

ADHERENCE COUNSELING FOR COUNSELORS

GENERAL OVERVIEW

- Discussion points are to be **interactive** with the participant. After each and every point, the counselor should make sure the person understands the point, and has contributed to the discussion.
- After each point, have the participant summarize back the important points of each section.
- Although this is a checklist, it is not a tutorial, each point should involve a discussion with the person about 1) if they understand what is being discussed, 2) what barriers may exist regarding each point, and 3) what they have to add to the discussion.
- For each point, it is important for the participant to have a **plan AND a back-up plan**.
- Use in-session rehearsal (e.g. role play, sorting of pills, imagining one's day) as much as possible.
- Non-judgmentality – while presenting the information, its important to do so in a nonjudgmental, open way.
- Note taking – TAKE NOTES on this form for each participant (make a copy of a separate checklist for each and every person so you can refer back to it). When they return for follow up visits, re-assess each major area to determine if problem-solving is necessary.
- Remember – behavioral change involves increasing **information, motivation, and skills** – all three are important.
- Remember – not everyone will be at a high “readiness to change”
- Remember – many people will say they understand but really do not.

MATERIALS NEEDED BEFORE THE ADHERENCE COUNSELING VISIT

- Visual materials to help explain adherence and the biomedical aspects of adherence.
- Adherence tools – pill box, diary card, reminders
- Knowledge of patient's regimen and potential side effects
- Pictures or tools for pill regimen to review and for patient to take home.
- Note card in case of questions for doctor

1. RAPPORT BUILDING DISCUSSION POINTS

- How long living with HIV?
- Reasons for joining the study.
- Reasons for maintaining one’s health (e.g. kids, family, goals).
- Much of this is complicated, and it is important that you understand what we discuss. Therefore, I will repeat things several times, and I will have you repeat the information back to me so that I am sure you understand.

Notes:

2. DEFINITION OF MEDICATION ADHERENCE:

- Adherence is the degree to which a person sticks to the regimen prescribed.
- Adherence is **collaborative** between the providers and the patient.
- Importance of taking an **active role** in one’s treatment.
- Importance of **feeling comfortable asking questions** and being honest about any problems.
- Adherence versus “compliance” – compliance is yielding or acquiescing – implying that the regimen is not a shared decision between provider and patient. Adherence – a shared decision.

Notes:

3. EDUCATION ABOUT HIV MEDICATIONS AND ADHERENCE

Utilize any pictures, models, visual materials, or cartoons available to explain the importance of adherence from a biomedical perspective.

3a. Discussion – replication and resistance: ●

- **Replication** - The HIV virus copies itself very quickly.
- When it copies itself so quickly, the virus can **change forms**. This is called mutation.
- Sometimes, since it copies itself so quickly, it can change to a new form (a mutation) that would be **resistant** to the medications.
- The combination of the medicines you will be receiving can **slow or stop** the virus from copying itself.
- When adherence is poor, however, the virus can still copy itself.
- The fact that some medicine is still there (but not enough to stop the virus from copying itself completely) increases the chances that the copies that survive can be ones that would be resistant to the medicines.
- Because of this, even though taking medicines and adhering to the regimen is the best solution, **poor adherence can actually lead to the virus being resistant to the medications you are taking**.
- **Repetition** – have the participant explain this back to you after you explain it.
- **What questions do you have so far?**
- **Please explain back to me why it is important to take all of your medicines as much as possible?**

3b Discussion – 95 to 100% adherence is optimal ●

- Discussion: studies have shown that **95% to 100%** adherence gives you the best chance of having an undetectable viral load.
- Discussion of **meaning of undetectable viral load**: This means that you still have virus in your blood stream, it just means that there is so little that typical machines do not detect it – but ultra sensitive machines still can).

3c. Discussion point – sharing of medications ●

- Discussion point - **sharing medications**: It is sometimes, understandably, tempting to share medications with others who do not have access to them. Unfortunately, the result may be **worse for both people** than not having any medicines at all – because of the possibility of developing resistance to the medications.

3d. Repeat and discuss 1) replication and resistance, 2) 95-100%

optimal, and 3) sharing of medicines

- **Repeat and discuss** any points that the person does not understand. Be sure the participant understands the concept of mutations and viral resistance as a result of poor adherence.
- What questions do you have about adherence and what we have discussed?
- Please explain back to me why it is important to be 95 to 100% adherent to the medicines.

