AIDS Report

Problems in Treating the HIV-Infected Patient

BY SIMSON L. GARFINKEL

A middle-aged patient complaining of a persistent cough sits on your examination table. Under his arms, you feel enlarged lymph nodes. On the side of his tongue, you spot a white patch indicative of hairy leukoplakia.

Does he have the acquired immunodeficiency syndrome (AIDS)?

Probably not, says Dr. Neal Rzepkowski, at the Fenway Community Health Center in Boston. But almost certainly the patient is infected with human immunodeficiency virus (HIV), he says, maintaining that he has never seen hairy leukoplakia on a patient who was not infected with the virus.

When the diagnosis is confirmed by the HIV antibody test, the most important thing for the physician to do is to assure the patient that HIV — and even full-blown AIDS—"is not a death sentence," says Dr. Rzepkowski.

Indeed, says Dr. Rzepkowski, patients who are developing HIV-related symptoms that haven't yet been tested for HIV "are living in the past. If they haven't had the test in the last four years, either they don't realize that they are at risk, or they don't realize that there is anything they can do about it."

Although fear and denial also play a role in preventing patients from getting tested, he says, many patients now developing symptoms of the disease are less informed than the well-networked, upper-middle-class homosexuals who were the first to develop the disease. Infection with the virus is increasingly cutting across cultural and economic lines.

Once Dr. Rzepkowski assures the patient that he is not going to die, he hand draws blood for a preliminary laboratory work-up and gives the patient a page entitled "AIDS Resources." He then schedules a follow-up appointment and encourages the patient to "do the research" and become an expert on the disease that will probably affect him for the rest of his life.

Dr. Rzepkowski estimates that he has seen at least 250 HIV-infected patients since the disease was first reported in 1981. The Fenway Community Health Center is well known in the Boston area for its work with the homosexual community.

Physician Recognition

Do physicians who work in practices that do not primarily cater to homosexual men or intravenous drug abusers need to concern themselves with the proper treatment of an HIV-infected person?

Definitely, says Dr. Sandy Pomerantz, a medical consultant to the State of California's Office of AIDS. Although many physicians believe that they do not have patients who are at risk for the disease, the real issue is that many physicians have not spoken frankly with their patients about the disease and the practices that cause its transmission. "They are in the practices already, so taking a detailed sexual and drug use history should be done on all patients," he says.

Many physicians who discover HIV-infected patients "are sending patients to other physicians who are known to be knowledgeable about HIV." This is a trend that Dr. Pomerantz says cannot continue.

"The number of HIV-infected individuals far outnumbers the number of so-called AIDS specialists," he says. "All primary-care physicians, to be sure, and in general, all clinicians, need to become more knowledgeable about HIV.

"It is ironic that many HIV-infected individuals have gotten to the point of understanding that HIV infection

doesn't mean necessarily death, whereas many physicians still hold on to that concept." HIV-infection really represents a spectrum of disease, says Dr. Pomerantz, that can be monitored and managed with prophylactic treatments by the primary-care physician for "long, long periods of time."

"AIDS Docs"

Dr. Kathleen Nolan, a physician and ethicist at the Hastings Institute in New York, amplifies the point: "The primary-care physician has to change his or her mind set and begin to see HIV infection as a problem that will be routinely handled in the private office or general clinic.

"I don't think that shift in mind set has really occurred. I think that there is still, in many people's mind, the idea of AIDS as a very difficult disease to manage, which it can become, and also the idea of AIDS as a very frightening disease that should be somebody else's responsibility," says Dr. Nolan. "What is needed is for people to realize that HIV-disease is a long-term disease where the patient can be managed by a nonspecialist for perhaps many years, and there is a responsibility for people to carry their share of the burden in terms of managing their share of the patients who are infected."

So far, that does not seem to be happening. In every state of the country, says attorney Ben Schatz, Director of National Gay Rights Advocates, there are physicians who are denying care to patients "because the person has or is perceived to have HIV." Doing so, says Mr. Schatz, is illegal under the laws of many states or if the physician is a recipient of Medicare.

Nevertheless, there is talk in the medical community of the growing number of "AIDS Docs"—physicians who have large parts of their case loads devoted in part or entirely to people who test positive for HIV.

Dr. Gary Blick is such a physician. Although his practice is in Greenwich, Connecticut, he draws his patients from nearly a quarter of the state: "I see people from Southbury, Connecticut, about an hour away. I see people from the other side of New Haven. If they are driving an hour and a half, it's because they can't get appropriate care—they don't find physicians who are open-minded to treating them and will sit down and give them any kind of discussion."

Once an HIV diagnosis is shared with the patient, the first thing that Dr. Blick does is sit down with the patient and spend 45 minutes finding out who they are, how they are psychologically approaching the diagnosis, and how they are caring for themselves. The most important thing, says Dr. Blick, is to give the patient a sense of hope.

"Its a totally different feeling now than it was two years ago," says Dr. Blick, adding that the hundred HIV-positive patients he treats make up roughly 10 percent of his workload. "It's just a chronic virus: we can treat HIV today. We couldn't say that several years ago. It's not a death sentence."

