



AIDS: *Critical Matters*

a Village Care of New York publication



TREATMENT ADHERENCE FOR THE DIFFICULT-TO-TREAT, TRIPLY-DIAGNOSED INDIVIDUAL

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AIDS: Critical Matters is a series of articles presented from the perspective of practitioners of care. In this forum, you will find a discussion of significant issues that impact individuals living with HIV/AIDS in our society, as well as a dialog on making sense of public policies and translating them into practice.

We invite others to submit outside commentaries for inclusion after a review by Village Care of New York. To inquire about submitting a paper for publication, please send an email to policyforum@vcny.org.

Acquired Immune Deficiency Syndrome is a worldwide crisis, and even in the face of dramatic treatment advances in the United States, AIDS remains a critical health issue. According to the Centers for Disease Control and Prevention, more than 944,000 people are living with HIV/AIDS in the United States. That number is believed to be 25 percent higher taking into account those who are infected and unaware of their status. In 2005, there were 37,331 new infections¹ and no signs of the spread of infection subsiding. New York City continues to reign as the epicenter of United States HIV/AIDS: as of June 2006, there were 97,524 New Yorkers living with HIV/AIDS.

The general perception is that AIDS has become a treatable, chronic disease in the United States. There is, in fact, much truth to this: studies have shown that with early and sustained treatment with highly active anti-retroviral therapy (HAART) and proper adherence, people with HIV may be approaching a normal life expectancy, with access to positive family life and productive careers.² Treatment availability in this country also contributes to the view that AIDS is a manageable chronic disease. Between the federal and state governments, we are spending over \$20

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¹ [2005 HIV Surveillance Report](#), Centers for Disease Control and Prevention

² "Extrapolating long-term HIV/AIDS survival in the post-HAART era," Justice, et. al.

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Hidden in plain sight: HIV continues to devastate lives.

billion for HIV/AIDS services, with 65 percent going to treatment.³ An HIV/AIDS diagnosis affords easier access to third-party insurance, including Medicaid and the AIDS Drug Assistance Program (ADAP), while some continued, but limited, domestic philanthropy expands access and treatment opportunities.

With avenues open to treatment, coupled with the effectiveness of that treatment, many people living with HIV/AIDS in the United States do indeed manage and live well.

There is a downside to this glowing perception we have of the state of AIDS treatment, because it overshadows another view, one that society in general does not see, or refuses to see. This view presents us with the continued devastation HIV infection brings to the lives of those struggling with social and psychological barriers to treatment. And it confronts us with an image of another face of AIDS, much different from the HIV medication advertisements that feature smiling, healthy people enjoying outdoor activities. This other face of AIDS is much more troubled and vulnerable and it is a face worn by a population where HIV infection continues to spread and cause morbidity and death right here in the United States at rates rivaling those of Sub-Saharan Africa.

It is well-documented that the prognosis for HIV/AIDS deteriorates dramatically when HAART is not properly adhered to. In addition, severe societal consequences also result from non-adherence that include continued transmission of HIV and, likely, crime. In terms of the spread of the disease, it is now generally accepted that because HAART reduces viral load, it renders individuals less infectious and reduces HIV transmission on both the individual and population level.⁴ In terms of crime, there is an understanding that adherence to proper treatment and harm reduction reduces high-risk behavior, substance use and related criminal activity.⁵ Poor adherence also leads to mutations and drug resistance, potentially

destroying the treatment gains that have indeed been made.

Treatment Adherence – The Pressing Agenda

For the medications to be effective—and for the related societal benefits to be advanced—individuals must be at least 95 percent adherent to their treatment. This is quite a high threshold, compared to the required adherence to control other chronic illnesses, and it is especially difficult for many people with AIDS who also struggle with mental illness and substance abuse. Treatment adherence is, however, an agenda item of the highest order if we are continue on course in this country to combat the spread of HIV infection.

In New York City, well over half of all people living with HIV/AIDS also suffer with mental health issues, and many of these are currently abusing drugs, alcohol and other substances. These are the “triple diagnosed,” who wage a difficult battle with AIDS that is marked by extremely poor treatment adherence, the onset of many more opportunistic infections and higher death rates. It is a far different picture that the popular image of AIDS in America. Consider this:

- » Patients with mental illness are more than seven times more likely not to adhere to HAART regimens.
- » More than two-thirds of HIV-infected substance abusers report sub-optimal adherence to treatment.
- » Persons with depression and persons abusing substances are at least twice as likely to die from AIDS-related causes.
- » Among residents at Rivington House, the 206-bed Village Care of New York skilled nursing facility for people with HIV/AIDS whose clinical needs are so severe they cannot be managed in the community, 75 percent have a psychiatric diagnosis and 75 percent report recent substance abuse.

This is an AIDS population that is not getting the attention it needs, either in a general societal recognition of its existence and a commitment to

3 Kaiser Family Foundation HIV/AIDS Policy Fact Sheet, 2006

4 Office of AIDS Research, NIH

5 United Nations Office on Drugs and Crime

help, nor in the dedication of resources that are needed.

