Patient Attitudes and Knowledge About HIV Infection and AIDS

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Background. Family physicians are caring for an increasing number of those with human immunodeficiency virus (HIV) infection, those at risk, and those concerned about HIV disease.

Methods. A questionnaire survey of attitudes and knowledge about HIV infection was conducted in 430 patients in three family practices in Monroe County, NY.

Results. The majority of those surveyed had worried about catching HIV and had spoken with friends or relatives about HIV. Approximately 7.5% had had the HIV test. Approximately half of all the respondents expressed a desire to discuss HIV-related issues with their family doctor; however, less than 8% had actually done so. The majority of the respondents believed their family doctor was competent to answer questions about HIV disease. Furthermore, the majority were well informed about the modes of transmission of HIV. Many of the respondents were unsure of the lack of risk from casual contact, however, and whether acquired immune deficiency syndrome (AIDS) is incurable at the present time.

Conclusions. Family physicians need to take a more active role in educating and counseling patients about HIV disease.

Key words. Acquired immunodeficiency syndrome, patient education, HIV. *J Fam Pract 1991; 32:373-377.*

As the epidemic of human immunodeficiency virus (HIV) infection spreads outside of the major cities to smaller communities,[1,2] family physicians will be at the forefront in the prevention, diagnosis, early intervention, and long-term management of HIV disease.[3–7] At present, the most effective strategy for control of the epidemic depends on education and counseling to reduce high-risk behaviors.[8] Family physicians are potential sources of such information and counseling. It is not known to what extent patients have discussed HIV-related issues with their family physicians, however, or whether patients desire more HIV-related discussion. The general level of knowledge of patients outside the major population centers has not been assessed, and it is not known which knowledge deficits need to be addressed. These are important factors in planning educational interventions for physicians in primary care settings.

This study was conducted to evaluate the degree of concern about HIV infection, the desire to discuss HIV-related issues, the sources of information about HIV, and the level of knowledge about HIV in a family practice population in Rochester, NY, and surrounding areas of Monroe County. Rochester is typical of other small cities that are experiencing a second wave of the HIV epidemic following the first wave, which occurred in large cities such as New York, San Francisco, and Miami. We assessed how many patients had actually discussed an HIV-related topic with their family physicians and how many had been tested for the presence of antibody to HIV. We were particularly interested in teenagers' responses since they have been identified as a group who may be poorly informed about HIV disease and may be at particular risk of acquiring HIV disease through drug use and unprotected sexual contact.[9,10]

Methods

The study was conducted during October and November 1988, in Monroe County, NY (population 950,000). In 1988, Monroe County had a reported cumulative AIDS incidence of 20 cases per 100,000 residents, defining the county as an area of high risk for HIV infection[11]. Three family practices were approached and agreed to partici-

Submitted, revised, September 17, 1990.

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ISSN 0094-3509

pate: an inner-city, hospital-affiliated private practice in Rochester, NY, serving a predominantly black and Hispanic working-class and poor population; an urban Rochester residency training practice serving a predominantly white lower-middle-class population; and a rural-suburban private practice 20 miles outside of Rochester serving a mixture of an upper-middle-class white suburban population and a middle-class-to-poor rural farming population.

Each practice received questionnaires in approximate proportion to the number of patients seen per week. The principal investigator met with the physicians, nurses, and administrative staff of each practice to describe the method of distributing and collecting the questionnaires. The staff was instructed to distribute the questionnaires consecutively over a period of 10 days to patients age 14 years and older, regardless of the presenting complaint. Each patient was asked to complete the questionnaire while in the examination room awaiting the doctor. The completed questionnaire was placed in a plain envelope that was collected by the secretary at the end of the visit. Patients were told that completion of the questionnaire had no connection with the doctor visit and that the information provided would be kept strictly confidential.

The questionnaire, which was originally developed for a study carried out in the United Kingdom and Eire, consisted of multiple response questions and open-ended comments designed to assess seven areas: HIV-related concerns; desire to discuss HIV-related issues with a family physician; whether respondents had actually discussed any of those topics with their family physicians; perceived competence of family physicians to discuss HIV-related issues; sources of information about HIV; and knowledge of HIV as determined by an 8-item scale. It was by coincidence, not by design, that the Surgeon General distributed an information booklet containing answers to these questions on HIV to all households during the month before the questionnaire was distributed.

