HIV-Related Disease: Family Physicians' Multiple Opportunities For Preventive Intervention

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Background: **The spread of the human immunodeficiency virus (HIV) and the increasing number of persons with acquired immunodeficiency syndrome (AIDS) are major health problems. HIV risk factors are well documented, and HIV disease is recognized as a chronic illness with a predictable course.**

Methods: **Since September 1987 the East Central AIDS Education and Training Center for Health Professionals has served Michigan, Ohio, Kentucky, and Tennessee. Activities include (1) educating and training primary health care providers on prevention and treatment of AIDS, (2) training selected individuals to train others, (3) providing guidance in multidisciplinary management of HIV disease, (4) disseminating updates about HIV and AIDS, and (5) serving as a support system through referral activities.**

Results: **Too many primary physicians, including family physicians, are uncomfortable with patients who are at risk for becoming infected with HIV or who are HIV-infected. Long-term concern and attention that might normally be offered to other patients with different chronic or fatal diseases are sometimes avoided. Patients also present barriers to care, making it difficult for family physicians to provide appropriate care.**

Conclusions: **Understanding the natural history of HIV infection is integral to family physicians' important roles in preventing and dealing with HIV. One role is screening at-risk persons; this function usually has associated opportunities for education. A second role is mainstreaming HIV-related illnesses; if family physicians treat HIV-positive persons, then AIDS is not "someone else's problem." A third role is leadership; as family physicians overcome fear and prejudice, they become role models. Each role is consistent with long-held traditions of family practice. (J Am Board Fam Pract 1994; 7:218-24.)**

The spread of human immunodeficiency virus (HIV) and the increasing number of persons developing the acquired immunodeficiency syndrome (AIDS) are global, as well as national, problems. How can family physicians respond effectively to this problem, even if the numbers of HIV-positive persons in their practices are low or maybe even nonexistent?

Most responses at this point would be preventive; some could be management decisions. Any response begins by addressing individuals who might be or will be vulnerable to HIV. Examples include discussing sexual and drug issues with young persons — for instance, during school, sports, or camp physical examinations; educating those seeking contraception advice; and counseling those who are in transition, as when ending a marriage. A response means openly discussing chastity, empowering persons to say no when having sex seems inappropriate, and explaining safer sex practices. A response requires special attention to those whose behavior or circumstances might put them at increased risk of acquiring HIV: gay men, alcohol and drug users and abusers, and sexual victims of incest, abuse, or rape. A response demands a constant awareness because few individuals want to think about the risk of HIV, and denial is endemic among those at highest risk for being, or who already are, HIV-infected. Finally, a response necessitates emphasizing one's abilities in management, at the very least the ability to refer effectively but, ideally, to share in the care of HIV-infected patients.

Our purpose in this paper is multifaceted. First, we present the devastation of AIDS in practical qualitative and quantitative terms to allow greater personal meaning to its course and consequences. Second, we depict the natural history of HIV-related disease as a chronic illness, the well-

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defined and predictable course of which provides family physicians many opportunities for prevention and intervention. Finally, we call attention to and suggest ways to overcome barriers that can impede optimal physician-patient relationships in HIV-related situations.

AIDS: Course and Consequences

The history of AIDS, especially in the United States, is largely unprecedented from epidemiological, medical, and psychosocial perspectives. HIV, determined in the early 1980s to cause AIDS, was identified first in gay communities nearly simultaneously on the two coasts.[1,2] A second wave of the epidemic was observed in the mid 1980s, largely on the East Coast; it was presumed to be related to overlap in populations of infected drug users and homosexual and bisexual men.[3] AIDS is now spreading more rapidly among heterosexual men and women, especially minorities, mainly because of intravenous drug use or unprotected sexual contact with an injection drug user.[4] Currently 14 million persons worldwide are estimated to be HIV-infected, a 100-fold increase since AIDS was first classified in 1981. By 1995, 6.9 million additional persons are estimated to become HIV-infected, bringing the worldwide total to more than 20 million.[5] Through 1992 slightly more than one-quarter million cumulative cases of AIDS were diagnosed in the United States.[6] By 1995 this number will probably increase to one-half million — approximately the population of Alaska.[7] About 60 percent will have died.