While the challenges of treatment adherence among the triply-diagnosed are many, there have been successes. One example is composed of the treatment adherence programs that are supported by the AIDS Institute of the New York State Department of Health.

Village Care of New York's Treatment Adherence Program in Manhattan, started in 1999, is built around the individual's own life goals, accepting and respecting his or her beliefs, aspirations and opinions with a harm-reduction philosophy. The thinking is that if your approach shows a client that he or she is "wrong" and must be "educated," you miss the opportunity to create internal motivation. It is with this internal motivation that Village Care's, Treatment Adherence Program succeeds. Using the evidence-based Motivational Interviewing technique, the Treatment Adherence Program's health educators help each client to identify his/her own life goals and barriers to those goals; they then work together to overcome those barriers and improve quality-of-life and treatment adherence. As a result, the Village Care Treatment Adherence Program increases the proportion of clients who achieve and maintain 95 percent adherence by roughly 11 percent each year.

Anecdotally, the program has also reduced substance use and crime participation and has improved HIV secondary prevention behaviors. This is a significant accomplishment in a population whose difficulties are deeply entrenched and whose engagement in their own health had previously disappeared. Here is one example of how treatment adherence makes a lasting impact:

Mr. X is a Hispanic gay male, who was diagnosed with both HIV and AIDS in 1995. He had multiple diagnoses, including mental illness and alcohol abuse, as well as severe pain. In 2004, he was referred to the Village Care Treatment Adherence program; Mr. X was then on the last available combination of antiretroviral therapy, because his long his-

tory of non-compliance led to multiple drug resistances.

During the first few treatment adherence sessions, the health educator helped the client to identify his barriers to adherence, and to understand how those barriers affected his quality-of-life. As sessions continued, the health educator and the client labored together to solve those barriers in ways that "worked" within the clients lifestyle. Some barriers—such as difficulty with side effects—were overcome with both additional prescriptions from his primary care provider (for which the health educator mediated communications) and counseling on specific side-effects management practices. With his acknowledgement that untreated depression was a major barrier to his quality-of-life, Mr. X agreed to start psychiatric medications as long as he could avoid psychotherapy.

The Treatment Adherence Programs' effectiveness lies in the development of a trusting relationship with a health care representative, which is proven across many populations and diseases to improve adherence and health. For many individuals, their physician is their trusted health care representative and thus managing their chronic disease is fairly routine. But for others—especially the triply-diagnosed—engagement with health care providers must be re-built from scratch and carefully supported.

Treatment Adherence for the Triply Diagnosed – Now Threatened

Thus, an opportunity to truly make an impact still exists: Treatment Adherence for the Triply-Diagnosed. This support creates access for the difficult-to-serve U.S. population, in much the same way that international funding has promoted access for poverty-stricken areas abroad.

Yet, the reality is that access for the triply diagnosed is under threat.

For one, here in the United States, philanthropic support has virtually dried up, with the focus and emphasis now going overseas. In fact, U.S. HIV/

Treatment adherence is built on trust.

Adherence works; but will today's limited funding even survive?

AIDS grantmakers (dominated by the Bill and Melinda Gates Foundation) commit about 90% of their funding overseas.⁶

In addition, a major governmental funding avenue for treatment adherence—the federal Ryan White Act—has been revised under the Ryan White HIV/AIDS Treatment Modernization Act, now requiring a full 75 percent of funds to be spent on “core services,” and the trust-building, psycho-social assistance provided in treatment adherence programs is being cut.

Moreover, calls for mandatory HIV/AIDS Medicaid managed care are getting stronger. Under such a structure, will true, effective treatment adherence be funded? Such support is often labor-intensive and not inexpensive, and the ultimate economic equation is unclear. Proper adherence does reduce unnecessary hospitalization and skilled nursing facility utilization, but it remains unproven that these savings compensate for the expense of health support programs, such as treatment adherence programs. New efforts that target only the most likely high-cost individuals are underway (building on the work of John Billings at New York University), but in these most-difficult-to-engage populations, behavior change is achieved only with a small number, and that change can be slow and incomplete. It seems unlikely that a savings-

based argument will sustain treatment adherence for all who may benefit.

While treatment adherence does also result in other societal economic benefits—including a reduction in the spread of HIV/AIDS and reductions in crime that avoid the impact on victims and criminal justice costs—these benefits accrue to the general public, not to any third-party payer who might consider funding treatment adherence support.

At the same time, it is important to note that the benefits of treatment adherence go beyond economics. Supporting the triply-diagnosed by enabling them to engage in health care and treatment successfully reaffirms our desire to ensure access to care for the most vulnerable among us, who have neither the resources nor the wherewithal to connect with services on their own.

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6 U.S. Philanthropic Commitments for HIV/AIDS 2005 and 2006, Funders Concerned about AIDS.