

Promoting Adherence to HIV Antiretroviral Therapy

New York State Department of Health AIDS Institute

INTRODUCTION

Adherence to treatment is an essential component of HIV care. Currently available antiretroviral drugs require that patients maintain almost perfect adherence to achieve undetectable viral loads and to avoid viral resistance. In the future, HIV treatment will ideally be more "forgiving," less complex, and easier to tolerate. Until that time, providers must be creative in devising strategies to overcome the problems that frequently interfere with adherence.

This book is designed for health care and supportive service providers who are engaged in designing or providing services to support access and adherence to combination antiretroviral therapy for HIV. Information contained in this book is intended to provide insight into barriers to adherence and practical strategies for maximizing treatment adherence.

Adherence to HIV treatment is critical to the success of improving the quality of life and survival of people with HIV/AIDS. Interventions and services should be multifaceted, tailored for each patient, and delivered through a multidisciplinary team approach that includes the patient in collaborative treatment planning. Through the New York State Department of Health AIDS Institute's Treatment Adherence Demonstration Projects and at other treatment adherence programs across the state, best practices and creative solutions to prepare individuals for and support them through the demands of therapy have been identified.

Several sites have been profiled in this manual. These sites have demonstrated success with certain techniques and populations. Their programs are described to illustrate some of the approaches HIV health care and service programs might use to address the problems of adherence. All of the case examples provided in this booklet are based on individuals who are receiving adherence support at the profiled centers. The individuals have been given fictitious names, and some details of the cases have been altered to protect anonymity. By reading about the insights and perspectives of successful colleagues and the stories of program participants, providers should be encouraged to adapt these strategies as they design or refine their own adherence programs.

The book offers an overview of adherence; addresses adherence issues, including barriers, optimizing strategies (e.g., tools and services), assessment, information access, and client education; and focuses on adherence programs and their settings, multidisciplinary adherence teams, staff-client relationships, community interaction, day treatment centers, adherence concerns for special populations, and utilizing quality initiatives to improve adherence. Also included are additional readings on treatment adherence and a compilation of internet resources that offer treatment adherence information and materials. Instruments for collecting and recording adherence information used by staff at some of the identified sites may be found included in the appendices.

I. OVERVIEW OF ADHERENCE

What Is Adherence?

Adherence: The act or quality of sticking to something; steady devotion; the act of adhering. Adherence is best achieved through a collaborative process that facilitates acceptance and integration of a medication regimen into an individual's daily life.

Compliance: The act of conforming, yielding or acquiescing. Compliance implies that the prescribed regimen is not a shared decision made between the individual and the provider.

The word adherence is defined as "the act or quality of sticking to something." Adherence connotes the acceptance of an active role in one's own health care. "Sticking to" the health care plan that has been developed is a crucial component of this accepted role. Ideally, the process of developing a health care plan will involve collaboration between individuals and their health care providers. Treatment plans should address the medical needs of the individual within the social context of his/her life and strategies to overcome barriers to adherence. This treatment adherence best practices manual will describe some successful ways that individuals and providers have collaborated to support efforts of people with HIV to take the medications that are so important to their health.

The term adherence is broader than the term compliance, which is used to describe the degree to which an individual follows the regimen prescribed by the provider. Adherence reflects collaboration between the patient and the provider in devising the medical regimen, not simply the following of instructions. A relationship that fosters trust and respect is essential for the care of individuals, especially for those with a chronic illness such as HIV.

Highly active antiretroviral therapy (HAART) involving the use of several medications at a time has become the standard regimen to achieve maximum viral suppression. However, these drug regimens are demanding and often "unforgiving." The amount of time the drugs remain active in the bloodstream and their interactions with food and other drugs make timing and regularity of dosing essential to effectiveness. Missing even a few doses can lead to an increase in viral replication. Given the high frequency of mutation in HIV, this can rapidly lead to drug resistance and treatment failure. For the individual, this outcome means loss of an effective therapy to suppress the virus in his/her body. The broader public health consequence of treatment failure is the possible spread of drug-resistant virus in the community. It is important, therefore, for both the individual and the community to ensure that the necessary supports for treatment adherence are available.

IMAGE: Doctor showing pill chart to patient. One of the key principles in developing a successful treatment adherence program is cooperation and collaboration between the person taking the medications and the person prescribing the medications. True cooperation and collaboration require that each person respects the integrity and dignity of the other, even if circumstances of life and choices differ. However, patients may not respond to therapy despite optimal practices and strict adherence. This is especially true for individuals who have experience with multiple drug regimens, have problems with malabsorption, or are infected with HIV drug-resistant virus.

Who Needs Help With Adherence?

The drug regimens of HAART are very complex. Physicians and nurses cannot accurately guess whether a person will be adherent; predicted non-adherence should not be used to exclude patients from treatment with HAART. Typically, three different medications are taken in divided

doses two or three times per day. Many of the medications have food requirements or restrictions, and some of the medications cannot be taken with others. Even as once-daily formulations become available, nearly all individuals will have some difficulty adhering to their prescribed schedules and will need some degree of assistance for lifelong therapy.

Everyone has needs that must be met in order to optimize his/her ability to adhere to complex drug regimens. However, there are important clues or predictors that indicate that some individuals may be more likely to have difficulty with adherence.

