Psychological aspects of living with HIV disease

A primary care perspective

Robert H Remien
Judith G Rabkin
HIV Center for Clinical and Behavioral Studies
Unit #15
New York State Psychiatric Institute
1051 Riverside Dr
New York, NY 10032
and
College of Physicians and Surgeons
Columbia University
New York, NY

Correspondence to:
Dr Remien
rhr1@columbia.edu

Competing interests: None declared

West J Med 2001;175:332-335

Most patients with serious, progressive illness confront a range of psychological challenges, including the prospect of real and anticipated losses, worsening quality of life, the fear of physical decline and death, and coping with uncertainty. HIV infection and/or AIDS brings additional challenges due to the rapidly changing treatment developments and outlook. In addition, this disease is unusual in the extent of stigma associated with it and the fact that HIV is both infectious and potentially fatal. Because of the risk of transmission, major and permanent changes are called for in sexual behavior and/or management of substance use, neither of which may be easily modifiable.

We summarize the psychological issues and challenges of living with HIV infection, the psychiatric conditions that are commonly seen, ways in which primary care physicians can help address these issues, and recommendations for when they should consider involving mental health specialists and other support services.

TESTING HIV-POSITIVE

Primary care physicians can play an important role in helping patients adjust to the news of a positive test result. Patients need to integrate this new information into their existing identity. This involves questioning assumptions about many aspects of their life, rethinking priorities and goals, and acquiring new skills that may be necessary to accomplish reformulated goals. An added challenge for many people who have become recently infected is the experience of guilt that they "should have known better." A supportive, nonjudgmental stance on the part of health care providers is crucial.

It is useful to anticipate and expect a patient to respond to the diagnosis of HIV infection with a wide range of feelings (see box). Expecting them, and perhaps alerting the patient to their possible occurrence, can be helpful. Empathy goes a long way, as does making the patient understand that he or she is not alone and that many people have gone through this and are currently functioning well. Referrals to a mental health professional, a support group, a local community-based organization, and online resources at this time are often useful.

Emotional responses to testing HIV-positive

- Shock
- Disbelief
- Panic
- Fear
- Guilt
- Anger
- Despair
- Hopelessness
- Numbness

DISCLOSURE OF HIV STATUS

Most people infected with HIV struggle with issues of disclosure to others, particularly when first diagnosed. Health care providers should encourage candor between patients and their sexual and needle-sharing partners and discuss issues of safer behaviors in a nonpunitive manner, while acknowledging the difficulty in both initiating and maintaining certain behavior changes. It is important to help patients resist the desire to either withdraw and isolate themselves, refusing to tell anyone, or the opposite tendency—to "tell the world." Neither extreme response is adaptive. Patients need to realize that there is time for disclosure to take place. The potential for gaining positive support and for negative consequences needs to be considered.

Additional resources can be found linked from this article on our web site

MAKING TREATMENT DECISIONS

Patients who take a strong interest in their medical care and participate actively in treatment decisions are more likely to adhere to their treatment plan and medication schedules.[1] However, for many patients, the concept of developing relationships with medical providers and becoming an active member of a medical team is foreign. Primary care physicians may assume that lack of patient discussion reflects understanding and agreement with proposed treatments, but this may not be the case. It is helpful to encourage patients to educate themselves about the appropriate options by suggesting local agencies serving HIV-positive clients or Internet sites that are informative. It also may be necessary to "license" patients to express their opinions, concerns, disagreements, or doubts about ongoing or proposed treatments to clear up misconceptions and engage their active participation. One simple way of doing this is to ask patients what they have heard about treatments, what their friends have experienced, and what they think of HIV drug therapy.

