Beyond Fear*

Resolving Ethical Dilemmas Regarding HIV Infection

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The human immunodeficiency virus (HIV) epidemic, by its devastating nature as an incurable, contagious disease primarily affecting young, previously healthy patients, presents care-givers with many ethical dilemmas. While the epidemic and the dilemmas it creates are novel, the ethical principles at our disposal are well established through our experience with other diseases.

In this article we review six major clinical problems confronting care-givers treating HIV antibody-positive patients: (1) indications for screening, (2) confidentiality of HIV test results and the notification of third parties at risk, (3) indications for life-sustaining treatment, (4) refusal of care for seropositive patients, (5) dilemmas regarding research protocols and experimental therapies, and (6) allocation of medical resources.

Bringing standard ethical principles to bear on these problems can make medical decision-making rational and consistent. Therefore, ethical principles that guide other medical decisions should also be applied in the case of HIV infection. These principles include autonomy, confidentiality, truth-telling, nonmaleficence, beneficence, and justice. We shall briefly review these principles before applying them to the specific case of HIV infection.

The principle of autonomy, or respect for persons, allows individuals to make decisions about their bodies and their health care, even if others consider those decisions unwise. Competent, informed patients may decline tests or treatments that their physicians recommend. The legal doctrine of informed consent is based on this principle of autonomy. Effective communication is essential if patients are to be informed, autonomous participants in their own health care.

Preserving the confidentiality of medical information protects a patient's privacy. It also encourages patients to seek care and to discuss their problems frankly with physicians and protects patients from adverse consequences. When confidentiality is breached, HIV-infected patients may encounter stigma and discrimination. Seropositive patients have lost jobs, housing, health insurance, and access to health care. The bureaucratic complexity of medicine makes breaches of confidentiality common. To better preserve confidentiality, most states have established alternative testing sites where HIV testing can be obtained anonymously.

The principle of truth-telling requires both physicians and patients not to misrepresent or deceive other persons. It requires HIV-seropositive patients to notify contacts of their risk.

Nonmaleficence requires persons to refrain from injuring others. In particular, seropositive persons have a moral duty to take steps to prevent infection of third parties.

Beneficence enjoins physicians to benefit their patients. The obligation of physicians to act for the good of their patients rather than for their own profit distinguishes the profession of medicine from a business.

Justice requires similar groups of patients to be treated equally. In particular, health care resources should be distributed equitably. Justice is particularly important with regard to HIV infection because seropositive persons may already be disadvantaged and discriminated against.

Application of these principles to real-life situations is not easy, however. It requires giving priority to some principles over others. For example, preventing infection in persons unknowingly exposed to HIV may conflict with respecting the autonomy of infected persons and the confidentiality of their HIV antibody test results. But, while individuals have a right to jeopardize their own health, they have no right to place others at risk. Thus, the duty of the physician to prevent harm may override the duty to protect confidentiality.

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INDICATIONS FOR HIV SCREENING

The goals of screening asymptomatic individuals are to allow seropositive persons to make informed decisions about sexual practices, childbirth, careers, and medical care and to decrease the spread of HIV infection. Identifying seropositive persons could enable them to prevent infection of sexual partners and children. Currently, mandatory screening is required for blood, organ, and sperm donors; for military personnel; for foreign service and Peace Corps employees; for immigrants; for inmates in federal prisons; and in some states for applicants for marriage licenses. More extensive mandatory testing has been rejected on both practical and ethical grounds, because it may drive persons at high risk for HIV infection away from the health care system.

Informed consent for HIV testing requires that before blood is drawn, the patient should be informed about the nature of the test, the risks and benefits, the alternatives to testing, and the implications of a positive test result. Unless testing is mandatory, informed consent should be obtained.

It is important to distinguish screening an asymptomatic, low-risk population from diagnostic HIV testing in symptomatic patients who may have AIDS. Screening a population with low prevalence of HIV infection has several problems. The positive predictive value of HIV testing may be unacceptably low, particularly when testing is not performed in reference laboratories. Thus, screening will be expensive and will identify only few true HIV positive cases. For example, a cost-benefit analysis projected that premarital screening in the United States would detect fewer than one-tenth of 1 percent of HIV-infected persons and prevent the birth of an estimated 250 infected infants each year, but would falsely identify 350 persons as seropositive. It is estimated that nationwide premarital screening would cost more than $100 million a year. In January 1988, mandatory premarital screening was instituted in Illinois. One month after this law was put into effect, applications for marriage licenses had decreased by 60 percent in Cook County because of the unacceptably long wait and the high cost of testing. At the same time, Wisconsin public health officials noted a fourfold increase in the number of marriages between Illinois residents in the five Wisconsin counties that border Illinois. The resources used on premarital HIV screening in low-risk populations could be used much more effectively for education, patient care, or research.

