Primary Medical and Emotional Care for HIV Infection

Lisa Capaldini, MD, MPH

In the early years of the AIDS epidemic, patients and clinicians tended to have their initial encounter late in the stage of HIV disease, often in the setting of an acute life-threatening infection such as Pneumocystis carinii pneumonia, or after months of progressive wasting and fevers. With the availability of HIV antibody tests, infected but well patients—"asymptomatic seropositives"—are comprising an increasing proportion of the HIV-infected patients seen by providers. Consequently, the care of these patients is shifting from diagnosing and treating AIDS to attempting to forestall the complications of HIV infection.

This article will outline current clinical practices, used by San Francisco physicians who care for people with HIV infection, for the medical management of a new seropositive patient including monitoring guidelines and treatment strategies. In addition, it will explore briefly the psychological stresses experienced by patients in the various stages of HIV disease. For purposes of this discussion, it will be assumed that appropriate pre- and post-test counseling have been provided to the patient.

Initial Evaluation of Seropositive Patients

On initial evaluation, physicians should perform a directed history and physical with the goal of identifying symptoms and signs of HIV disease. These include obvious symptoms such as night sweats, fatigue, and weight loss, and subtle symptoms like recurrent dermatitis, painful mouth ulcers, chronic, intermittent diarrhea, persistent sinus infections, and mild memory problems.

The history should also address psychosocial issues. Has the patient had symptoms of anxiety, depression, delirium, or dementia? With whom does the patient live? Is there a history of substance abuse? What are the demands of the patient’s work? Who can the patient depend upon for help? What, if any, life crisis has the patient experienced before, and how has he or she coped with it? A good history offers an opportunity to counsel patients, as well as to assess their psychological coping skills and knowledge about HIV-related disease.

The physical examination should include examination of the lymph glands, a functional psychoneurological assessment (balance, strength, speech, gait, affect), a dermatologic evaluation, a funduscopic exam (an eye exam) and a thorough oral exam. (Thrush and hairy leukoplakia are often the only abnormalities that show up in a history and physical in otherwise asymptomatic patients with advanced immune dysfunction.)

Even if the history and physical reveal no clinical evidence of HIV infection, the seropositive patient should undergo laboratory screening. Because severe immune impairment may be present in patients with no signs or symptoms of HIV infection, all seropositive patients require laboratory screening to be accurately staged. Many investigators consider the T-cell, or CD4, count the most helpful laboratory parameter as patients with low T-cell counts (less than 200) are at the highest risk for developing AIDS. T-cell testing is limited by non-HIV-related T-cell changes due to minor medical problems, lab variation, stress, and even the time of day when the sample is drawn.

Other lab tests are helpful in predicting the risk of a seropositive patient developing AIDS. These include anemia, elevated sedimentation rate, p24 antigenemia, decreased T-helper/Suppressor ratio, and elevated beta, microglobulin. In general, if an asymptomatic seropositive patient has a relatively high (greater than 500) T-cell count, it is not necessary to perform these tests. If there is a discrepancy between a patients’ T-cell counts and their clinical symptoms, or if the clinician needs additional lab data to make treatment decisions, these studies are indicated. Other baseline lab studies may include tests for syphilis (VDRL) and tuberculosis (PPD skin test), a chest x-ray, and a chemistry panel.

Ongoing Monitoring and Treatment Options

Periodic clinical and laboratory monitoring are important for treatment of HIV infection and should be dictated by the stage of a patient’s illness. Asymptomatic patients with T-cell counts greater than 500 should be evaluated every four to six months. Symptomatic patients and all patients with T-cell counts of less than 200 should be monitored every one to three months, with T-cell testing performed every three months.