AIDS takes a toll in many ways, often too numerous and too difficult to comprehend either in quantitative or qualitative terms. Selected statistics, however, hint at the devastation of AIDS both from a personal and a national perspective. At a rate of 1 person every 15 minutes, more than 100 persons die every day of AIDS.[8] AIDS has become the sixth leading cause of premature death, before the age of 65 years, for all Americans. Between the ages of 25 to 44 years, AIDS is the second and sixth leading killer of men and women, respectively.[9] Current lifetime costs of treating a person with AIDS, from diagnosis to death, are $102,000. By 1995 the cost of treating all persons in the United States with HIV, including those with AIDS diagnosed, is predicted to reach $15.2 billion.[10]

Natural History of HIV Infection: Overview of Prevention and Intervention

Understanding basic aspects of the natural history of HIV infection is integral to family physicians' important roles in preventing and dealing with the spread of HIV. One role is screening persons for risk of becoming HIV-infected; this function has great potential for education about prevention of infection. A second role is accepting and mainstreaming HIV-related illnesses; if family physicians care for HIV-positive persons in their practices, then AIDS is not "someone else's problem." A third important role is leadership; as family physicians overcome fear and prejudice, they become role models for others. Each role is consistent with the long-held traditions of family practice.

Figure 1 depicts both cellular (CD4+ [T-helper] lymphocyte counts) and humoral (anti-HIV antibodies) immune system changes with duration of chronic HIV infection and presents HIV p24 antigen as a readily available measure of bloodstream viral load. After an initial burst of viral replication, the HIV p24 antigen usually drops to unmeasurable levels as the immune system responds. With the development of anti-HIV antibodies 6 to 12 weeks after infection, seroconversion occurs (anti-HIV antibodies are detected). Subsequently, HIV continues to replicate, and its principal target cell, the CD4+ lymphocyte, diminishes from a normal cell count of 1000/μL (range 500–2000/μL) to nearly 0/μL as death approaches. The median time from infection to AIDS-defining illness is 10 years. In general, HIV infection can be divided into three phases based on clinical manifestations, laboratory markers, and time since infection. These also are depicted in Figure 1.

The acute phase, or period of primary infection, is sometimes associated with a self-limited acute viral syndrome,[11] transient immune suppression and HIV viremia,[12,13] and the emergence of antibodies against HIV. There is increasing evidence that persons in the primary phase of infection, before seroconversion, are at increased risk for transmitting HIV to sexual or drug-use partners because of high titers of virus in blood and other body fluids during the primary infection stage.[14] Related preventive efforts of the family physician, therefore, need to be focused on the early recognition of and behavioral interventions

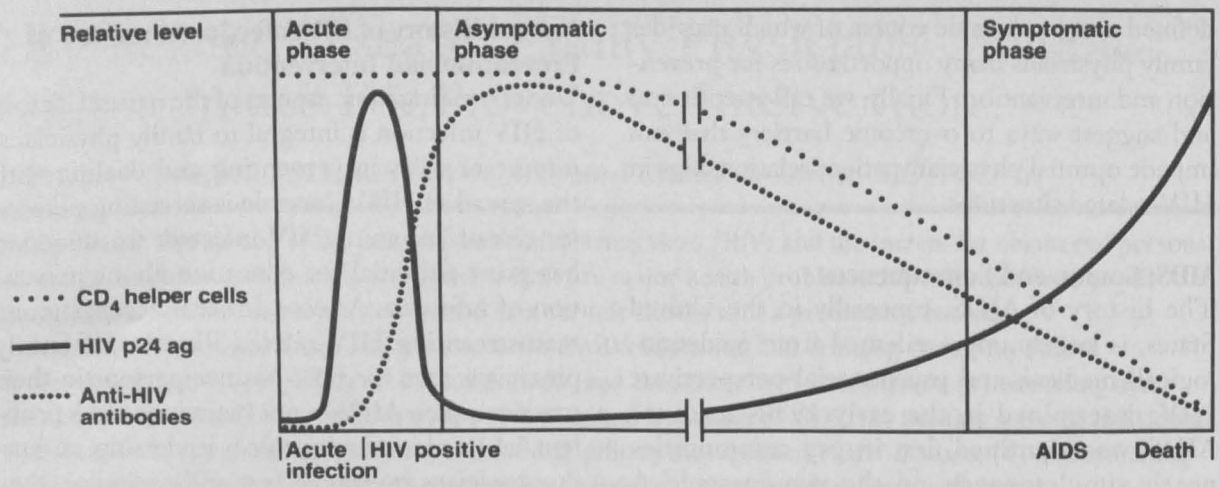

Figure 1. Natural history of HIV infection.
Source: Ostrow DG, Wren PA. The natural history and classification of HIV-1 infection. In: Barr PA, ed. Mental health aspects of HIV/AIDS. Ann Arbor, MI: University of Michigan, 1991:55.

