

CLEAR Facilitator's Manual

Module 3

Stay Well: Self-care/ Health-care Behaviors

Session #16: Medication Schedules: Can I Stay on Track? (1.5 hrs.)

OBJECTIVES:

1. Youth will continue developing substance use management skills.
2. Youth will review the basic facts regarding HIV replication and antiretroviral therapy.
3. Youth will explore feelings about taking antiretroviral medications.
4. Youth will practice reframing cognitions that inhibit medication adherence.
5. Youth will practice self-monitoring and cognitive reframing in daily living.

RATIONALE:

Research data shows that over 50% of patients do not follow their medication regimens. The inherent complexity of antiretroviral cocktail regimens and the spectrum of possible side effects exacerbate adherence issues. However, few medical conditions are as sensitive to even one missed dose. The next two sessions focus on identifying barriers and learning medication adherence skills.

SUMMARY:

1. Welcome participant, review goals, introduce the day's topic, and give a thank you gift. (20 minutes)
2. Link feelings to issues involved in taking antiretroviral medications. (15 minutes)
3. Review facts on HIV replication and antiretroviral therapies as a rationale for improving compliance. (20 minutes)
4. Introduce reframing as a cognitive skill and practice identifying problematic cognitions and reframing them. (20 minutes)
5. End with a review and between-sessions goal. (15 minutes)

MATERIALS:

Attendance Sheet
Cohort Rosters
Thank you gift
Goal Summary Sheet
Tape Recorder
90-min Audio Tape
Facilitator's Manual
Participant's Workbook
Participant Data Binder
Pens and Notepads

NOTES TO THE FACILITATORS:

Text in **bold** letters tells you what the purpose of each exercise is. Text in CAPITAL letters tells you what to do. Text in small letters tells you what to say. Once you become familiar with what to say, please put it in your own words. Do not read text in small letters verbatim, make it natural.

The times listed under the headings of each exercise are to help you keep on target and move the workshop along. Exercises may be lengthened or shortened as needed as long as all material is covered.

Exercise 1: What Happened Between Sessions?
(20 minutes)

[The purposes of this exercise are to enhance self-esteem, to create a pleasant environment, to continue substance use management skills development, and to introduce the topic of the session. Welcoming participant, reviewing Drug and Alcohol Report use and medical appointment compliance goals, introducing medication adherence, and giving a thank you gift are used.]

Welcome to this fourth session on staying healthy for the long run.

You had three goals from last week. One was to complete a Drug and Alcohol Report if you used.

Let's review those now.

HAVE YOUTH REPORT ON HIS/HER SUBSTANCE USE GOALS:

HOW MANY DAYS THEY X'D OFF ON HIS/HER CALENDAR THIS WEEK;

WHAT TRIGGERS THEY IDENTIFIED FROM THE D&A REPORTS (IF USED SUBSTANCES)

BRIEFLY SUGGEST TRIGGER MANAGEMENT SKILLS AS NEEDED.

The other goal was one you chose to help you keep your medical appointments.

Tell me how that worked out for you.

FOCUS ON REINFORCING PROGRESS MADE.

BREIFLY PROBLEM-SOLVE 1 OR 2 BARRIERS REACHING GOALS RELATED TO ATTENDING MEDICAL APPOINTMENTS.

Thanks for sharing, and keep up the good work!

Today I want you to appreciate how important it is to stay on schedule with your medications.

Staying on track with your anti-retroviral medications is one of the best ways to stay healthy for the long run.

Are you ever late with some of your doses?

Do you sometimes miss doses?

Do you miss a dose because you simply forget about it until the next dose was due?

Does how you think about your anti-retroviral meds ever get in the way of your taking them?

Today we are going to start building skills to increase your compliance with anti-retroviral medication regimens.

I realize that you may chose to be on medications at this time.

If you are not on antiretroviral medications this information may still be very important for you.

You may have friends or others you care about who are having a hard time taking their medications on schedule, even though they want to.

