

Current Report—HIV

Counseling Patients About HIV Test Results

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Informing patients and their families of the diagnosis of any serious illness is a difficult but familiar task for family physicians. Few of us are trained for this role. We develop a personal style based on the observation of others, approaches and philosophies advocated in the medical literature,^{1,2} and notions of how we would want this information made known to ourselves or to members of our families. But mainly our style is developed by trial and error.

Notifying patients that their test for the human immunodeficiency virus (HIV) is positive can be particularly difficult, given the seriousness of the diagnosis from both a medical and a social perspective. When performed skillfully, this undertaking can provide the foundation for a strong physician-patient relationship. Negative impact on the patient and family can be kept within reasonable limits. When done poorly, the patient is left with feelings of isolation, despair, and antagonism toward the health care system. The physician-patient relationship may never recover.

Much has been learned about HIV testing and counseling that can provide guidance for physicians. Patient education and pre-test and post-test counseling, as well as an understanding and sensitive approach, are keys to this challenging interaction.³⁻⁵ This *Current Report—HIV* offers some suggestions based on our experiences and those of HIV counseling and testing services.⁶

Pre-Test Counseling

Effective management of HIV testing begins with pre-test counseling. Testing should not be performed until there has been adequate education about HIV and informed consent has been obtained. If the patient does not appear emotionally prepared for the possibility of an HIV-positive result, it may be advisable to postpone testing until additional counseling is performed.

Risk factors for HIV should be identified by obtaining a thorough sexual and drug history and inquiring about the receipt of blood products between 1978 and 1985. For patients who request HIV testing but have no stated risk factors, it is usually wise to perform the test. Some patients will need the additional reassurance a negative HIV test result can provide; others have risk factors they are unwilling to disclose. Guidelines for risk avoidance, including safer sex, drug rehabilitation, and safer injection drug use need to be discussed at this time. These guidelines are important regardless of risk factors or HIV status.

The best time for education is during pre-test counseling. Asking what the patient already knows can help clarify misconceptions and guide the discussion. Many patients need an explanation of what HIV is, how long the latency period between infection and disease can be, and the difference between being HIV-positive and having AIDS. A discussion of the antibody tests is important.⁷ Proper testing for HIV antibodies begins with a screening test, the enzyme-linked immunosorbent assay (ELISA). If this test is positive, it is followed by a confirmatory test, either the Western blot test or the immunofluorescent antibody test. The patient must understand that a "window" period exists between infection and seroconversion. During that time, false-negative test results can occur. Most persons will seroconvert by 6 to 8 weeks after exposure, and the vast majority by 3

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months. Occasionally, seroconversion does not occur for many months thereafter or, rarely, not at all. Retesting is advised for persons who might be in this window period.

Informed consent for HIV testing requires that the risks and benefits be discussed in detail. Just having the test done, regardless of the result, carries some risk. Others may assume that the person belongs to a high-risk group. Insurance companies have refused coverage after finding out that an HIV test was performed. Finally, false-positive and false-negative results, although uncommon, can result in serious personal, medical, and social problems.

For the person who is antibody-negative, the negative test results provide reassurance but can give a misleading sense of security, which can result in unsafe behaviors and failure to be appropriately retested. For persons testing HIV-positive, benefits include preventing transmission by changing risk behaviors, early diagnosis and treatment, and partner notification (by the patient, physician, or health department). In addition, many patients will have spent months or years worrying about their HIV status. Even for those whose tests are positive, it can be a relief to resolve this uncertainty. Risks include depression, substance abuse, and suicide. Social consequences, such as isolation, discrimination,^{8,9} and abandonment by friends and family, occur frequently.

Loss of confidentiality is another important risk to HIV-positive patients. Confidentiality can be difficult to assure in a primary care practice that functions much like a small community. Physicians, nurses, laboratory technicians, and office staff often have access to HIV test results. Special measures may be required to protect the patient's privacy. In addition, many patients are concerned about disclosure of test results to insurance companies and public health authorities. Laws regarding the release of information vary from state to state. Before consenting to antibody testing, the patient must know to whom the test results might be disclosed. When confidentiality cannot be guaranteed, anonymous testing should be strongly considered. Anonymous testing requires that specific patient identification is not used. This form of testing can prevent social problems resulting from the re-

lease of information to other parties, including family members, friends, acquaintances, co-workers, and employers.

The physician needs to assess how the patient will cope while waiting for the test result. Understanding the patient's social support network (family, friends, social and religious groups) can provide the physician with important insight into the patient's needs. Finding out who patients will inform about their decision to be tested can identify sources of support as well as potential problems. Knowing about previous response patterns to stress can help predict what might occur if the test result is positive.