Predictors of poor adherence include:

- Active psychiatric illness (especially depression).
- Active drug and/or alcohol use.
- History of non-adherence.
- Medication side effects (including metabolic and morphologic side effects of HAART).
- Lack of education about treatment.

II. BARRIERS TO ADHERENCE

Barriers vary from person to person, from time to time, and from setting to setting. The treatment planning process should ensure that potential and/or actual barriers to adherence are identified and addressed. The patient and the provider can work together in a dynamic collaboration to reduce these impediments to adherence. By anticipating these barriers, programs can develop services that address the particular needs of the individuals that they serve.

Barriers to adherence include:

- Communication difficulties that arise when the patient's attitude about disease and therapy is different from that of the provider's. Without open and non-judgmental communication from the health care team, patients may not trust or may misunderstand the regimen they are prescribed.
- Unstable living situations (including limited or absent social support).
- Discomfort with disclosure of HIV status, which becomes known when medications are taken.
- Inability to set long-term goals.
- Inadequate knowledge about disease and effectiveness of medications or healthy living, including a patient's lack of belief in his/her ability to take medications regularly.
- Difficulty accessing adequate health care.
- Housing, food, lack of childcare, or other immediate life needs, which are viewed as more pressing than taking the medications regularly.

Language Barriers

Many people with HIV use a language other than English as their primary language. It is important to have providers available who speak the same language as the patient. If this is not possible, adequate translation services should be provided. Use of community or family members as interpreters should be avoided. Although this option may be appealing, especially when the patient brings a family member to appointments, the patient may not be comfortable sharing personal information in front of another family member. Family interpreters may also alter translations by incorporating their own perceptions of what the provider and the patient say and

mean. Also, using family interpreters, especially the patient's children, places an unfair burden on those family members. Professional, trained interpreters should be used whenever possible, even though this may be difficult, especially when individuals speak an uncommon language. Sometimes, telephone translation services can be helpful.

The following are strategies specific to language barriers which may facilitate adherence:

- Signs in languages other than English (e.g., "Informacion") can help to make patients feel welcome. From such signs, individuals may more easily identify the site as a comfortable place where staff members speak their language.
- Multilingual staff should be hired, especially if a significant proportion of the service population does not speak English well. Even if a patient speaks English as a second language, the provider should ensure that he/she is fully comfortable discussing his/her health care in English and should allow the person to request translation services.
- Sign language interpretation should be available for deaf and hard-of-hearing patients.
- Large print materials or disk readers should be provided for the blind or visually impaired.
- Written materials should be available in as many languages and reading levels as applicable. Resources for materials include community-based organizations (CBO) that target specific populations, as well as Internet resources, such as the AETC National Resource Center and the Centers for Disease Control and Prevention National Prevention Information Network (see Internet Resources).
- Translated educational materials which should be reviewed by providers or other community-based professionals who speak the language of the document. Literal translations into an English text may not be clear for a provider's or a program's clientele because of local or cultural variations and may create ill feelings or confusion.

Literacy Barriers

Low literacy levels also pose barriers to adherence. Some of the strategies for addressing literacy issues include:

- **Reviewing written materials with each patient** and describing technical terms that may be used so that the patient does not find him/herself in an uncomfortable situation where literacy deficits have to be revealed.
- **Assessing reading levels of individuals** so that providers are better prepared to tailor information to them. Written materials limited to three or four topics should be used to educate individuals with low reading levels.
- **Providing patients with pictorial or verbal information**, and with models or diagrams to supplement written materials. Pictorial information (e.g., comic books or videos) should be available free of charge in convenient locations (e.g., waiting rooms, exam rooms, and staff offices). Displaying materials in both private and public areas creates a safe space for a person to view the materials and may prompt a person to speak with a clinician about the issues raised in the printed material.
- **Using medication stickers** which should represent the exact number of pills a person is taking and should correspond to the appropriate dose. Stickers should also include clues for when the medication is to be taken (e.g., symbol for morning for A.M. dose and symbol for food when medication is required to be taken with food).

Barriers Associated With the Medication Regimen:

- Frequency of dosing
- Number of pills
- Food requirements/restrictions
- Frequency and severity of side effects
- Complexity of regimen
- Medication access/storage

Barriers Associated With Medication Side Effects:

Many of the medications used in HAART regimens can have adverse health consequences. Individuals, especially those who are asymptomatic or only mildly symptomatic from HIV and who are experiencing adverse effects from their medications, may be likely to skip doses. Diarrhea, nausea, headaches, peripheral neuropathies, and other adverse effects may make a person disinclined to adhere to his/her regimen.

Proactive side effect management includes:

- **Discussing possible side effects** (e.g., potential drug and food interactions) prior to a person beginning a particular medication.
- **Concentrating efforts to plan for and to manage side effects** at times when a new drug or regimen is being started and thus medication side effects are most likely to occur.
- **Giving prompt attention to medication problems.** Phone access to the medical team in addition to walk-in clinic hours can facilitate prompt assessment of severity of problems and timely remedies. IMAGE:Counseling session
- **Initiating a discussion regarding an individual's side effects** can assist those who may be hesitant to address such issues, especially when the subjects are perceived as embarrassing or socially unacceptable.
- **Referring to peer educators and/or group meetings** as good sources for individuals to share practical management tips.

Proper management of side effects is essential to adherence. Long-term drug therapy is difficult, and even minor side effects can develop into major hurdles to medication adherence.

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