e.g. perhaps the disclosure process had unintended results)

Referrals and Networking

- Follow-up on any referrals made during the previous session
- Determine if the patient could benefit from a home visit

Develop Adherence Plan

- Go through each of the adherence challenges identified during the session and assist the adolescent/caregiver to modify their original adherence plan to address each of the issues. It is important to let the patient come up with the solutions so that they own them
- Give another short motivational speech on how you believe in the patient! You know they can do this! Together you will make sure that they suppress their viral load!!
- Agree on a follow-up date for the next session

Session 3 (usually 2-4 weeks after Session 2, preferably with the same provider)

Review Adherence Plan

- Ask the adolescent/caregiver if he/she thinks adherence has improved since the last visit. Enquire in a friendly way if any doses have been missed
- Review the patient's barriers to adherence documented during the first session and if strategies identified have been taken up. If not, discuss why not

Identify Any New Issues

- Discuss specific reasons why the patient may have missed their pills or a clinic appointment since the last counselling session, and determine if it is a new issue that wasn't addressed during the first session
- Discuss if other issues have come up because of implementing the adherence plan (e.g., perhaps the disclosure process had unintended results)

Referrals and Networking

- Follow-up on any referrals made during the previous session
- Determine if the patient could benefit from a home visit

Develop Adherence Plan

- Go through each of the adherence challenges identified during the session and assist the caregiver or adolescent to modify their original adherence plan to address each of the issues. It is important to let them come up with the solutions so that they own them
- Give another short motivational speech on how you believe in them! You know they can do this! Together you will make sure that they suppress their viral load!!
- Agree on a follow-up date for the next session

Repeat Viral Load

If the adherence is good: plan for the next VL testing after 3 months and explain possible ways forward, emphasizing the roles of the adolescent/caregiver, the support systems and the health facility. You can continue follow-up adherence counselling sessions during the 3-month period if you and the caregiver/adolescent think there would be a benefit to them

"If your results come back and your VL is undetectable then you will be able to continue with same ART. If your viral load is still greater than 1,000 copies/ml then you will need to switch to a new regimen, probably after doing some additional testing to see which regimen may work best for you. If your viral load is detectable but less than 1,000 copies/ml we will discuss options, including changing regimens or continuing to monitor." (Adapt to individual patient/context)

If adherence challenges persist plan further Enhanced Adherence Counselling Sessions before repeating the VL

Session to Discuss Repeat Viral Load Results (after the repeat VL results are back, preferably with the same provider)

Discuss Viral Load Results

If suppressed (VL undetectable) CONGRATULATE the patient!!!

Explain the way forward: will continue with same ART regimen and repeat the VL again in 6 months

If viral load is $\geq 1,000$ copies/ml

Explain the way forward: will probably need to switch to a new ART regimen after discussing as an MDT, and additional testing to see which regimen may work for the adolescent/child

Summarize the case with the MDT; if the patient cannot switch to standard 2nd line ART, or is failing

2nd line ART, forward to the Regional Technical Working Group (Bonde La Ufa TWG) for next steps

If viral load is detectable but $< 1,000$ copies/ml, Explain the way forward: may continue monitoring or switch to a new ART regimen after discussing as an MDT

Summarize the case with the MDT and forward to the Regional or National HIV Clinical Technical Working Group for next steps