One of the goals of periodic monitoring is to determine when to initiate measures such as AZT and prophylaxis against Pneumocystis carinii pneumonia. Official indications for AZT currently are limited to patients with full blown AIDS, or seropositive patients with T-cell counts of less than 200. On the basis of anecdotal experience, however, many clinicians consider progressive constitutional or neurologic symptoms, p24 antigenemia, HIV-enteropathy (culture-negative chronic diarrhea), thrombocytopenia (loss of blood platelets), and significant dermatological illness (for instance, recurrent folliculitis) indications for initiating AZT therapy. There are no studies proving the reasonable assumption that AZT might prevent immune impairment if used prior to the development of symptoms. Anecdotal experience suggests that asymptomatic patients with T-cell counts of less than 200 who take AZT may be less prone to developing dementia. Arguments against using AZT in the earlier stages of HIV infection include its toxicity, the possibility of producing viral resistance, and its demonstrated effectiveness in patients with less advanced HIV disease.

While the official dosage recommendation for AZT is two 100-milligram capsules every four hours, many clinicians advise their patients to omit the middle-of-the-night dose to avoid sleep disruption, or to take smaller doses three to four times a day. These practices are based on the dose relationship of AZT toxicity and increased patient satisfaction with less frequent dosing schedules. The unresolved question is defining the trade off, when using lower-dose AZT. Between decreased toxicity and possibly decreased efficacy. Many physicians also choose the low-dose regimen for seropositive patients who are using AZT as a preventative measure, prior to an AIDS diagnosis, or for patients with pre-existing cytopenias (low blood cell counts) that may preclude full dose AZT. Researchers are investigating the role of other treatments, such as acyclovir, DDI and DDC, in augmenting the effects of AZT and reducing its toxicity.

continued on page 2
Primary Medical Care. . .

continued from cover

All patients with T-cell counts of less than 200 should be treated prophylactically for Pneumocystis carinii pneumonia (PCP). This recommendation is based on several factors: the likelihood that without prophylaxis patients will develop PCP, the 10 percent mortality associated with AIDS-related PCP, the safety and efficacy of available prophylactic treatments, and the possible long-term functional sequelae seen in survivors of PCP. Many patients never recover fully from the debilitation and nutritional compromise that commonly accompany PCP.

PCP prophylaxis comprises aerosolized pentamidine every two to four weeks, oral Septra and oral Dapsone. Aerosolized pentamidine is well tolerated; common complications include a metallic taste in the mouth and bronchospasm or cough. The main disadvantages of aerosolized pentamidine are its cost and the requirement of using special nebulizer equipment designed to deliver the particles to the lungs. Oral Dapsone and Septra are easily administered but often cause drug rashes and cytophenias.

While the purpose of these interventions is primarily preventive, they may have active benefits as well. Patients on AZT therapy may note improved energy levels, decreased itching, better concentration, and decreased night sweats. Indeed, many so-called "asymptomatic" seropositive patients become aware of subtle symptoms of HIV infection after noting their improved function after beginning AZT.

The early identification of function-threatening and life-threatening sequelae of HIV infection is crucial in helping HIV-infected patients cope. A relatively subtle symptom such as hand clumsiness may be a clue of central nervous system toxoplasmosis; unexplained night sweats may be an indication of early PCP. Like diabetic patients, seropositive patients with advanced HIV disease may not "look" as sick as they are. Conversely, it is important to remember that HIV-infected patients can and do get routine outpatient illnesses such as upper respiratory infections and tension headaches that may mimic more serious illnesses.

Alternative Therapies and Self-Care

Many seropositive patients express interest in experimental or alternative therapies for HIV infection. Some of these treatments, for example, acyclovir or dextran sulfate, may include conventional drugs used unconventionally to treat HIV infection. Other alternative treatments may include herbs, visualization and nutritional programs. With few exceptions, these therapies are of unknown efficacy, making it difficult for the clinician to provide firm advice about their use. Some patients, however, derive clear psychological benefit from taking these treatments.

In counseling patients about these therapies, practitioners should emphasize three points. First, is the treatment potentially toxic? (This includes non-drug interventions, such as severely limited diets, megavitamin therapy, or overly stressful exercise programs.) Second, experimental and alternative treatments can be used to complement, rather than replace conventional treatments, such as AZT and aerosolized pentamidine. Finally, interventions such as support groups, massage, and counseling may significantly improve the spirit of seropositive patients.