with persons at risk of becoming infected. Reduction of HIV risk will also reduce unwanted pregnancies and decrease the occurrence of other sexually transmitted diseases, such as herpes.

The asymptomatic phase occurs between the appearance of HIV antibodies and the onset of marked immunodeficiency and related symptoms. This period, lasting anywhere from several months to years, is a time of subclinical HIV infection but continuing viral replication and slow immune system deterioration. Although little is known about the determinants of the rate of progression of immunodeficiency in HIV infection, there is increasing evidence that host, viral, and environmental factors might all influence the length of the asymptomatic phase. For example, exposure to other sexually transmitted diseases around the time of seroconversion seems to predict more rapid development of AIDS among men.[15] There is increasing evidence that strains of HIV vary in virulence and that differences between the strains could account for differences in the rate of HIV progression. The family physician would want to educate persons about these facts and strongly recommend protective techniques during sexual activities as a way to help slow HIV spread.

The symptomatic phase of illness usually heralds considerable immunosuppression with CD4+ lymphocyte counts well below 500 cells/μL. Symptoms progress from mild to severe and include weight loss, night sweats, diarrhea, persistent rashes and skin infections, fevers, and fatigue. Further progression leads to the last stage of HIV infection, AIDS. Patients meeting the case definition of AIDS have developed severe neurological impairment, life-threatening opportunistic infections, an HIV-related neoplasm, or wasting syndrome.[16] In January 1993 the CDC expanded the AIDS case definition to include HIV-infected individuals with active tuberculosis, invasive cervi-

Table 1. Case Definition of AIDS by the Centers for Disease Control and Prevention.

Signs	Examples
Confirmed positive HIV antibody test	
plus	
1 or more of the following	
CD4+ count <200 cells/μL* *or* CD4+% <20%*	
Opportunistic infection	*Pneumocystis carinii* pneumonia
	Cryptococcal meningitis
	Atypical mycobacteria (MAI)
	Cytomegalovirus (CMV) retinitis
	Candida esophagitis
	Toxoplasma encephalitis
	Active tuberculosis*
HIV-associated neoplasms	Kaposi sarcoma
	Lymphoma
	Invasive cervical cancer*
Wasting syndrome	
HIV-related dementia	

*New additions to the case definition as of January 1993.

cal cancer, or a CD4+ lymphocyte count of fewer than 200 cells/μL (Table 1).[17]

During the past decade, major advances in the clinical management of HIV infection have been made, including the ability to diagnose and treat AIDS-defining conditions more readily and to prevent some opportunistic infections with prophylactic treatments. Although the diagnosis of AIDS is still associated with a terminal prognosis, the advent of antiretroviral and prophylactic treatments — often administered in the primary care setting — means that persons with late-stage illness can live lives of reasonable quality for increasing lengths of time. Even in the terminal stages of life, the help of a caring family physician is a great comfort to patients and their families. Family physicians can and must be key to management throughout the illness.

Methods

Beginning 1 September 1987 and continuing through the present, the East Central AIDS Education and Training Center for Health Professionals (ECAETC) has functioned to serve the four-state region of Michigan, Ohio, Kentucky, and Tennessee. ECAETC is guided by five unique but interrelated goals that have been established on the basis of function: organization, materials development, education and training, information collection and dissemination, and undergraduate and graduate curriculum infusion. These function-oriented goals provide the framework for the following activities of ECAETC: (1) educating and training primary health care providers about prevention and treatment of AIDS, with particular emphasis on ambulatory settings; (2) conducting additional training with selected individuals to qualify them for extending the training to others in their communities; (3) providing guidance in multidisciplinary management of HIV-related conditions; (4) disseminating updates of new and timely information about HIV and AIDS to primary and secondary health care providers; and (5) serving as a support system by coordinating hotlines, clearinghouses, referral activities, and other information resources.