Finally, the patient should be told that results, whether positive or negative, will be given in person at the follow-up visit. Because telephone notification of positive results is dangerous, and contrary to the principles of a positive physician-patient relationship, the physician can insist upon a policy of personal post-test counseling.

Post-Test Counseling

During post-test counseling, little information will be absorbed, especially if the test result is positive. At the beginning of the session, the patient can be given the opportunity to bring up any problems or questions that have come up since the last visit. Most patients will be anxious to find out their test results, and the physician should proceed without delay.

HIV-Negative Result

For the seronegative patient, HIV testing can provide an opportunity to change high-risk behaviors. Counseling about safer sex, clean needle use, and treatment for drug dependency can be successful at this time. For patients with recent or ongoing risk behaviors who may be in the window period, a plan for follow-up testing is essential.

HIV-Positive Result

A clear statement should be made that the test is positive and the patient is infected with the HIV virus. A positive HIV test is interpreted by most patients as the diagnosis of a terminal illness or even as a death sentence. Some degree of psychological shock usually follows. Therefore, most patients are not able to take in much

information. This encounter is not the time for detailed explanations of immunology, the spectrum of HIV disease, safe sex practices, or an elaborate health care plan. The patient's own questions and concerns should guide the rest of the session.

Having a positive HIV test often creates profound feelings of isolation and fear of being abandoned by others, including health care providers.¹⁰ One of the most important goals of this session is to convey the message that the physician, patient, and family will continue to work closely together. We use the definition of a family as "a group of intimates with a history and a future."¹¹ p 1099

The physician needs to convey some sense of hope. Clinical illness might not occur for years, the development of new antiviral drugs is promising, and effective treatments for most complications of HIV disease are now available. The physician's willingness to provide comprehensive primary care can be comforting. Use of the word "we" when talking about the patient's care can foster a sense of togetherness rather than isolation.

Under these stressful circumstances, however, such reassurance may offer little consolation. The physician should assess how the patient will cope with this crisis and whom he or she will tell. The potential for suicide, drug abuse, or other self-destructive behavior needs to be addressed. Partner notification may be an immediate and pressing issue at this time.

A clear, short-term plan should be in place by the end of this session. Periodic physical examinations, laboratory testing, and specific treatments can be mentioned briefly as part of the plan. Further discussion of a comprehensive and individualized treatment plan can be reserved for future visits. A return visit within a week should be scheduled. A written appointment slip will avoid confusion and emphasize the active management plan that is now in effect. During the interval before the next visit, the patient should be encouraged to contact the office on-call system, community support services, or national hotlines if further problems or questions arise. Members of the family and support network can be encouraged to use these services as well.

Above all, the session should build a sense of connection between the patient and physician. We recommend a handshake or other form of physical contact to strengthen that connection and to give the unspoken message that HIV is not casually transmitted. The patient should leave the office knowing that the physician will be at the center of a team that includes the patient, family, support network, and other medical specialists and social service agencies to assure the best possible care.

Conclusion

Family physicians are in an ideal position to identify HIV-infected persons and provide comprehensive HIV care. HIV testing and counseling can be the foundation for that care. The techniques described above are intended to help in this challenging task.

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References

1. Brewin TB. Three ways of giving bad news. *Lancet* 1991; 337:1207-9.
2. *Idem*. The cancer patient: communication and morale. *Br Med J* 1977; 2:1623-7.
3. Koop CE. Talking to patients about AIDS. *J Fam Pract* 1991; 32:367-8.
4. Kaminski MA, Hartman PM. HIV testing: issues for the family physician. *Am Fam Physician* 1988; 38:117-22.
5. Paauw DS, O'Neill JF. Human immunodeficiency virus and the primary care physician. *J Fam Pract* 1990; 31:646-50.
6. Public Health Service guidelines for counseling and antibody testing to prevent HIV infection and AIDS. *MMWR* 1987; 36:509-15.
7. Goldschmidt RH. Laboratory testing for the presence of HIV infection and the progression of HIV disease. *J Am Board Fam Pract* 1990; 3:60-2.
8. Sherer R. Physician use of the HIV antibody test. The need for consent, counseling, confidentiality, and caution. *JAMA* 1988; 259:264-5.
9. Blendon RJ, Donelan K. Discrimination against people with AIDS: the public's perspective. *N Engl J Med* 1988; 319:1022-6.
10. Kelly JA, St. Lawrence JS, Smith S Jr, Hood HV, Cook DJ. Stigmatization of AIDS patients by physicians. *Am J Public Health* 1987; 77:789-91.
11. Ransom DC, Vandervoort HE. The development of family medicine. Problematic trends. *JAMA* 1973; 225:1098-102.