Some physicians and surgeons advocate HIV antibody testing for all hospitalized or surgical patients. They think that they can better protect themselves from HIV exposure if they know which patients are seropositive. Screening as a guide to infection control, however, presents difficulties. Negative tests may give a false sense of security, since early in the course of infection patients may be seronegative but still contagious. In one study HIV was successfully cultured from 6 percent of seronegative, high-risk homosexual men. For this reason, a positive test result should not be the only trigger for instituting infection control measures. On the other hand, in low prevalence areas, a substantial proportion of positive tests will be falsely positive. The joint false positive rate of the enzyme-linked immunosorbant assay (ELISA) and the Western blot tests when performed in series has been estimated to be as high as 1/1,250. Burke et al studied the frequency of false positive HIV test results in a retrospective review of civilian applicants for military service from rural, low prevalence areas. They found that with a multistep algorithm that requires two confirmatory Western blot tests rather than one and rigorous quality control measures in the laboratory, they were able to achieve the very low false positive rate of 1/135,187. However, it is unlikely that this low false positive rate could be achieved in smaller, community-based laboratories. It is impossible to estimate the economic and social impact of erroneously informing patients that they have antibodies against HIV. Because confidentiality would be impossible if infection control precautions were instituted only on seropositive patients, such false positive tests could be particularly damaging.

Because of these problems with HIV testing, the CDC recommended universal body fluid precautions. Gloves, masks, gowns, or goggles should be worn whenever health care workers may be exposed to blood or body fluids. In other words, all patients should be treated as if they are seropositive. Hospitals have a duty to make such equipment readily available to health care workers. Universal precautions will change medical and surgical practice. New surgical procedures, such as changes in suturing techniques, will probably increase the duration of operations and, therefore, perioperative morbidity, but patients and surgeons may have to accept this increased morbidity to decrease occupational risk to health care workers.

CONFIDENTIALITY OF HIV TEST RESULTS AND THE NOTIFICATION OF THIRD PARTIES AT RISK

Before an HIV test is performed, care-givers and patients should discuss to whom the results will be disclosed, such as third parties at risk for infection, other health care workers, or public health officials. Much in the way that a physician is required to explain the risks and benefits of a diagnostic procedure before obtaining consent, it is essential to explain the risk of the rare occurrence of a breach of confidentiality.

Aside from the illness itself, seropositive persons...
most fear discrimination. Since current public health strategies for the prevention of the spread of HIV depend on voluntary testing and the cooperation of seropositive persons, it is essential that every effort be made to protect the confidentiality of seropositive patients.

Seropositive patients have a moral duty to notify third parties who are unknowingly at risk for infection. Health care workers should strongly encourage patients to notify sexual partners and should offer support and assistance. If seropositive patients refuse to notify their sexual partners, physicians may have an ethical and legal duty to do so.

In California and New York, recent laws allow physicians to notify sexual and IV drug-using contacts of seropositive persons about their risk without the consent of the index case (California Senate Bill 2788 and New York Assembly Bill 9765-A). The name of the index case may not be disclosed during the notification process. Alternatively, the physician may ask a public health official to notify contacts. In both states, physicians are required to notify the patient of the intent to inform contacts before doing so. These bills also provide that no physician will be held civilly or criminally liable for disclosing this information to contacts at risk. Mandatory notification of contacts is not required and would be impossible, since the notification process depends on the voluntary cooperation of the index case to provide information about potential contacts. Therefore, without the patient’s cooperation, contact tracing is impossible.

Some seropositive patients may prefer that third parties be notified by public health officials rather than by their personal physicians. Public health officials may better preserve the anonymity of the index case. On the other hand, others may want their own physicians to notify their contacts. Such patient preferences should be respected whenever possible.

Balancing the confidentiality of the seropositive index case and the protection of third parties at risk will continue to present difficulties until society decreases the stigma of HIV infection. If laws are enacted to protect against discrimination of seropositive patients, HIV testing and contact tracing will be more widely accepted, as they are for other infections and sexually transmitted diseases.