To date, ECAETC has sponsored 63 clinical training programs (mean: 16.5 hours), 581 presentations (mean: 2.25 hours), 67 workshops (mean: 6.5 hours), 7 state or regional conferences (mean: 14.6 hours), and 29 regional, national, or international teleconferences (mean: 2.5 hours). In total, more than 57,000 persons have participated in one or more ECAETC-sponsored education and training events, and an estimated 180,000 have participated in the teleconferences. The ECAETC product line consists of 5 computer-assisted instruction modules, 9 sets of videotape and facilitator's guide instructional materials, 8 sets of profession-specific educational materials, 8 units of core-interdisciplinary educational materials, various user-friendly computer data bases, and a quarterly distribution of 5000 of the *AIDS LINK* newsletter. Integral to these accomplishments is the network of 250 regional and national associations and organizations established through ECAETC efforts. Based upon our experience with the above programs during the last 6 years, together with the reported experience of others in this field, we present the following discussion concerning physicians' and patients' barriers to care.

Overcoming Physicians' Barriers to Care

With AIDS so serious and widespread, family physicians are increasingly important both to its prevention and management. Many physicians, however, are uncomfortable caring for HIV-infected patients.[18] Consciously or unconsciously, even family physicians often avoid the kind of long-term personal concern and attention they might offer routinely to other patients who have different fatal or chronic illnesses.[19] There are many reasons for the aversion, but they generally fall into two categories — AIDS as a disease and the persons who get AIDS.

Foremost, perhaps, is the fear of contagion. Despite all scientific knowledge to the contrary, the communicability of HIV has attained the mythic proportions that leprosy, the bubonic plague, and yellow fever did in the past. Though most physicians realize that risk is extremely low for transmission from patient to health care worker, still there remains a nagging fear that can inhibit care. This anxiety is best controlled with knowledge about transmission, acknowledgment of concerns, and the desensitization that comes only from actual experience with HIV-infected patients.

Similarly, many physicians worry about contracting an opportunistic infection from an AIDS patient. These fears are generally unfounded in

that these infections are caused by organisms that tend to be ubiquitous in the environment and virtually never infect an immunocompetent host. One exception is tuberculosis. There is a much higher rate of tuberculosis among AIDS patients. All physicians must take care to screen carefully and regularly for tuberculosis in potentially HIV-infected individuals, using PPD testing (4 mm induration is considered positive in an HIV patient) and chest radiographs. Conversely, all patients with active tuberculosis should be tested for HIV.

Many family physicians also see AIDS as too complicated for the primary care specialist. AIDS jargon abounds with three-word, Latin-named infections (e.g. *Pneumocystis carinii* pneumonia, *Mycobacterium avium* complex) and chemotherapy-sounding abbreviations (AZT, DDI, DDC, D4T). Immune system deficits have long been the province of other specialists, and most generalist physicians were trained well before lymphocyte subset assays, such as the CD4+ cell count, came into common use.

Figure 1 represents a familiar conceptual model for family physicians; that is, HIV disease is a chronic illness with a relatively well-defined and predictable course. The CD4+ lymphocyte count is a very simple and fairly reliable marker for severity. Further, the first two phases of HIV-related conditions are remarkable for minor recurrent illness but major psychosocial impact. The major needs are for education, secondary prevention, and support. Meeting such needs is the special province of family physicians.

Beyond the virus and related opportunistic illnesses, other concerns of physicians often are related to issues surrounding persons who contract HIV. Despite changing demographics of the infection, most persons currently infected in the United States are men who have had sex with men or are persons who inject drugs. Most persons, including physicians, are uncomfortable with lifestyle choices that accompany these high-risk behaviors. Family physicians must recognize that the essence of their professionalism is to leave personal biases at the office door. By focusing on humans in need, as opposed to stereotypes, barriers can be lowered.

Aside from these two broad categories of barriers, other reasons exist that prevent optimum care of HIV-infected persons. For some physicians, caring for a dying patient, especially a young person, can be a wrenching experience. For other physicians, issues of hospice care are difficult when they otherwise have fairly young and healthy patient populations. Reimbursement for services can be problematic; many AIDS patients have lost their jobs and insurance, and they must rely on public assistance. Male physicians, especially those who are younger and less established, might worry that people will think they are gay if they are too active in HIV-related care. Finally, physicians might perceive that if they care for AIDS patients, their other patients would object and would change physicians.