Notes:

4. SIDE EFFECTS.

- Discussion of **what particular** side effects may occur with the regimen the person is taking (e.g. diarrhea, nausea, headaches, peripheral neuropathy, other adverse effects.)
- Discussion of how side effects sometimes get in the way of adherence.
- Discussion about how after a while, your HIV might get better after taking medications, but that the side effects may make you feel worse – so this **might make you want to stop** taking the medicines.
- Discussion of **possible remedies** for side effects (adjunctive medications, relaxation/yoga, etc.).
- Encourage patient to speak with the counselor and / or the study doctor about any side effects that come up and a possible plan for them if they do (before deciding not to take medicines because of the side effects).
- What questions do you have about side effects?

Notes:

5. COMMUNICATION WITH THE DOCTOR AND TEAM ABOUT PILL

TAKING

- Although we want you to be as adherent as possible, we also know that everyone will struggle with adherence.
- The best thing for you and the best thing for the study is to be honest about adherence issues and to ask whatever questions you have.
- Assess if participant has any questions that they have not previously asked. Answer them or write them down for the study doctor to answer for him or her.
- General discussion about communication with the study doctor and any difficulties that might get in the way of this.
- It is normal to not understand everything at first – HIV treatment information can be complicated at first. It is also normal to forget some of the points we discuss today – so we will review them at different visits.

Notes:

6. INTRODUCTION OF ART REGIMEN

- Show patient each pill and say its name.
- Describe what each pill does.
- Use visual prescription – give to patient to take home (picture of pills, number and timing)
- Discuss timing of each pill and any food restrictions.
- What questions do you have about your regimen?

Notes:

7. CONCRETE DAILY MEDICATION SCHEDULE AND SORTING ●

- Sort pills with participant regarding when to take – if possible – using pill box or other method (e.g. sorted bags for each dose that can be labeled, using a punch card).
- Discuss timing of doses.
- Tie pill taking to another behavior that might occur at the same time (e.g. meals, right when participant wakes up).
- Identify times when the schedule might vary (e.g. days when working versus days when not working; days when family is home versus days when family is not at home).
- Make sure times to be taking pills coincide with food restrictions if there are any.
- Review schedule as exactly as possible (for some this might not be possible) – for example, twice a day = as close to every 12 hours versus once at 8 am, and then again at 1pm (five hours later).
- Review - Simplify schedule as much as possible to include meals, other regularly occurring tasks, timing of doses, scheduling sleep, and tying pill taking to a regularly occurring activity (e.g. eating, waking).
- What questions do you have about your medication schedule?

Notes:

8. Reminder strategies ●

- Involvement of partner if possible, or identifiable person to help them remember to take pills.
- Overt reminders – watch, timer, reminders to put different places?
- Storage of pills

Notes:

9. Family, community, social support, and privacy

- Discussion – who in your life knows about your HIV status
- Who can help you with pills
- Who can support you about the difficulties involved with receiving HIV treatment?
- Who do you want to keep your HIV status private from?
- How will privacy affect adherence?
- Where will you store the pills (privacy concerns but also should be in a place that is easy)

Notes:

10. Additional potential barriers to adherence

- Discussion of any other things that might get in the way (e.g. travel, food, life problems, lack of electricity in the home, work outside of the home, privacy, substance use, access to water, child care, family commitments etc.).
- Attempt to come up with a problem solving plan for them,

Notes:

11. Handling slips

- Although the goal is optimal adherence, no one is perfect.
- Discussion of how to get back on track as soon as possible after a slip.
- Continued communication with provider and counselor to handle a slip.

Notes:

12. GETTING TO APPOINTMENTS

- Plan and backup plan for transportation to the clinic.
- Backup plan for when transportation cannot be arranged.
- Plan for child care or additional barriers to appointments (e.g. work, life problems, access to transportation, commitments).

Notes:

13. REVIEW

- Have participant repeat back his or her medication regimen/schedule
- Give them a medication schedule with visual cues (pictures of the pills)
- Hand out any written or visual materials about pill taking
- Give contact information for participant to be able to call you if they have a phone.
- Make list with all of the strategies discussed above and re-review them.
- Schedule follow-up appointment to review.
- Take any questions that emerged to the physician and have them come back and answer them – or find out the answers and answer them.