It can be useful for the provider to acknowledge the range of opinions about when to initiate antiretroviral treatment and which agents to select. Given the ongoing changes in federal guidelines, this can be difficult and confusing for patients and their providers. Patients are often resistant to initiating antiretroviral therapy (still described as "lifetime" therapy), particularly when they are asymptomatic. People infected with HIV are increasingly aware of the unpleasant medication side effects and are concerned about long-term toxic effects. Many patients have not benefited greatly from current combination therapy because of prior sequential monotherapy, typically recommended by physicians in the past. And many patients are aware that as new antiretroviral medications and new combination regimens become available, those who show the greatest treatment response are those who remained "treatment naive" before initiation of the new regimen. Because many patients are uncertain, ambivalent, and anxious about initiating therapy, they should be given time to decide.

Kevin Nicholson/BMJ

Physicians can help patients adjust to the news of a positive test result

ADHERENCE TO COMBINATION THERAPY

Combination antiretroviral therapy is particularly challenging because of its demanding dosing schedule, common adverse side effects, and the threat of the relatively rapid development of resistance. The requirement of 95% or better adherence to achieve virologic success is not the norm for other diseases, where 80% adherence is usually considered adequate, and it is difficult to achieve. Although optimal adherence needs to be facilitated, providers need to adopt a nonjudgmental stance regarding the "normalcy" of missing medication doses from time to time and to communicate that to patients. Such a stance encourages patients to be open about problems they have with adherence. Other members of the treatment team, such as a nurse or social worker, may have more time to spend with a patient to address the many possible barriers to adherence and to facilitate strategies to improve and maintain optimal adherence.

MAINTAINING A HEALTHY LIFESTYLE

Important areas within the patient's control may influence the course of HIV disease and, in any case, influence quality of life and psychological well-being. These behaviors include good nutrition, exercise, control of recreational substance use, and alterations in sexual risk behavior. Taking charge by making improvements in these areas can enhance patients' feelings of well-being and mastery of their lives. Primary care providers can encourage and advocate for these positive behaviors with their patients in a supportive way.

Substance use

Apart from being a public health issue with respect to infection of needle-sharing or sexual partners, continued substance use puts an HIV-positive person at risk of exposure to new infections, such as hepatitis C. Hepatitis C is becoming more widespread, and it may interfere with antiretroviral drug use because of liver damage. Furthermore, heavy drug or alcohol use is likely to interfere with medication adherence and medical care in general.

In the absence of consistent or clear evidence that mild to moderate substance use is significantly detrimental to

the course of HIV illness, patients need not be told to abstain entirely. However, when the frequency, amount, and context of the substance use are judged to be maladaptive or problematic for a given patient, counseling and then referral for treatment of substance use may be indicated.

Sex and relationships

Typically when someone is first diagnosed with HIV infection or AIDS, there is a significant decline in sexual interest and activity. Over time, however, most people will want to resume sexual activity. The process of reengaging in sexual activity and romantic relationships can be difficult because of anxiety over disclosure and fear of rejection from potential partners, fear of infecting others, and negotiating safer sex.

On the other hand, combination antiretroviral therapy has introduced a new dynamic into the epidemiologic features of HIV transmission and, consequently, to prevention efforts. A false sense of security may arise because of a belief in reduced infectivity associated with reduced or "undetectable" viral load.[2-4] Many patients and their HIV-negative partners think that "undetectable" means "absent." Also, many patients ignore the possibility that they can transmit drug-resistant strains of HIV to others. An increasing number of newly infected people are being found to have HIV strains that show resistance to at least one class of antiretroviral drugs.[5] To clarify the meaning of undetectable viral load, phrases such as "below the threshold of detectability" or "fewer copies than the test can detect" may be used instead.

ASSESSING PSYCHIATRIC STATUS

During specific times in the course of HIV disease, patients are particularly vulnerable to acute distress, such as when first notified of a positive HIV status, the initial onset of physical symptoms, a sudden decline in the number of CD4 cells, the first opportunistic infection, or the first hospitalization. Continuing to maintain hope in the context of illness progression is a great psychological challenge for patients and care providers. Normal levels of distress in the context of stressful events need to be distinguished from psychiatric conditions deserving special attention.