All HIV-infected patients should be counseled regarding general health maintenance measures such as a well-rounded diet, adequate sleep, avoidance of heavy alcohol or illicit drug use, regular exercise, and stress reduction. For many patients, undertaking a health maintenance regimen enables them to participate actively in their health care. Physicians should monitor patients' self-care strategies and counsel patients to adopt interventions that maximize a sense of control and well-being.

Emotional Care

Talking with patients about how they are coping with HIV infection is a critical component of good clinical care. Seropositive patients require active and regular counseling about practical issues such as ability to work, and psychological issues such as dealing with anxiety or grief. Clinicians may be concerned that this task may open a Pandora's box of patient's concerns. However, an open-ended inquiry such as, "How are things going?" or "What's going well and what's not going well?" may help the patient summarize his or her functional status, and identify specific problems that can be ameliorated with brief office therapy or that may mandate a referral for more intensive counseling.

Another strategy practitioners can use is to reflect back to a patient the feelings the practitioner believes the patient is expressing: "You seem to be upset and down," or, "It seems like the risk of dementia scares you the most." By addressing these feelings, a practitioner can validate a patient's struggle with a difficult issue, and help the patient externalize it. The goal of this intervention is to help prevent the anxiety, depression, and learned helplessness that tend to accompany chronic and life-threatening illnesses. Just as patients may be overwhelmed by the physical and psychological aspects of HIV infection, clinicians also may feel burdened by their clients' multiple needs. Clinicians can cope better with the stresses involved in caring for HIV-infected patients by following certain steps, including: accepting limited goals; acknowledging, rather than denying, the suffering they encounter, and seeking support to deal with their own feelings; considering psychiatric referral for patients who are significantly depressed or anxious; using empathy to support patients emotionally; being honest with patients about the limits of a clinician's knowledge; and regularly assessing the patient's and the physician's goals.

At times, the physician and patient may find they are communicating poorly, or that compliance with medical advice is low. These conflicts may be clues to goal disparity. Perhaps the patient is ready to stop active intervention, or perhaps the physician is feeling overwhelmed by the patient's numerous complications. At this point, it is best for the patient and physician to define explicitly short- and long-term goals: the patient setting the goals and the clinician outlining various ways to achieve these goals.

Many clinicians, aware of the limitations of medicine in curing HIV-infection, forget about the ability to heal that stands separate from medical practices. For many patients, who are aware of the limits of medical intervention, working with an empathic physician can lessen the anxiety associated with having a progressive or terminal disease. Empathy does not mean taking total responsibility for the patient's emotional well-being. It does mean respectful listening, effectively conveying a sense of caring, and being attentive to the emotional as well as the physiological ramifications of each episode of illness.

Empathy, honesty and a common assessment of goals, in particular, imply communicating in ways that may be unconventional for many physicians who are trained to rely on science alone in their interactions with patients. While practitioners tend to withdraw from patients when they have no curative therapies to offer, it is at this juncture that our healing abilities become even more crucial and powerful.

Lisa Capaldini, MD, MPH is Assistant Clinical Professor of Medicine at the University of California San Francisco.

References


Request for Submissions and Comments

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals, including a summary of the idea and a detailed outline of the article. Send correspondence to:

FOCUS: A Guide to AIDS Research and Counseling
UCSF AIDS Health Project, Box 0884
San Francisco, CA 94143-0884
Developing Peer Support for Those Living with HIV Infection

Pierre Ludington and Paul Wychules

As medical and social service providers begin to perceive HIV infection as a more manageable chronic disease, they also are recognizing the importance of interventions, including psychological support services, for asymptomatic people infected with HIV. During the past two years, organizations throughout the United States have formed to provide support to this population, and to help them deal with the psychological ramifications of HIV infection, gain access to information about potential treatments, integrate the bewildering amount of information about HIV infection and take a more active role in their health care.

This article describes the range of interventions used by these groups and focuses on the peer support group component of their programs, particularly in San Francisco and New York City.