Bivariate relationships between variables were conducted using the chi-square test, the Student's *t* test, and analysis of variance (ANOVA) as appropriate. Tests were two-tailed, with a significance level of .05. The data were further analyzed using multiple linear regression analysis for continuous variables and multiple logistic regression for dichotomous variables. Age, sex, and practice location were the independent variables. Adjusted odds ratios were calculated from the results of the logistic regression.

Because the responses within each section of the questionnaire were highly correlated, dichotomous scales were created for global assessment of HIV-related concerns, desire to discuss HIV-related topics with a family physician, and perceived HIV-related competence of family physicians. An HIV-related concern scale was constructed such that a response of "often" or "very often" to any of the four questions determining concern about HIV (Table 1) was considered a high level of concern. All other responses were considered to indicate a low level of concern. Cronbach's alpha,[12] a measure of the internal consistency of a scale, was 0.78. Similarly, a "desire to discuss" scale was created (Cronbach's alpha = 0.92) by taking the response that indicated the highest level of interest in discussing HIV of any of the four questions. A "perceived competence" scale was created by summing the responses to the questions asking whether the respondents believed that family physicians knew enough to answer patients' questions about four HIV-related topics (Cronbach's alpha = 0.89). These were further analyzed using multiple linear and logistic regression analysis. Alternative analyses using continuous (rather than dichotomous) scales yielded similar results and are not reported here. In addition, the data from each practice and the data from teenagers were analyzed separately.

Results

Characteristics of Respondents

Four hundred ninety questionnaires were distributed at three family practice sites. Sixty (12.3%) were not completed; there was no significant variation by practice location. The following were the most common reasons for a patient not completing a questionnaire: the patient had to attend to acutely ill or distressed children, was too ill, was mentally retarded, had cerebral palsy, had dementia, or was unable to read English. The remaining 430 questionnaires were completed by 302 women (70.2%) and 128 men (29.8%). One hundred seventy-two (40.0%) of the respondents were from rural practices, while 175 (40.7%) and 83 (19.3%) were from urban and inner-city practices, respectively. The mean age was 35.9 years (±14.5 years). There were 40 (9.3%) respondents between the ages of 13 and 19 years.

HIV-Related Concerns

The majority of those surveyed had worried about catching HIV (Table 1). Thirty-two (7.5%) of those surveyed reported having had the HIV-antibody test. Those under 30 years of age were more likely to have been tested (13.8% vs 5.0%, $\chi^2 = 9.3$, $df = 1$, $P = .002$). Approximately 13% of men, compared with 5.0% of women, reported having had the HIV test ($\chi^2 = 9.67$, $df = 1$,

Table 1. Patients' Expressed Concern About HIV (n = 430)

	Percent of Respondents			
	Never	Sometimes	Often	Very Often
Have you ever worried about catching HIV?	41.3	47.9	5.2	5.6
Have you ever wanted to talk to somebody about whether you have caught HIV?	71.3	24.7	2.6	1.4
Have you ever discussed this with anyone?	56.7	35.5	5.4	2.4
Have you ever thought about having the HIV test?	66.0	26.7	5.0	2.4

$P = .002$). There were no significant differences between the percentage of patients who had been tested in the three practices. Approximately one half had talked with someone about HIV, most commonly, with friends (111), relatives (81), or physicians (30). Of those who reported thinking often or very often about having the HIV test, only 32.3% had been tested.

Approximately 19% of the respondents answered "often" or "very often" to at least one of the four questions assessing concern about HIV, and only 26.7% reported no HIV-related concerns. Multiple logistic regression analysis using age, sex, and practice as independent variables showed that HIV-related concern was greatest in teenagers and decreased with increasing age ($F = 18.11$, $P < .0001$). More male than female respondents answered "very often" to one of the four questions (24.2% vs 16.2%, odds ratio = 1.3, 95% CI = 1.0–1.7), as did those from the urban practices compared with those from the rural practice (21.5% vs 13.6%, odds ratio = 1.4, 95% CI = 1.0–1.8, $P = .029$).

