MENTAL HEALTH TREATMENT ISSUES

HIV Fact Sheet

Promoting Adherence to Antiretroviral Treatment

Introduction. Combination antiretroviral therapy or highly active antiretroviral treatment (HAART) has given new hope to those infected with HIV, but the combination of at least three medications used in this therapy make this one of the most difficult of regimens to follow. Medications may need to be taken with or without food in multiple doses throughout the day, often in combination with other HIV-related medicines. The interactions of antiretroviral medications, especially the protease inhibitors, with other drugs are complex. The regimen's side effects can be discouraging. The consequences of not taking the drugs properly may be severe: resistance can develop rapidly, and the potential benefits of the treatment can be entirely lost. There is also the danger of cross-resistance—resistance to one medication can result in the decreased effectiveness of many others, restricting future options.

Studies show that adherence to medical treatment is a universal problem. As psychiatrists trained to deal with both medical illness and the less rational aspects of human behavior, we are in a unique position to assist patients and AIDS providers in addressing non-adherent behavior. This fact sheet outlines the multiple strategies that have proven useful.

Institutional Factors. How a health care system is structured will strongly influence whether providers and patients can work together collaboratively. Here are some of the elements that set the stage for success.

A respectful, culturally sensitive environment.

Integration of medical, substance use, and mental health treatment, as well as reproductive services.

Availability and continuity of providers over time.

Communication with patients in their primary language.

Use of a multidisciplinary team approach and peer support.

Twenty-four -hour-a-day phone coverage to handle crises that might disrupt a regimen (e.g., severe side effects, loss of medication).

Provider caseloads that permit time for adequate discussion with patients.

Mechanisms for handling financial/logistical barriers to obtaining medication and following the regimen, including assistance with benefits, childcare, transportation, etc.

Provider Factors.

Assess Readiness. Before beginning the regimen it is essential to prepare the patient well. Antiretroviral treatment is rarely an emergency. Because the best chance at viral suppression is the first regimen, it makes sense to wait until the patient is ready. The norm is to expect difficulty with adherence to these complicated regimens.

Determine the patient's goals. The patient is the one who needs to follow through on the treatment regimen. The provider needs to work with what the patient is able to do, rather than what the provider thinks is optimal. Providers can help patients achieve more ambitious goals by working collaboratively with them over time.

Proceed slowly and informatively. Have the patient paraphrase. Patients are often anxious when they first hear information, and they will usually miss important points that need to be repeated. You can only be sure what patients have understood when you hear what they repeat back to you.

* **Teach science (e.g., viral suppression and resistance).** Patients should know why it is essential to take every dose of their antiretroviral medications, especially if they are asymptomatic and have to tolerate side effects when they are otherwise feeling well. Patients need to understand that their bodies are fighting a powerful war between a rapidly replicating virus and a highly activated immune system, and that missing doses of medication will increase circulating virus in the bloodstream and risk the creation of resistant strains that could lead to a permanent loss of the regimen's effectiveness. Following their CD4 cell counts and viral load may help patients concretize the purpose of the medications.

Get feedback, including the patient's health beliefs and perceived barriers to carrying out a regimen. Patients' perceptions about health and treatment, as well as their lifestyles, can interfere with adherence and must be specifically taken into account when designing a regimen.

Consider a practice run without medication. Because antiretroviral regimens are so unforgiving (that is, even skipping a small number of doses can lead to viral resistance), it is useful to have clients do a practice run using placebo,

vitamins, or another substitute to establish the regimen of pill-taking prior to beginning active treatment. No patient should get prescriptions for antiretrovirals in their first appointment with their HIV provider.

Assess each patient as a unique individual. Providers often either overestimate adherence or categorize certain groups as non-adherent, such as injection drug users or people with severe mental illness. Expect non-adherence as the norm. All patients are at risk for being non-adherent, and having a comorbid condition does not necessarily prevent a patient from following through

Include the patient's support system, and enhance support wherever possible. Those who are close to the patient can either enhance adherence or undermine it. They need to be included in the process. Refer patients to self-help/support groups as available and appropriate.