You can be a big help to them by sharing what you will learn here.

You will also be way ahead of the game should you decide to or need to start medications in the future.

Are you taking antiretroviral medications at this time? Have they been prescribed to you?

DISCUSS YOUTH'S CURRENT MEDICATIONS.

IF YOUTH HAS BEEN PRESCRIBED MEDICATIONS, BUT HAS DECIDED NOT TO TAKE THEM, DISCUSS HIS/HER REASONS FOR DOING SO.

LISTEN TO YOUTH'S REASONS AND BE REFLECTIVE AND NONJUDGMENTAL.

IF YOUTH IS NOT CURRENTLY TAKING MEDICATIONS AND THERE IS A SIMILAR ISSUE THE YOUTH WANTS TO WORK ON (I.E., USING THESE SKILLS TO HELP REMEMBER MEDICAL APPOINTMENTS), USE BOTH THE "HELPING OTHERS" AND YOUTH IDENTIFIED PROBLEM FOR THE SKILL BUILDING EXERCISES IN THIS AND THE NEXT SESSION.

Before we get started with today's topic, let me give you the thank you gift.

GIVE YOUTH THANK YOU GIFT.

Exercise 2: What Is Today's Session About?
(15 minutes)

[The purposes of this exercise are to introduce the topic and to link the topic to feelings in order to make the issues more real. A script and the Feeling Thermometer are used.]

To get into today's topic, let's try another soap scene.

DECIDE WHO WILL READ EACH PART, ASSIGNING GENDER-APPROPRIATE ROLES.

Would you like to play Bonnie/ Bruce or Martha/ Mark?

Here is the script for your workbook.

READ THE SCRIPT:

SOMETIMES

BONNIE/BILL: Look at all the pills. What are they for?

MARTHA/MARK: Some for this; some for that.

B: Do you take them all at the same time? What a mouthful!

M: Not all of them. They are special instructions for each kind.

B: How do you keep them straight?

M: I don't really.

B: Do you want to sell some?

M: They won't do you any good, and you can't get high on them anyway.

B: I like the colors of some of them. What do they do for you?

M: Well, most of them work together as part of the same treatment, called a “cocktail.” Some of them counteract the effects of the other ones.

B: I'd be too confused. Makes no sense to me. I don't know how you do it.

M: Well, I don't take them exactly as I'm supposed to.

B: Why not?

M: Sometimes I forget. Other times I just don't feel like it.

B: Won't you get sick?

M: Maybe. I wonder if the medicine isn't worse than the illness.

B: I hope they find a cure before I start showing any signs.

THE END

Thank you. That was great!

For much of the next two sessions we will be working on taking medication.

The goal is to help you figure out the best way to make your meds work for you.

That means having the desire, skills, and attitudes needed to take anti-retroviral medications exactly as prescribed.

How you feel about taking medication can make a big difference in whether or not you will end up doing it.

We will begin by finding out how you feel in situations that involve taking medication.

Remember the Feeling Thermometer?

A temperature reading of 100 means you are very uncomfortable.

A temperature reading of 0 means you are completely comfortable.

This page has a Feeling Thermometer and some situations to get us started.

Put this page in your workbook.

PAUSE.

I would like to know what your temperature readings would be in these situations?

When I read the situation, please give your thermometer reading for that situation.

PROCEED WITH THE SITUATIONS AS FOLLOWS.

ENCOURAGE SHARING OF TEMPERATURE READINGS.

MEDICATION SITUATIONS

You changed to a new medication and began having headaches and nausea.

Your pills got mixed and you couldn't remember which ones to take when.

You stopped taking your medication for three months and are now due for a doctor's appointment to check on your blood cell counts.

You read that the medication you are on can make you feel tired all the time.

You are not feeling sick but your doctor wants to put you on medication.

Thank you! That was great!

Now I would like you to think of your own situations around taking HIV medications.

Tell me what your temperature readings are for those situations.

Think of some of your more challenging experiences taking medications.

How do you feel about them?