Discussion of HIV-Related Issues with a Family Physician

Forty-seven percent of the respondents answered that they would definitely or probably want to discuss one or more of the four HIV-related topics with a family physician (Table 2). There was greater interest expressed by younger age groups, with 67.5% of teenagers reporting that they would definitely like to discuss at least one of the four HIV-related topics with their family doctor ($\chi^2 = 29.9$, $df = 4$, $P > .001$). Multiple logistic regression analysis indicated that there was a significantly greater number from urban practices than from the rural practice who reported that they would like to discuss HIV-related issues with a family physician (odds ratio = 1.3, 95% CI = 1.1–1.3). There were no differences based on sex.

Table 2. Patients' Desire to Discuss HIV-Related Issues With a Family Doctor (n = 430)

Would you like to discuss the following with your family doctor?	Percent of Respondents			
	Definitely	Probably	No	Don't Know
The HIV test?	8.9	18.3	55.6	17.3
How to avoid catching the HIV?	17.7	19.9	56.0	6.5
Symptoms of AIDS?	22.5	19.8	50.6	7.2
Treatment of AIDS?	19.5	17.8	54.5	8.3

Only 8.1% of respondents reported that they had discussed any of the four HIV-related topics with their family physician. Although there appeared to be a trend for younger, female, and urban respondents to have discussed HIV-related topics, this did not reach statistical significance.

More than 80% believed that family physicians probably or definitely know enough to answer patients' questions about testing, prevention, symptoms, and treatment of HIV. There were no differences according to age, sex, or practice location. Other sources of information about HIV disease are summarized in Table 3.

Knowledge About HIV Disease and AIDS.

Respondents had a mean score of 84.3% on the eight-item knowledge scale (Table 4). Forty-two percent answered all questions correctly, and an additional 26.7% answered seven of the eight questions correctly. Seven-

Table 3. Patients' Sources of Information About HIV Infection (n = 430)

You can get information about HIV infection and AIDS in a number of ways. How helpful have you found the following?	Percent of Respondents			
	Helpful	Fairly Helpful	Not Much Help	No Help
Advertisements	39.2	34.9	22.2	3.7
TV and radio shows	55.8	31.8	9.9	2.5
Books, leaflets, newspapers, magazines	56.4	33.7	8.7	1.2
Organizations, telephone helplines	26.3	25.8	26.9	21.0
Family, friends, co-workers	14.0	26.4	40.4	19.1
Family doctor	36.4	27.2	13.9	22.5

Table 4. Patients' Knowledge About HIV Disease and AIDS (n = 430)

	Percent of Respondents		
	Yes	No	Don't Know
Is it possible to catch the HIV by: Having sex without a condom?	93.2	1.4	5.4
Sharing other peoples' needles/ syringes to inject yourself?	96.5	0.8	2.7
Drinking out of other peoples' cups/glasses?	6.8	70.8	22.4
Sitting next to someone with HIV in their blood?	0.5	93.5	6.0
Can a pregnant woman with HIV in her blood give it to her baby?	89.9	0.5	9.5
Can both men and women catch the HIV?	94.9	0.5	4.6
Does everyone with HIV in their blood have AIDS?	6.8	67.1	26.1
Is there a cure for HIV infection?	3.0	71.4	25.7

teen percent had five or fewer correct answers. The vast majority of those who did not answer correctly answered "don't know"; there were few incorrect answers. Those 60 years old and older scored significantly lower (72.1%, $F = 3.53$, $df = 4$, $P = .008$). There were no differences based on sex or practice location.

Discussion

These findings indicate that the majority of patients in the family practices surveyed were concerned about HIV. Nearly one half expressed a desire to discuss HIV-related issues with their family doctor; however, less than 8% actually had discussed these concerns with their family doctor. The vast majority believed that their family doctor probably or definitely knew enough to answer patients' questions about HIV. These conclusions are consistent with those of Gerbert et al,[13] who surveyed 2000 randomly selected households in the United States. In their sample, 94% had seen a physician in the past 5 years, but only 15% had discussed HIV-related topics with a physician. Most, they found, would not object to talking with their physician, and 27% reported that they strongly desired to do so.