Attend to availability and coordination of treatment for co-morbid conditions, especially substance use and mental illness. Patients with untreated alcohol/substance use disorders, depression, psychotic illnesses, or personality disorders will be more likely to adhere if these other disorders receive treatment. Moreover, such treatment will help with the stabilization of the patient in general. Furthermore, if the patient is motivated to begin antiretroviral treatment, this can be a good opportunity to introduce psychiatric and/or substance use treatment.

Initiating and Providing Ongoing Care. Studies of adherence to any medication regimen demonstrate the alarming rates at which patients do not fill prescriptions, take medication intermittently and/or incorrectly, or stop the regimen without seeking medical advice. These problems are often not reported to treating physicians. There is no simple solution to the problem, and given the high stakes with antiretroviral treatment, multiple approaches are needed. Thus, every health provider who is part of the treatment team is responsible for helping patients adhere.

Use the simplest effective regimen (e.g., # doses, # times). Extensive research demonstrates that the simpler the regimen the more likely the patient is to follow it.

Provide simple written information sheets and/or videos. These are much more useful than complex consent forms, and allow patients to review points they may have missed or forgotten. Keep pictures of the medications where patients can see them and learn to recognize them.

Use memory aides. Research shows how useful pill boxes are in improving adherence. Other strategies include alarms, electronic monitoring, and incorporating pill taking within another established routine.

Schedule a follow-up appointment soon after initiating the regimen. Working out the problems of a regimen is most critical at its beginning. Review the details of where medication is kept, how the medication box is filled, what side effects have occurred, etc.

Help patients plan medication-taking. Weekends, the middle of the day, and time spent away from home are the most common times for patients to miss doses.

Review and discuss medication-taking behavior at each visit and allow honest reporting of non-adherence. Have the patient bring the medication to the appointment to assess adherence. Avoid anger and criticism while addressing the essential nature of following the regimen. Angry or threatening responses to reports of non-adherence encourage a lack of patient disclosure about adherence problems, which then cannot be addressed by the provider, and increase the patient's sense of failure, which undermines problem-solving skills.

Role-play problem scenarios. Patients should understand where to get immediate help with problems that interfere with adherence, such as nausea, vomiting, diarrhea, lost medication, and so on.

Clarify substance use issues. Substance use, not abuse, is common to most people. Clarify what it means "not to drink alcohol with this medication." It is important to be realistic and clear to avoid patients skipping medications when they drink.

Understand the factors that interfere with adherence. These include asymptomatic illness, chronic illness, presence of side-effects, and discouragement and hopelessness. Providers need to be alert to these factors so they can offer additional support.

In the face of non-adherence, consider completely discontinuing and restarting combination treatment at a later point. This is an opportunity to assess the factors interfering with adherence and develop a realistic treatment plan.

Help patients develop an approach when adverse life events threaten to disrupt adherence. Loss of housing, illness of a child, death of a partner, and change in health insurance benefits are examples of events that can disrupt a regimen.

Conclusion. Adhering to antiretroviral treatment presents a great challenge. The task is daunting: treating a stigmatizing illness with a lifetime regimen, often of considerable complexity, and with medications likely to be accompanied by unpleasant side-effects. As experts in human behavior and motivation, psychiatrists are unique among physicians in their ability to help patients and providers address these problems.

About this Fact Sheet. This fact sheet was written by Francine Cournos, MD and Milton L. Wainberg, MD in collaboration with the APA Commission on AIDS. Other fact sheets in this series concern HIV among people with severe mental illness and HIV among adolescents. For more information contact American Psychiatric Association, AIDS Program Office, 1400 K Street NW, Washington DC 20005, phone 202.682.6163, fax 202.789.1874 or e-mail AIDS@psych.org. Visit our web site at www.psych.org/AIDS.