Although it is important to begin medical treatment early, says Dr. Blick, it is more important to deal with psychological issues first. "The mind is three-fourths of the battle dealing against this virus. The psychological issues have to be dealt with. You have to get the people into positive thinking."

Next, Dr. Blick focuses the patient's attention on nutrition and exercise. A lot of HIV-infected people do not have a balanced diet; some are on "fad diets" to lose weight, he notes. Between 35 and 47 percent of the patients may be deficient or borderline deficient in vitamin B-6 or B-12.

As for exercise, Dr. Blick recommends "aerobics exercise—getting that heart beating for a steady 20 or 25 minutes, three times a week, is very important in stimulating that immune system." Other physicians agree that aerobic exercise three times a week is one of the most important things to recommend to a presymptomatic HIV-infected patient.

Basic laboratory work, says Dr. Blick, ranges from T-cell profiles, beta-2-microglobulin, HIV-P24 antigen, and the anti-HIV-P24 antibody test, all of which can give indications of the progression of the disease. While the patient's T4 count remains above 500, Dr. Blick is comfortable simply monitoring the patient every six months.

When the patient's T-cell count drops below 500, Dr. Blick begins T-cell monitoring every three months or less. He starts a low-dose regimen of zidovudine (azidothymidine, or AZT) when the count dips between 300 and 400, in contrast to the Food and Drug Administration's approved regimen of high-dose AZT when the T-cell count drops below 200. It is also vital that the patient begins prophylactic measures against *Pneumocystis carinii* pneumonia. Commonly used prophylaxes include trimethoprim-sulfamethoxazole and aerosolized pentamidine.

Instead of having his patients wake up in the middle of the night to take their medication, as was once common practice, Dr. Blick has his patients get a full night's sleep and take the drug at 7AM, 11AM, 3PM, 7PM, and 11PM. "It's very important to have a full night of sleep," he says.

Many other treatments are available. "I am very open minded to any therapy people want to use," says Dr. Blick. "I will follow people in any therapy people want to use as long as it is not going to harm them. If you believe in a therapy, I'll be the last to tell you that it's not going to do you any benefit." Just believing in a self-prescribed, self-administered therapy, Dr. Blick says, is often enough to get positive results.

Physician Confidentiality

Because of the mechanisms of transmission and the groups that have most often been infected, a physician's obligation of confidentiality holds new importance when AIDS and HIV infection is involved.

"Physicians need to be extremely careful about patient confidentiality and need to make sure they instruct their staff about confidentiality," says Mr. Schatz. Many of the cases that he handles involve situations in which a nurse or clerical personnel learned of a patient's infection.

In Arkansas, for example, a nurse learned that a hairdresser had tested positive for HIV infection: "The nurse and her husband took it upon themselves to call his customers and told them not to go to him any more because [the hairdresser] had HIV," Mr. Schatz says.

Indeed, he says, "the majority of the calls I receive have been the result of someone on the staff making phone calls and getting the information out, although there have been physicians violating [confidentiality] as well.

"The physician is legally responsible if a staff member violates confidentiality," he notes.

Mr. Schatz says that physicians should be very careful about the sort of information they write into a patient's medical chart—particularly information "that may not be medically important but may be damaging from an insurance perspective. Physicians need to think two or three times before they write that someone is a gay man in the medical chart or that they had come asking information about AIDS. That's the kind of information that if an insurance company gets a hold of may very [well be used] to deny insurance, even though neither has a particular medical significance."

But once a patient tests positive for HIV, says Dr. Rzepkowski, it becomes unreasonable to try to keep that information out of the patient's records. Although he knows of some physicians who maintain lists of their patients who have tested HIV-positive, such lists present confidentiality problems of their own. And, says Dr. Rzepkowski, when patients begin to develop opportunistic diseases that are nearly synonymous with AIDS, the fact that a patient's HIV status is not in the chart becomes meaningless.

Current Clinical Trials

At the National Institute of Allergy and Infectious Diseases' AIDS Clinic, Dr. Clifford Lane says that there is a growing interest in the AIDS-research community on conducting long-term studies on HIV-infected patients with healthy immune systems in an attempt to find ways of staving off the disease. A national toll-free hotline for information about these and other trials has been established (800-TRIALSA). A quarterly updated directory of trials is also published by the American Foundation for AIDS Research and can be ordered by calling 800-458-5231. Physicians with patients interested in such trials can also call Dr. Lane at 301-496-9054.

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PATIENTS AT HIGH RISK OF HIV INFECTION

Nearly all physicians have patients in their practices who are at risk for AIDS, says Dr. Sandy Pomerantz, a medical consultant to the State of California's Office of AIDS. In particular, patients considered at high risk include:

- Any man who has engaged in sex with another man since 1977.
- Any person who has had heterosexual (vaginal) or anal intercourse with an unknown partner since 1977, and more so since the mid-1980s
- Any person who has used intravenous drugs since 1977.
- Any person who has had sex with an intravenous drug abuser.
- Any person who had a blood transfusion or received blood products, especially products containing blood factors 8 and 9, between 1977 and 1985 (the year in which the blood supply started being tested for HIV).