Whether to record HIV antibody status in the medical record is a complex issue. Physicians, particularly in emergencies, may need to know HIV test results in order to provide high quality of care. For example, a patient with fever, cough, and dyspnea would undergo a dramatically different diagnostic evaluation if he was known to be infected with HIV. Therefore, omission of HIV test results, "secret codes" in the medical record, or separate records may not serve the patient’s best interests. But if HIV test results are recorded in the medical record, the patient may suffer adverse consequences if the information is disclosed to an employer or insurer. Individual patients should be allowed to weigh the potential risks and benefits to themselves of placing their HIV antibody test results in the medical record and should make an informed decision on this matter. Most patients will want information communicated to other care-givers if it will improve their care.

Because health care workers may feel at greater personal risk if they do not know who is seropositive, they may want HIV test results placed in the medical record. However, instituting infection control precautions on the basis of HIV test results is flawed, as we have discussed. Thus, care-giver concerns about safety should not override patient requests that HIV test results not be recorded in the chart.

**Decisions About Life-sustaining Treatment**

Guidelines regarding life-sustaining treatment in other diseases should also be applied to patients with AIDS. Informed, competent patients may refuse life-sustaining treatment, such as cardiopulmonary resuscitation, ICU care, transfusions, or antibiotics. Patients have the right to refuse therapy, even if their physicians, families, or friends disagree or if refusal may shorten their lives.

Patients need to be informed about the risks and benefits of life-sustaining treatment. Effective communication between care-givers and patients is essential if the patient is to be able to make an informed decision about his treatment. Physicians must also correct misconceptions about HIV infection and treatments in language and with a level of detail that is comprehensible to patients or to their surrogates. Ruark and Raffin provide specific guidelines for effective communication in their recent review.

Patients with HIV infection may not be capable of making decisions about their medical care. They may suffer from HIV-related dementia and opportunistic CNS infections. When patients are incompetent, their previously expressed preferences should guide decisions. Such preferences may have been expressed in conversations with care-givers, family, or friends, or in legal documents such as the durable power of attorney for health care.

The durable power of attorney is the best way for competent patients to designate who should make decisions for them in case they become unable to do so themselves and what type of care they would want. Several states have explicit laws that allow for durable power of attorney for health care. In states where laws addressing durable power of attorney for health care do not exist, general laws about durable power of attorney may apply to health care. Several test cases have upheld this use.
Physicians should encourage their patients to express their preferences for care and to designate a surrogate decision maker in the event that they become incompetent. Their preferences should be documented in the medical record. Gay men with AIDS who wish their partners or friends to act as surrogate decision makers should be urged to execute a durable power of attorney for health care. Otherwise, family members will generally be asked to act as proxies. Most gay men with AIDS want to discuss these issues in advance and do not want aggressive therapy.\textsuperscript{12} Even without formal legal documentation, the previously expressed wishes of the incompetent patient have priority over the family’s wishes if there is a conflict.

If the incompetent patient’s wishes are unclear or unknown, decisions should be based on what is best for the patient. Because deciding what is best for the incompetent patient is often difficult and controversial, it is preferable to discuss patient preferences regarding life-sustaining treatment while they are still competent.

Physicians are not obligated to provide futile care, even if the patient or family requests it.\textsuperscript{13} But it is difficult to define futile. In the strictest sense medical futility exists when, in the care-giver’s best judgment, the patient has failed treatment and will die within 24 to 48 hours regardless of further interventions. In clinical practice more liberal definitions of medical futility are used, but these are fraught with ambiguity, value judgments, and assumptions about acceptable quality of life.\textsuperscript{24}

Patients or surrogates may insist on care that the physician believes is not indicated. These demands create a conflict between the ethical principles of nonmaleficence and autonomy. These conflicts are best resolved with sensitive communication.\textsuperscript{2} If the caregiver explains that there is minimal hope for survival and that treatment will not increase the chance for recovery, and provides reassurance about relief of suffering and continued care, the patient or proxy will usually accept the prognosis and the plan to limit life-sustaining treatment.

**Refusal to Care for Seropositive Patients**

Even if health care workers follow the recommended precautions when caring for patients who are HIV positive, they may contract AIDS from needlesticks or other accidents. After sustaining needlesticks, cuts, or splashes from seropositive patients, 1 of 200 health care workers may develop antibodies to HIV.\textsuperscript{25} Hagen et al\textsuperscript{26} used surgical glove puncture rates and known seroconversion rates for hepatitis B to estimate the HIV seroconversion rate among surgeons. Their data suggest that this risk falls between 1/4,500 and 1/130,000 when operating on a seropositive patient. Fear of contracting a fatal illness leads some physicians to refuse to provide care for seropositive patients. This fear may be intensified or inflated by physicians’ psychologic or moral discomfort related to the behaviors associated with the transmission of AIDS.\textsuperscript{27} Such refusals may make it impossible for seropositive patients to receive care that would benefit them.

