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ENHANCED ADHERENCE COUNSELING FOR PATIENTS WITH SUSPECTED OR CONFIRMED TREATMENT FAILURE Note: for children/adolescents, the script below should be modified towards the caregiver

SESSION I:

- Assess patient's understanding of 'viral load', 'high viral load' and 'suppressed viral load'. Ask the patient to explain what each of these terms mean. Provide education if patient requires more explanation
 - Provide VL result and explanation of result:
- "You 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 does the patient feel concerning 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 patient had previous problems with adherence and/or missed appointments
- Ask:
- "Why do you think your viral load is high?"
- Sometimes the patient already knows why his/her 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 your pills?"
- Assess for Possible Barriers to Adherence
- Cognitive Barriers (HIV and ART knowledge)
- Assess patient'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?"
- Behavioural Barriers
- Review how the patient takes drugs
 - "Please explain how do you take your drugs, and at what time?" "How does treatment fit in your daily routines?"
 - Establish with the patient whether the time they are meant to take their medication is appropriate or

- whether the time is a problem. For example, if the patient has chosen 9 pm, but is already asleep in bed by 9 pm, then that is not a good dosing time. If the time is a problem then determine a new, more appropriate time with the patient based on their schedule
- Remind the patient/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 patient 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 patient's 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 patient if s/he has any side effects from the ARVs, and if they sometimes find it difficult to take ARV
 - because of the side effects. Ask how s/he manages side effects and if it influences the way s/he takes the drugs.
- "What are the most difficult situations for you to take drugs?"
 - Check for alcohol or drug use. Ask the patient in a casual way (not in an
 accusing way) if they sometimes use substances; emphasize treatment
 planning in case they do
 - "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 adherence, are you ready to be referred to some professionals that may help you to work on that problem?"
 - Emotional Barriers
 - Review the patient's motivation: "How do you feel about taking drugs every day?" "What are your ambitions in life?"
 - Review the patient's disclosure of their HIV status
 - You can use motivation cards for this: Ask the patient 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 the patient to read the notecard every day, preferably right before they take their medication 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 patient 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

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- "Do you have any people in your life who you can talk to about your HIV status and ART?"
- Discuss how the patient can enlist the support of their family, friends, and/or co-workers in reminding them to take their medication if they have not already done so
- Support from a treatment buddy: if the patient came with treatment buddy, assess their input towards adherence. If patient did not come with treatment buddy, explain the role of a treatment buddy and encourage the patient to come with a person they trust next visit
- Support in family/community/support group: explore support systems, in addition to the treatment buddy, that the patient is currently using and options that the patient can start using. Discuss the advantages of joining a support group and any reasons the patient is hesitant to join
- Profession, income generating resources: review the patient's and family's sources of income and how well they cover their needs
- Specific barriers to come to health centre on regular basis: ask the patient 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 HIV status accidentally?" "Do you feel like people treat you differently when they know your 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 patient has tried faith healing, or if they have ever stopped taking their
- medicine because of their religious beliefs
- Referrals and Networking
- Review the patient'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, substance abuse groups, etc
- Ask the patient if they attended the appointments, check in on their experience with the referral services and re-organize referrals as necessary
- 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 patient 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:
- Behavioural barriers: using a reminder tool; using a pill box; redefining the medication schedule to fit with the patient's daily 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

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• Emotional barriers: emotional support or refer to clinician for mental health management Agree on a follow-up date for the next session

SESSION II:(usually 2-4 weeks after Session I, preferably with the same provider)

Review Adherence Plan

- Ask the patient 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 patient 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 III: (Usually 2-4 weeks after session 2, preferably with the same provider)

Review Adherence Plan

- Ask the patient 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

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- 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
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Referrals and Networking

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- 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 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 patient, the support systems and the health facility. You can continue follow-up adherence counselling sessions during the 3-month period if you and the patient 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 ≥ 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
 patient
- 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 or National HIV Clinical Technical Working Group for the 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

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