As with many other health care concerns, family physicians have a critical role to play in the area of leadership in their response to the AIDS crisis.[20] Patients look to their family physician for direction on issues of health care. As family physicians overcome their biases, fears, and prejudices, they go a long way in removing AIDS from a Dark Ages mentality to treat it as they would any other serious disease — worthy of care and compassion.

Overcoming Patient Barriers to Care

The reasons for patients' denial regarding HIV infection are understandable. No other disease is associated with so many stigmas — sex, homosexuality, drugs, contagion, prolonged suffering, and death. To disclose one's infection is to invite the most personal of questions, spoken and unspoken. Disclosure also risks loss of relationships with family members and friends; of sex with intimate partners; of job, and with that possibly insurance, housing, and financial security; and most of all, self-esteem. Issues about illness and mortality can pervade thought, crowding out any remaining peace of mind. Denial, even to an extreme, might seem preferable to reality or any semblance thereof.

Yet as with many other illnesses and diseases, denial often results in premature debility, death, or both. Moreover, evidence suggests that knowledge of one's HIV-positive status is a successful motivator of risk-related behavioral change. Thus, the family physician's challenge, and opportunity to be responsive, in overcoming denial is not only to help the patient but also to prevent others from acquiring HIV.

Family physicians know that one of the most effective means to overcome patients' denial is to show patients they are willing to listen carefully

and to converse gently, but candidly, about any subject. With HIV-infected patients there is a need to establish trust that presupposes knowledge, compassion, and confidentiality.[21]

Assuming there are about 1.5 million HIV-infected persons in the nation, it seems plausible that most family physicians have someone in their practice with HIV.[22] Straightforward, nonjudgmental questions as a part of a normal history seem to work best in the medical detective work of overcoming a patient's denial and recognizing those persons who, if not HIV-positive, at least are at risk of becoming so. "Have you been sexually active during the last 12 years?" If yes, "Has it been with men, women, or both?" For a drug history, make it a general rule to extend the usual questions about caffeine, tobacco, and alcohol to include marijuana, cocaine or crack, and needle-delivered drugs, doing so in a natural progression.

It is not pejorative, if done as professional assessment of risk, to be alert to social signs, such as mannerisms, speech pattern, employment, marital status, roommates, jewelry, and clothing. Be aware that any hint of judgmental assessment or reaction can foster denial and fear.

Attention to clinical cues is paramount. HIV infection in the early phase(s) is a very subtle diagnosis. Frequent or recurrent skin and mucous membrane infection should prompt at least a further assessment of risk.[23] Especially in young people, fungal infections, such as seborrhea, thrush, onychomycosis, and tinea, should bring to mind HIV. Viral conditions, such as zoster, molluscum, hairy leukoplakia, and recurrent common warts, might be clues. Other conditions, such as recurrent folliculitis, weight loss, adenopathy, night sweats, or drug reactions, can well spell immune dysfunction. Of course any kind of sexually transmitted disease, including common minor infections, such as trichomonas or condylomatous changes found on a Papanicolaou smear, should elicit an offer to test for HIV. Even if the risk of current infection seems low, the test itself is a powerful educational motivator.

The most important encouragement in overcoming patients' denial is certainty that there is benefit in knowing. Patients must realize that the equation is not HIV=AIDS=death. They must be reassured that their personal physician will be there to provide information, to be supportive, and to facilitate the health care process. They must know that they are not alone and that there are positive, important things they can do. In fact, patients have been found to want information and counseling from their family physician about HIV and AIDS.[24]

Summary

For a disease not known to exist essentially a decade ago, AIDS has had an intense short history. It now ranks ninth in leading causes of death among persons of all ages and much higher than that for younger persons, aged 25 to 44 years. Family physicians can, and must, be active in preventing and managing AIDS-related illnesses. Many family physicians already provide important leadership, individually and collectively, in the response to the AIDS crisis at local, state, and national levels. Although barriers exist to professional involvement, more family physicians are needed to prevent and manage HIV-related conditions.

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