Now that antiretroviral therapy is available for early HIV infection,[14,15] there is an even greater imperative to test those at risk. Many of those surveyed had been tested for HIV. On the other hand, 60% of those who had thought about the test often had not yet been tested, which indicates that there is more work to be done in motivating those at risk to be tested. It will be important in follow-up studies to determine where this testing is taking place (anonymous testing sites, STD clinics, other physicians' offices). Also, it will be useful to know whether the primary care physician is made aware of the HIV test result, or even informed that his or her patient has had the HIV test. Of the potential sources of information, mass media sources were rated as the most helpful, reflecting the high profile that the AIDS epidemic was receiving on television and radio at the time the survey was conducted.

It is not clear why so few of the respondents had discussed HIV-related topics with their family doctor. There are several possible explanations. The populations at greatest risk for HIV infection, young adults and teenagers, generally visit physicians for acute illnesses, and symptomatic treatment is often the focus of the visit. Second, the education campaigns by the Surgeon General and by the mass media were peaking at the time the questionnaires were completed, possibly obscuring the impact of any AIDS education programs being conducted in the physicians' offices. More important, the lack of discussion about HIV-related topics between family physicians and their patients may be due to the physicians' reluctance to bring up potentially sensitive topics because of fear of embarrassment or rejection. It has been well documented that many physicians are uncomfortable talking about sexual behavior, and harbor prejudicial attitudes toward homosexuals, drug users, and AIDS patients.[16–22] Patients may be waiting for their physicians to assure them that it is acceptable to bring up the topic of HIV and risk behaviors for infection.

It is encouraging that the majority of respondents were well informed about HIV, especially regarding the spread of HIV through unprotected sex and the sharing of needles. Many respondents were unsure about the lack of risk from casual exposure and did not know whether there is a cure for HIV. This is somewhat worrisome, as the imperative for reducing risk of exposure to the HIV comes from the fact that HIV disease, at the present time, is incurable. It was unexpected and reassuring to find the level of knowledge about HIV to be no different among teenagers or among patients in the inner-city practice. The respondents' concern about HIV and their desire to talk to their family physicians about HIV indicate that they recognize their need for more information about the disease. This finding is consistent with other studies on teenagers' knowledge and attitudes about AIDS[9,10].

The conclusions that can be drawn from this study are limited by several factors. The sample size was relatively small and was drawn from only three practices. These practices were not chosen at random, and their

respective patient populations may not be representative of the patients in other, smaller practices in Monroe County or in other regions. The sampling was biased in favor of those patients who visit their family physicians frequently, since they were more likely to visit during the time when the study was conducted. It is unclear whether the results of the study will apply to those who seldom or never visit doctors. Finally, the study did not examine directly the relationship of race, ethnic background, educational background, socioeconomic status, or sexual orientation to HIV-related attitudes or knowledge. These issues will be important to examine in future studies.

Family physicians need to take a more active role in educating and counseling patients about HIV disease.[23] This study and others[13] indicate that most patients seen in primary care practices would respond well to family physicians who express interest in providing information and counseling about HIV infection. Educational efforts are especially important with teenagers, the urban poor, and others whose knowledge deficits, sexual behaviors, or drug use put them at risk for HIV transmission.

Knowledge about HIV and actual risk behavior may be poorly correlated, and it is essential to address both.[10,24] Information provided by primary care physicians must be accompanied by counseling to help patients to modify risk behaviors for HIV infection. Many family physicians have had little or no training in sexual risk-reduction counseling[25,26] or in drug treatment, and may feel uncomfortable raising or discussing these issues with patients. It will be important to assess these issues from the physician's perspective so that appropriate educational and training programs for family physicians can be developed.

Acknowledgments

Paul Wallace, MD, originated the questionnaire used in this study; Peter Franks, MD, Cleveland Shields, PhD, and Jeff Harp, MD, helped in data analysis; Karen Vane assisted with the preparation of the manuscript; and Deborah Fox provided editorial commentary.

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For editorial comment, see page 367.