ENCOURAGE SHARING OF SITUATIONS.

REPEAT SITUATIONS AS THEY ARE SHARED AND THEN ASK FOR THERMOMETER READINGS/ COMFORT LEVELS.

NOTE: MAKE A LIST OF ANY PROBLEMATIC ATTITUDES/ BELIEFS AS THEY ARE SHARED FOR LATER USE IN EXERCISE 4.

IF NECESSARY, PROMPT YOUTH WITH SITUATIONS THAT MAY HAVE COME UP IN PREVIOUS SESSIONS.

Thank you for sharing your situations and temperature readings.

What effect do these feelings have on your taking medication?

EXPLORE THE IMPACT OF FEELINGS ON TAKING MEDICATION AS PRESCRIBED.

You can see that knowing how you feel is important when it comes to staying on schedule with HIV medications.

Your feelings can tell you that something is going on for you and that maybe there is something else you need to work on to be able to follow what the doctor has recommended.

Exercise 3: Do I Remember What My HIV Medications Are All About?
(20 minutes)

[The purposes of this exercise are to clarify basic information and reduce misconceptions about HIV replication and antiretroviral therapy, to provide a rationale for medication adherence, and to standardize terminology used in the intervention. Reviewing and discussing points of information is the method used.]

The rest of today's session, and the next session as well, will focus on tools for improving your ability to stay on target with complicated medication schedules.

IF YOUTH IS NOT CURRENTLY TAKING MEDICATIONS, REINFORCE SHARING SKILLS WITH OTHERS AND IF APPROPRIATE, WORKING ON A DIFFERENT ISSUE (E.G., REMEMBERING MEDICAL APPOINTMENTS)

We are going to call those tools the 5 R's.

Before we move on to the Five R's, lets do a brief review to make sure we are all on the same page with the ideas and words we will be using.

Here are some of the points I want to bring up.

Please follow along as I go over these and you can put this in your workbook.

Just interrupt me at any time if there is something you don't understand.

Remember to use that assertive talk, even with me!

Okay, here are the points as they are listed in your workbook.

READ EACH POINT SLOWLY AND CLEARLY, PAUSING AFTER EACH.

CONSIDER ALTERNATING THE READING OF TOPICS BETWEEN FACILITATOR AND YOUTH.

RESPOND TO QUESTIONS IN THE SIMPLEST WAY POSSIBLE, TO REFLECT AND CLARIFY THE POINT GIVEN.

DO NOT ATTEMPT TO ANSWER DEEPER QUESTIONS OR THOSE REGARDING SPECIFIC REGIMENS.

REFER PARTICIPANTS TO THEIR HEALTH CARE PROFESSIONALS FOR ANSWERS TO THOSE QUESTIONS.

AS YOU ARE READING THE LIST, CHECK WITH YOUTH:

IF THIS INFORMATION IS FAMILIAR?

HAVE THEY DISCUSSED IT WITH SOMEONE BEFORE?

DID HE/SHE LEARN ANYTHING NEW?

WHAT IS HIV AND WHAT IS AIDS?

- 1) HIV is the virus that causes AIDS.
- 2) When HIV gets into the bloodstream it invades specific blood cells, called T-cells.
- 3) Once inside T-cells, HIV can make many new copies of itself.
- 4) The new copies then break out of the T-cells, destroying the T-cells in the process.
- 5) Now moving freely in the blood, all the new HIV copies can then invade more T-cells.
- 6) Without treatment, the process continues.
- 7) The number of HIV copies, or “viral load,” goes up; and the number of T-cells, or “T-cell count” goes down.
- 8) This is serious because without enough T-cells the body has a hard time fighting off even minor infections.
- 9) When the T-cell count goes low enough, or the person with HIV starts getting certain infections that the body would normally fight off, they are said to have AIDS.

WHY ANTIRETROVIRAL MEDICATIONS?

- 1) There is no known cure for HIV Disease.