History and Benefits of Peer Support

There are many organizations in the U.S. that provide support to asymptomatic people with HIV infection. The most common and successful method they use is the peer support group. The idea of these systems is that new people come together to share in crises of being infected, and an opportunity to see that there are others who are dealing successfully with similar issues and feelings. In this setting, participants can discuss the powerlessness, fear and uncertainty that accompany HIV infection and explore coping mechanisms to help them respond to these feelings. The groups also provide a setting in which treatment information, intimacy and sexuality (including safer sex practices) and societal issues may be addressed.

Peer support groups counter the isolation of a positive HIV antibody test result by providing a safe and nurturing atmosphere in which participants confront the reality of being infected.

Both peer support models address many of the same issues, including: confidentiality, disclosure, sexuality, handling relationships, the medical uncertainty of HIV infection and evaluating treatment, dealing with feelings of fear and anger, as well as isolation, stress reduction, and ways to remain active. Ground rules for both groups tend to be practical and simple: start and finish on time, come to sessions drug and alcohol free, and wait one’s turn to speak. Any rules in addition to these are determined by group consensus. Both programs provide groups for women who are infected, as well as for seronegative people, and both programs have drop-in groups.

While The Body Positive and Positives Being Positive are established programs, it is important to state that they both started simply, as grass roots organizations. Each has grown as participants have expressed needs for enhanced services. For new organizations, the most important objective should not be to decide on the specific structure of peer support groups, but simply to establish groups. Once started, a group will take on a personality of its own and its structure, in keeping with the needs of its particular community, will evolve over time. In addition, peer support groups can be successful in areas where there are both large and small numbers of people affected by the epidemic. Each group can involve as few as two participants as long as they both are grappling with the same issues.

While the needs of people with AIDS appropriately inspired intensive efforts to develop medical and psychological support services, handling the emotional needs of asymptomatic people with HIV infection now has become increasingly important. Peer support provides one way of effectively and economically meeting this need.

Pierre Ludington is coordinator of the Positives Being Positive program of the UCSF AIDS Health Project. Paul Wychules is Executive Director of The Body Positive in New York.

The first international organization dedicated to addressing the concerns of people affected by HIV was founded in April 1989. WHIV's primary goal is to develop support and educational organizations throughout the 140 countries that report evidence of HIV infection.

WHIV affirms in its Statement of Principles that HIV disease is a chronic and treatable condition, ranging from asymptomatic infection to severe immuno-suppression. Those infected are entitled to a variety of rights including freedom from stigma and discrimination, access to education, emotional support, and treatment, including early inclusion in research trials, universal freedom of travel, and guaranteed third party and governmental health coverage for all levels of HIV infection.

Focus on Counseling Rather than Diagnostic Testing in Medical Practice. Guide to Clinical Preventative Services, U.S. Preventative Services Task Force, Department of Health and Human Services, Steven H. Woolf, MD, MPH, Scientific Editor, Room 2132, Switzer Building, 330 C Street SW, Washington, DC 20201. (To order the report, call 800-638-0672.)

A 300-page report released in May 1989 suggests that physicians seeking ways to prevent illness among their patients should order fewer diagnostic tests and devote more time to counseling patients about ways to avoid health risks.

The U.S. Preventative Services Task Force, impaneled in 1984 by the Assistant Secretary for Health, surveyed 2,400 studies dealing with more than 100 preventative services for 60 preventable diseases and conditions.

The report presents four broad conclusions. 1) A selective periodic health examination tailored to individual risks is a more appropriate clinical strategy than the annual physical examination. 2) There is a need for greater selectivity in the use of screening tests. 3) Providing education and counseling is one of the most effective forms of prevention available to the clinician, particularly for injury prevention, avoidance of sexually-transmitted diseases, and problems associated with diet, smoking, and drug and alcohol use. 4) The roles of clinicians and patients will continue to change as patients assume greater responsibility for their own health and clinicians develop new skills in risk assessment, counseling and patient education.


A study of 4,540 gay and bisexual men found that neither alcohol nor commonly used psychoactive drugs act as important cofactors in the progression to AIDS in HIV-1 seropositive men.