In general, there is no legal duty to treat a patient unless a physician has a contractual agreement to do so, as through an employment contract in a public hospital or health maintenance organization. But even in private practice there may be a discrepancy between what care one is required legally to provide, and the ethical ideal that the medical profession should provide appropriate care for all patients who need it. Further, denial of care to seropositive patients could be considered inappropriate discrimination against handicapped or disabled persons and therefore illegal. The contract-based model of care, if adopted as an acceptable standard, may be inadequate for meeting the medical needs of the projected numbers of HIV positive patients.

Decisions about refusal of care for HIV-positive patients must balance altruism and self-interest. Indeed, some physicians contend that a prior voluntary commitment to the profession of healing obligates physicians to accept the risk of caring for HIV-positive patients.\textsuperscript{28} Refusal to care for contagious patients creates a tension between self-effacement by the physician and self-interest. Felligrino\textsuperscript{29} contends that “to refuse to care for AIDS patients, even if the danger were much greater than it is, is to abnegate what is essential to being a physician. The physician is no more free to flee from danger in performance of his or her duties than the fireman, policeman, or soldier.”

The American Medical Association Council on Ethical and Judicial Affairs\textsuperscript{30} states that “a physician may not ethically refuse to treat a patient whose condition is within the physician’s current realm of competence solely because the patient is seropositive. If a physician is not able to provide the services required by persons with AIDS, he or she should make the appropriate referral to those physicians or facilities that are equipped to provide such services.” Annas\textsuperscript{31} observes that the AMA has always stood for the rights of its members to treat whomever they want to (except in emergencies) and that this statement seems to represent a change in position. The AMA’s recommendation for “referral to those physicians that are equipped to provide such services” could create a serious access problem if large numbers of physicians elect to use this option and not care for HIV-positive patients.

The American College of Physicians and the Society for Infectious Disease state clearly that there is an obligation to treat HIV-infected patients.\textsuperscript{32} Despite these declarations by professional organizations, some
physicians claim that the risk to health care workers overrides an obligation to care for seropositive patients.

One strategy to limit exposure to HIV infection while providing needed services would be to withhold futile care. As already discussed, physicians have no ethical obligation to provide treatment that will not benefit the patient. In deciding whether a treatment is futile, physicians should ask what the medical indications would be if the patient had a prognostically similar disease that was not contagious. For example, mechanical ventilation for an AIDS patient who has failed treatment of Pneumocystis carinii pneumonia is as futile as mechanical ventilation in a patient with end-stage COPD.

When a treatment has proved substantial or probable benefit to the patient, patient preference for treatment should prevail over care-giver concerns about personal risk. Examples of these situations include obstetric delivery and emergency treatment of trauma cases. Since it is currently the standard of care to provide these services, discussion should focus on how physicians can alter techniques or use protective equipment to reduce their risk, not on whether they should provide these services.

However, when the benefits of care are uncertain, minor, or unlikely, physician concern about personal infection should be given more weight. In some circumstances, care-giver safety may be decisive. For example, if a patient has AIDS (rather than asymptomatic HIV infection), total hip replacement or elective coronary bypass surgery may be unwarranted owing to the limited life expectancy of the patient and the risks to the surgical team.

Another approach to reduce the risk to care-givers is developing safer procedures, such as using induced sputum samples rather than bronchoscopy to diagnose P carinii pneumonia.33

Dilemmas in Research

The safety and efficacy of experimental therapies for AIDS can be rigorously evaluated only in double-blind, controlled trials. But it may be difficult to recruit patients with HIV infection for placebo-controlled trials, since they might be willing to receive only active treatment, not a placebo. Indeed, some patients enrolled in clinical trials may seek additional treatments. Such behavior, or course, will confound the findings of a study and make it difficult to evaluate new therapies rigorously.

Because AIDS is a fatal illness, there is pressure to release new therapies as soon as possible. Clearly, delays in testing and releasing effective new drugs are unconscionable. Further, the FDA may allow promising investigational new drugs (INDs) to be given to patients with life-threatening disease for which other treatments have failed.34 While making new drugs more available could benefit patients, it also could harm them, because unknown side effects may shorten their lives or decrease their quality of life. This policy may also waste scarce resources on toxic or ineffective therapies.