- 2) Medication and healthy living are the best ways to manage HIV disease, to stay as healthy as possible for as long as possible.
- 3) Most people living with HIV have been prescribed a combination of medications called an “antiretroviral cocktail.”
- 4) No one medication alone is successful in stopping the virus from multiplying.
- 5) Each medication in the cocktail works in a different way to keep HIV from making copies of itself.
- 6) The fewer copies of HIV in the blood, the fewer T-cells will be destroyed.
- 7) When your blood tests show that your viral load is going down, or that your T-cell count is going up, this means that your medications are working.
- 8) Many people living with HIV who consistently stick to their medication schedules have gotten their viral load down to what is called “undetectable” levels.
- 9) While this is a really good goal to shoot for, be aware that undetectable does not mean that the person is cured. There is still some HIV in their blood and other body fluids, and they can still infect others.
- 10) An undetectable viral level is not an invitation to return to unprotected sex, or to discontinue medication unless your doctor tells you otherwise.

WHY IS STAYING ON SCHEDULE SO IMPORTANT?

- 1) Taking these medications on schedule means that they can fight HIV at their full strength.
- 2) These medications have to be taken *exactly* the way the prescription says to take them.
- 3) “Close” is not close enough if the medications are to work at full strength against HIV.
- 4) Missing a single dose or being very late with a dose can sometimes have a negative effect on all future doses of that medication.
- 5) When you get off schedule with your meds, HIV can learn how to work around that medication - and similar medications too!
- 6) When this happens, HIV is said to have developed “resistance” to that medication.

- 7) When HIV becomes resistant to one or more types of medications, that reduces the options for successful treatment.
- 8) And staying well becomes more and more challenging.

WHAT DOES IT MEAN TO STAY ON SCHEDULE?

- 1) There are three parts to your medication schedule: the amount (for example, the number of pills) of each medication you are to take at each dose; when you are to take each dose; and how you are to take each dose.
- 2) If you did not take the total number of pills prescribed for you on a given day, you were off schedule that day.
- 3) If you took all the pills you were supposed to take, but you were more than an hour late with one or more of your doses, you were off schedule that day.
- 4) If you were supposed to take one of your meds with food, but took a dose with only water, you were off schedule that day.
- 5) Remember that you have to take your medications *exactly* as prescribed, every dose, every day, if they are going to work their best for you.
- 6) “Adherence” is a term that describes how well you stay on your medication schedule. The goal is to work on improving your medication adherence until you take the right amount of medication, at the right time, and in the right way, all of the time.

Okay, are there any more questions before we move on?

BRIEFLY ANSWER ANY REMAINING QUESTIONS.

While staying on schedule is challenging for everyone using antiretroviral cocktails, the tools you are about to learn will make the job much easier.

The last point I would like you to remember, especially when staying on schedule with your meds gets tough, is this:

You are worth it!

Exercise 4: Improving Adherence: Reframing
(20 minutes)

[The purpose of this exercise is to increase participant's motivation to improve adherence through the use of the cognitive skill, reframing. Practicing reframes of limiting thoughts, beliefs and attitudes is the method employed.]

When learning to change substance use patterns and sexual behaviors we learned how important our thoughts can be.

A simple thought like "I am worth it" can make the difference between using a condom or giving in to pressure to go "bareback;" or on whether or not you will get loaded.

We also discovered that some thoughts may limit progress we would like to make.

For example, a thought like "Nothing else makes me feel good" can get in the way of staying sober.

You learned that replacing that thought with a statement like "I feel best when I am expressing my higher self" can keep you right on track with your substance use goals.

Changing limiting thoughts into ones that move you toward your goals is called "reframing."

There are a lot of thoughts about using antiretroviral medications that can reduce your adherence.

Here is a common one: "No one knows how long these medications will work, so why bother?"

How can you argue against that statement to reframe into a reason to stay adherent?

SOLICIT, SHAPE AND REINFORCE RESPONSES.