The proportion of seropositive men at enrollment who developed AIDS during the following 18 months ranged from 5.5 to 8.2 percent in 1,597 alcohol drinkers versus 9.2 percent in 109 nondrinkers, and from 6.3 to 9.6 percent in 1,662 psychoactive drug users versus 8.3 percent for 83 nonusers.

Beginning in April 1984, 4,954 gay and bisexual men without AIDS were enrolled in a study that required semiannual physical examinations including laboratory testing for HIV-1 antibody and CD4 and CD8 lymphocyte surface markers. The present study includes only those men who seroconverted during the period between the first two semiannual visits.

The researchers studied history of use (within the previous two-year, six-month and seven-day periods), frequency of use (daily, weekly, monthly, or less often) and route of administration in the use of 10 classes of psychoactive drugs, and frequency and amount of alcohol consumption. The exhaustive study tested for several outcomes: progression to AIDS; AIDS-related manifestations; persistent generalized lymphadenopathy; low CD4+ cell count; a low proportion of CD4+ cells; and, for substance users, total white blood cell, neutrophil, monocyte and lymphocyte counts.

It also explored several relationships: between substance use, history of use, and the occurrence of AIDS within 18 months after enrollment; between continued substance use after enrollment and the occurrence of AIDS within 18 months; between substance use before enrollment and the presence at enrollment of generalized lymphadenopathy, clinical manifestations of immunodeficiency, low CD4+ cell counts, or low proportion of CD4+ cells; between continued substance use after enrollment and changes in CD4+ cell counts in a defined interval; and between substance use before enrollment and mean cell counts at enrollment.

The results were uniform in almost all categories for all markers, showing no significant difference in immunodeficiency between those who used drugs or alcohol and those who did not. The researchers conclude: "These reassuring findings should not diminish concern about the influence drug and alcohol use may exert on behavior [emphasis added] leading to acquisition or dissemination of HIV-1 or other sexually-transmitted infections."

Information on HIV-related Clinical Trials. The National Institutes of Health provides weekly updates of information about trials occurring throughout the country. Callers may request a Spanish-speaking operator, and may call Monday through Friday from 9:00 a.m. to 7:00 p.m. EST: 1-800-TRIALS-A.

Next Month

The relationships of couples in which one partner is seronegative and the other is seropositive may be complicated in ways that add to the overwhelming task of dealing with a life-threatening disease. For gay men, in particular, whose relationships have traditionally received little validation from society, the issues are even more complex. In the August issue of FOCUS, Tom Caldarola, MA, MFCC, a San Francisco counselor affiliated with Operation Concern and the AIDS Health Project, and Michael Helquist, founding editor of FOCUS and a Program Officer for AIDS COM, discuss the difficulties such gay couples face and interventions counselors can offer them.

Another effect of AIDS unrelated to its pathology may be its impact on seronegative people in populations hardest hit by the epidemic, like the gay community in San Francisco. Also in the August issue, Rachel Schochet, MA, MFCC, a San Francisco therapist, explores the psychological issues for seronegative gay men, including post-traumatic stress and survivor guilt.

FOCUS A GUIDE TO AIDS RESEARCH AND COUNSELING

JULY 1989. A monthly publication of the AIDS Health Project, which is affiliated with the University of California San Francisco and the San Francisco Department of Public Health. Published in part with an equipment grant from Apple Computer, Inc., Community Affairs Department. ©1989 UC Regents. All rights reserved.

Executive Editor and Director, AIDS Health Project: James W. Dilley, MD; Editor: Robert Marks; Founding Editor and Advisor: Michael Helquist; Medical Advisor: Stephen Follansbee, MD; Marketing Coordinator: Paul Causey; Administrative Assistant: Joseph Wilson

SUBSCRIPTIONS: 12 monthly issues of FOCUS are $36 for U.S. residents, $42 for those with limited income, $48 for individuals in other countries, $90 for U.S. institutions, and $110 for institutions in other countries. Make checks payable to "UC Regents"; address subscription requests and correspondence to: FOCUS, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884. Back issues are $3 per issue. For a description, write to the above address or call (415) 476-6430.

MOVING? To ensure uninterrupted delivery of FOCUS, send your new address four weeks before the change becomes effective.