Depression is the most common psychiatric disorder observed among HIV-positive patients. Whereas early reports based on clinical observation or medical record reviews indicated high rates of distress and depressive symptoms among those infected with HIV or who had AIDS,[6,7] later studies that used structured psychiatric evaluations and community samples with HIV-negative comparison groups showed rates of psychiatric disorder to be largely equivalent between HIV-positive and -negative people.[8-12]

The picture is somewhat different in unselected samples of HIV-positive patients with whom briefer depression screens are used. Recently, Bing and colleagues assessed a national probability sample of nearly 3,000 adults receiving care for HIV infection and found that more than a third screened positive for clinical depression, the most common disorder identified.[13] Half reported the use of an illicit drug in the past year. Drug dependence was associated with screening positive for a psychiatric disorder.

The message for primary care providers is that psychiatric distress is common among HIV-positive patients. Psychiatric illness in the context of HIV infection can contribute to diminished health outcomes, increased substance use, poor treatment adherence, increased risky sexual behavior, or other maladaptive behaviors. It is, therefore, advisable to screen for the presence of depression and drug and alcohol abuse and to treat or refer these patients to specialists when problems are suspected. Depression, substance use disorders, and cognitive impairment are the most commonly observed neuropsychiatric disorders in patients infected with HIV, although any psychiatric disorder may be encountered, as in the general population. Patients with serious and persistent psychiatric disorders require specialist evaluation and treatment.

ASSESSMENT AND TREATMENT OF DEPRESSION

Patients are often reluctant to mention mood problems to their physicians. Also, depressive symptoms, such as fatigue or loss of appetite, can be attributable to HIV infection or medications. Physicians should ask about feelings of distress if patients appear to be sad, if their mood seems altered, if they seem to be spending most of their time at home alone (in the absence of medical problems requiring this), or if they seem isolated. Simple queries such as, "Do you feel depressed more days than not, most of the day, for a couple of weeks at a time?" can be useful.

Several clinician and patient rating scales developed for use in primary care settings can detect the presence of depression, such as the Primary Care Evaluation of Mental Disorders (PRIME-MD)[14] and the Patient Health Questionnaire (PHQ) (available from Dr Spitzer at rls8@columbia.edu).[15]

Primary care physicians can successfully treat patients who are clearly depressed by using standard antidepressant medication. Clinical trials have demonstrated the efficacy of medications such as fluoxetine hydrochloride and paroxetine in treating depressed patients who are HIV-positive,[16-18] and no clinically significant interactions with antiretroviral medications have been reported. If treating patients on their own, primary care physicians may want to refer those who do not respond at all in about 8 weeks to a psychiatrist for consultation or treatment. Such patients may require dose increases if there has been a partial

response, augmentation with another medication, or a switch to another antidepressant drug class.

Not all depressed patients need or want antidepressant medication. For those with mild but persistent depression, support groups or counseling (or both) may be helpful. For others, structured forms of psychotherapy may alleviate distress. Both cognitive behavioral therapy and interpersonal therapy have been shown to alleviate depression in HIV-positive patients.[19]

The choice of treatment for depression is most usefully determined by any past history of treatment, the patient's preferences, and available options including insurance coverage. It should be made clear to patients that depression is not the norm among HIV-positive people and that treatment is available and generally effective. The central task of primary care physicians is to identify the presence, duration, and severity of distress and depression and then to provide treatment or refer patients to acceptable and accessible therapeutic resources.

References

1 Rabkin JG, Remien RH, Wilson C.*Good Doctors, Good Patients: Partners in HIV Treatment.* New York, NY: NCM Publishers; 1994.

2 Dilley JW, Woods WJ, McFarland W. Are advances in treatment changing views about high-risk sex? [letter] *N Engl J Med* 1997;337:501-502.

3 Kelly JA, Hoffman RG, Rompa D, Gray M. Protease inhibitor combination therapies and perceptions of gay men regarding AIDS severity and the need to maintain safer sex. *AIDS* 1998;12:F91-F95.