SUMMARIZE AS FOLLOWS:

Yes, reminding yourself that the best way to ensure you'll be around to take advantage of new and improved treatments, or even a cure in the future, is by adhering to the treatments available now.

Now I'd like you share one of your biggest thoughts or concerns that often gets in the way when you think about taking your medications.

Then you and I can pitch in together to come up with a reframe that will help you keep on track with medication adherence.

What's a thought that discourages you from taking your medications on schedule?

AS PARTICIPANTS RESPOND, RESTATE AND SIMPLIFY/ CLARIFY THE THOUGHT AS NEEDED.

HAVE EACH PARTICIPANT SELECT A REFRAME FOR THEIR OWN BARRIER THOUGHT AFTER BRAINSTORMING A FEW OPTIONS.

IF A YOUTH IS NOT ON MEDS OR CANNOT IDENTIFY AN ADHERENCE BARRIER THOUGHT, SUGGEST ONE FROM THOSE NOTED IN EXERCISE 2.

IF THE FOLLOWING ISSUES ARE NOT RAISED, REVIEW EACH OF THE FOLLOWING BEFORE MOVING ON:

Thought: "I don't take my pills when I am out in public because I don't want anybody to get in my business."

Reframe: "I can always excuse myself to the bathroom or somewhere private long enough to take my meds. I'll enjoy myself more if I don't have to worry about missing a dose."

Thought: "I hate putting up with the side effects. It's not worth the aggravation."

Reframe: "Side effects are signals that the medications are working! When I distract myself with something interesting to do or to think about, the side effects don't seem nearly as bad."

Thought: “I hate to think that I have to take all these pills forever.”

Reframe: “I don’t have to worry about forever. If I always focus on keeping on schedule with just my next dose, the future will take care of itself.”

Thought: “There are too many things to keep track of; this is too overwhelming for me.”

Reframe: “Keeping focused and staying on schedule with my antiretroviral medications helps me feel in control. I know I am taking charge of my health.”

Exercise 7: What Goals Should I Select?
(15 minutes)

[The purposes of this exercise are to establish situations where what was learned in the session is transferred to the real world, to increase self-esteem, and to build group cohesion. Goal setting and giving appreciation are the methods employed.]

Congratulations!

You just learned “Reframes,” the first of five major tools for improving medication adherence.

We will call these tools the 5 R’s.

Next week we will learn the other four: Routines, Reminders, Rewards, and Reserves.

Now it’s time to set goals for the next week.

Some of the time you pick your own goals, and sometimes we pick goals for you.

This week we picked three goals for you, and both are about using your tools.

The first goal is to keep your tools and skills for managing substance use sharp.

Continue to fill out your Calendar each day this week.

If you should use any substances, be sure to fill out a D&A Report for each time you used.

We will review your Reports next session.

Here is a to help with the second goal.

I'd like you to take a look at your medications and write down which you take and when you're supposed to take them.

Sometimes people don't realize how complicated these meds are.

By writing them out, it can help you appreciate what you've already been able to do, and it might help with making your plan for taking care of yourself and taking your meds the way they're prescribed.

There are some extra lines on the bottom of the page to help with your last goal.

Each time you take your meds this week, do a "thought scan" for barriers to adherence.

See if you are having any thoughts that discourage you from staying on schedule.

Whenever you identify one that you have not written in the log yet, write it down on a "barrier thought" blank.

Then think of a reframe for that thought and write it down.

Use these reframes whenever the barrier thoughts come up.

Try to follow through and take your meds on schedule each and every dose. That is most important.

Do you have any questions about the three goals for this week?

BRIEFLY RESPOND TO QUESTIONS.

Great! Let's hear about the best thing you got from today's session.

HAVE YOUTH REPORT ON BENEFIT OF SESSION.

GIVE APPRECIATION TO YOUTH FOR PARTICIPATION, POINT OUT ONE THING YOUTH DID DURING SESSION YOU PARTICULARLY APPRECIATED.

Thank You. I really appreciated your participation today.

THE END OF SESSION 16