

what is the role of adherence in HIV treatment?

why is adherence important?

The introduction of highly active antiretroviral therapy (HAART) has extended and improved the quality of life for people living with HIV by reducing viral load, often to undetectable levels. However, the initial enthusiasm for these drugs has been dampened somewhat by the discovery that they require near perfect adherence to prevent virus replication and mutation. Studies have shown that 95% adherence is needed for viral suppression and that even a small decrease in adherence can greatly increase viral load.¹

If the virus is allowed to mutate into drug resistant strains, the treatment regimen can become ineffective, which reduces treatment options both for the non-adherent individuals and for any partners they may infect with these strains.²

how do you measure adherence?

Adherence is usually measured through self-report, pill count, electronic pill bottle caps (MEMS caps) and laboratory tests.³ Self-report through doctor's office visits, questionnaires, structured interviews or diaries provides a simple and practical way of determining the self-perceived level of adherence.⁴ However, many individuals forget whether or not they took all their pills or may forget to complete their diary every day, and others may misrepresent their adherence in order to please the interviewer or clinician. Diaries may also not be feasible in settings where literacy is an issue.

Pill count, particularly if unannounced, may provide a more accurate assessment of adherence rates than self-report. However, it is labor intensive and may be perceived as intrusive, especially if conducted during unannounced home visits. In such situations, in-clinic pill count may work better. MEMS caps record each time the bottle cap is removed by the patient. They have been found to correlate highly with concurrent viral load.⁵ However, they are expensive to use and may under-report adherence in patients who remove more than one dose at a time for using medi-sets pill organizers.⁶ All of these methods assume that patients have actually taken all missing pills.

Laboratory tests, an indirect measure of adherence, can include viral load, CD4 counts, and blood levels of drug metabolites. These measures are less commonly used and very expensive. The results give no specific information about number of doses missed or adherence to medication schedule. They can also be influenced by other factors, such as the presence of drug resistant virus. Still, lab measures are often considered a useful adherence measure when combined with patient self-report and/or pill counts.

what are barriers?

Adhering to medications is hard to do. Most people have a problem finishing even a 5-day dose of antibiotics. Adherence is even more difficult when taking multiple drugs with different dosing requirements and severe, unpleasant side effects such as diarrhea, nerve damage and changes in body composition. Many people with HIV also have other complicating factors in their lives, including mental health issues, economic worries, lack of stable housing and alcohol or drug use, making it difficult to prioritize adherence.

Adherence barriers are often divided into regimen-specific, social/psychological and institutional.⁷ Regimen-specific issues, such as the complexity of the treatment and taking many pills at different times, as well as side effects of the medication, can lead persons to miss doses.⁸ Scheduling demands such as work, travel and mealtimes can also be barriers.

Social and psychological factors influence adherence. Mental health issues (such as depression or psychological distress), attitudes toward treatment and toward HIV, and support from health care workers, family and friends are key to adherence.⁹ Positive responses promote adherence and negative responses (lack of support, pessimism, etc.) can make it more difficult to adhere to treatment regimens.

Institutional factors such as incarceration, clinic setting and access to reliable health care and medication affect adherence. Factors that promote adherence are pleasantness of the clinic, convenience of scheduling, confidentiality and availability of transportation and childcare.¹⁰

Says who?

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what's being done?

Action Point, a storefront drop-in center in San Francisco, CA, offers adherence support for the urban poor with active drug or alcohol addiction. Located in an area of high rates of drug-related arrests and deaths, Action Point is open 6 days a week and operates on a harm reduction principle that encourages any positive change in health. The program offers adherence case management, prescription dispensing, nursing care, acupuncture and referrals to mental health and substance abuse services. After one month of enrollment, clients are offered a pager that receives e-mail messages to remind clients to take their medications. After six months, 61% of Action Point clients were taking HAART and 81% reported greater than 90% adherence.¹¹

In New York, patients who had not previously been on HAART were offered an individualized, three-module program on basic understanding of HIV, adherence and regimen options. Counselors discussed with each patient in detail potential adherence barriers, anticipated toxicities, pill burdens, dosing intervals and drug preferences. These were evaluated, reported to their provider and used to select an individualized regimen. Patients were given tools such as pillboxes, dose cards and beepers, if needed. They also provided intensive coaching and a dedicated phone line for patients. The program increased adherence and enhanced virologic response.¹²

One promising new adherence strategy is directly observed therapy (DOT) for antiretrovirals, or DAART. Based on DOT for tuberculosis, DAART has been used in settings where patients have frequent interactions with health care workers, such as prisons and methadone maintenance clinics. Some complications of using DAART include the fact that medications need to be taken for a lifetime and dosing is usually more than once a day.¹³

what can we do?

Because adherence to HAART is a complex process, interventions to improve adherence are best designed to be multifaceted. Factors to consider include regimen complexity, side effects, patient-related factors and even the patient-health care worker relationship, each of which affects adherence to medications. Overall, the better that a regimen "fits" with a patient's lifestyle, the greater adherence is likely to be.¹⁴

Health care workers can help increase adherence by: involving the patient in selecting a regimen with tolerable dosing schedules; preparing for and managing side effects; addressing and treating mental health and drug use issues; addressing concrete issues such as lack of transportation and homelessness; providing memory aids and anticipating treatment fatigue.¹⁵

Patients can help by: learning about HIV disease and anti-HIV drugs and what they do; finding treatment goals that are not HIV-related (seeing children grow up, remaining healthy and looking good); recruiting friends or family to act as adherence monitors and anticipating changes in routine such as travel.¹⁵

what needs to be done?

Everyone can be adherent with proper support. HIV+ persons may combat not just HIV disease, but drug addiction, homelessness and/or incarceration. Many of the barriers to adherence can be overcome with treatment and the right tools. For example, depression and other mental health problems that get in the way of optimal adherence are often treatable and should be diagnosed and treated.

Because adherence is complex, it often requires an "adherence team." Collaboration between the patient, physician, nurse, case manager, social worker, pharmacist, counselor and family or friends is essential.

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For information on how this affects prevention, please see Fact Sheet #27 "Do new HIV drugs affect HIV prevention?" www.caps.ucsf.edu/newdrugs.html