4 Remien RH, Wagner G, Carballo-Dieguez A, Dolezal C. Who may be engaging in high-risk sex due to medical treatment advances? [letter] *AIDS* 1998;12:1560-1561.

5 Stephenson J. 20 years after AIDS emerges, HIV's complexities still loom large [news]. *JAMA* 2001;285:1279-1281.

6 Dilley JW, Ochitill HN, Perl M, Volberding P. Findings in psychiatric consultations with patients with acquired immune deficiency syndrome. *Am J Psychiatry* 1985;142:82-86.

7 Nichols S. Psychosocial reactions of persons with acquired immunodeficiency syndrome. *Ann Intern Med* 1985;103:765-767.

8 Lipsitz J, Williams JB, Rabkin JG, et al. Psychopathology in male and female intravenous drug users with and without HIV infection. *Am J Psychiatry* 1994;151:1662-1688.

9 Perkins DO, Stern RA, Golden RN, Murphy C, Naftolowitz D, Evans DL. Mood disorders in HIV infection: prevalence and risk factors in nonepicenter of the AIDS epidemic. *Am J Psychiatry* 1994;151:233-236.

10 Perry S, Jacobsberg L, Card CA, Ashman T, Frances A, Fishman B. Severity of psychiatric symptoms after HIV testing. *Am J Psychiatry* 1993;150:775-779.

11 Rosenberger PH, Bornstein RA, Nasrallah HA, et al. Psychopathology in human immunodeficiency virus infection: lifetime and current assessment. *Compr Psychiatry* 1993;34:150-158.

12 Williams JBW, Rabkin JG, Remien RH, Gorman JM, Ehrhardt A. Multidisciplinary baseline assessment of homosexual men with and without human immunodeficiency virus infection. II. Standardized clinical assessment of current and lifetime psychopathology. *Arch Gen Psychiatry* 1991;48:124-130.

13 Bing EG, Burnam MA, Longshore D, et al. Psychiatric disorders and drug use among human immunodeficiency virus-infected adults in the United States. *Arch Gen Psychiatry* 2001;58:721-728.

14 Spitzer RL, Williams JBW, Kroenke K, et al. Utility of a new procedure for diagnosing mental disorders in primary care: the PRIME-MD 1000 study. *JAMA* 1994;272:1749-1756.

15 Spitzer RL, Kroenke K, Williams JBW. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA* 1999;282:1737-1744.

16 Elliott AJ, Uldall KK, Bergam K, Russo J, Claypoole K, Roy-Byrne PP. Randomized, placebo-contolled trial of paroxetine versus imipramine in depressed HIV-positive outpatients. *Am J Psychiatry* 1998;155:367-372.

17 Rabkin JG, Wagner GJ, Rabkin R. Fluoxetine treatment for depression in patients with HIV and AIDS: a randomized, placebo-controlled trial. *Am J Psychiatry* 1999;156:101-107.

18 Zisook S, Peterkin J, Goggin KJ, Sledge P, Atkinson JH, Grant I. Treatment of major depression in HIV-seropositive men. HIV Neurobehavioral Research Center Group. *J Clin Psychiatry* 1998;59:217-224.

19 Markowitz JC, Rabkin JG, Perry SW. Treating depression in HIV-positive patients. *AIDS* 1994;8:403-412.

ANY QUESTIONS?

Do you have a clinical question you'd like to see answered? If so, here's your chance to get a curbside consult from our expert team, which includes many of the top clinicians in the West.

ANY ANSWERS?

Maybe you have strong views about something you read in this issue—something we got wrong perhaps? Or do you have further clinical experience you'd like to share? Perhaps you have suggestions for new topics you'd like to see us address from an evidence-based perspective.

Whatever questions, comments, or other contributions you have, we'd like to receive them. We realize that it's experience like yours that makes the journal come alive. Please send your questions, ideas, or comments to us by email: wjm@ewjm.com.