Unproved therapies may cause a conflict between patient autonomy and the physician’s duty to do no harm. Patients may be willing to accept the risks and uncertainties of unproved treatments or multiple simultaneous therapies. The sense of regaining control over the illness may in itself be beneficial. There is no obligation for physicians to provide therapies that have no efficacy. However, care-givers may be willing to respect patient requests for treatments whose benefits are controversial or unknown if there is no other hope of preventing the progression of disease and there are no known adverse reactions to the proposed therapy.

Allocation of Health Care Resources

By 1991 it is estimated that there will be 270,000 AIDS cases in the United States.35 While the cost of AIDS will rise sharply by 1991, the total direct cost of AIDS will be only 1.5 percent of total health expenditures. The financial burden of caring for persons with AIDS will fall disproportionately on urban areas with large populations of gay men and IV drug users. By 1991, 12.4 percent of acute-care beds in San Francisco and 8.1 percent in New York will be needed for persons with AIDS. Similarly, such persons will require 16.2 percent of inpatient hospital costs in San Francisco in 1991 and 8.4 percent in New York. The total cost of caring for an AIDS patient is similar to costs of other serious illness, such as cancer or heart disease.36

Owing to their lack of medical insurance and financial resources, many persons with AIDS receive care in public hospitals that are already financially stressed. In New York in 1987, local tax revenues paid 27 percent of the total costs of AIDS care.36 Studies have estimated that Medicaid pays for the care of 12 to 65 percent of patients with AIDS.37 Even with additional funding, increasing demands for AIDS care may require municipal hospitals to reduce care for other patients, such as trauma or obstetric patients.

Limited resources may force changes in the delivery of care to persons with AIDS. Some changes may save money while improving quality of care. For instance, outpatient or home care may be less expensive and more humane than inpatient care. Similarly, diagnosing Pneumocystis pneumonia using cyto logic examination of induced sputum is less expensive and, in many cases, as effective as diagnosis by bronchoscopy.53 However, budgetary constraints may also create pressures to restrict care that offers some benefit for patients. For instance, patients with AIDS and Pneumocystis pneumonia causing respiratory failure may
benefit from mechanical ventilation, but restricting access to ICUs may be an attractive means of reducing the cost of caring for patients with AIDS. Such restrictions may not be a just allocation of medical resources, since an AIDS patient's chance for survival is greater than that of other patients who have ready access to ICU beds, such as bone marrow transplant patients with respiratory failure. The AIDS epidemic may force physicians to consider the prognosis of all patients who might benefit from ICU care, when faced with limited ICU resources.

In allocating finite resources for AIDS, society must balance competing needs, such as for inpatient care, treatments like azidothymidine, which prolong survival but cost over $8,000 a year for each patient, long-term care, home care, and education to prevent HIV infection in high-risk groups. While the total amount spent on the AIDS epidemic may increase, it is likely that difficult trade-offs among competing priorities will have to be made.

Physicians caring for HIV-infected patients confront a variety of ethical dilemmas. These issues are complicated by a fear of contagion, possible discrimination against these vulnerable patients, and a health care system that has not resolved how to finance their care. In grappling with these ethical dilemmas, physicians and society must respect patients' autonomy and confidentiality, benefit patients, and third parties at risk, and must allocate resources fairly. In addition, the AIDS epidemic challenges individual physicians and society as a whole to act humanely and compassionately in the patients' best interests.

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REFERENCES
7 Meyer K, Paulaker S. Screening for HIV: can we afford the false positive rate? N Engl J Med 1987; 317:238-41
8 Cleary PD, Barry MJ, Mayer KH, Brandt AM, Gostin L, Fineberg HV. Compulsory premarital screening for the human immunodeficiency virus. JAMA 1987; 258:1757-62
10 Belongia E, Vergeront J. Border hopping as a consequence of premarital HIV screening: the Kenosha diamond. JAMA 1988; 260:1853-84
14 MMWR. Recommendations for prevention of HIV transmission in health care settings. MMWR 1987; 36(suppl 22):35-35
25 CDC. Recommendations for prevention of HIV transmission in health-care settings. MMWR 1987; 36 (suppl):IS-18S
26 Hagen MD, Meyer KB, Pauker SG. Routine preoperative screening for HIV: does the risk to the surgeon outweigh the risk to the patient? JAMA 1988; 259:1357-59
29 Pellegrino ED. Altruism, self-interest, and medical ethics. JAMA 1987; 258:1939-40
30 AMA. Ethical issues involved in the growing AIDS crisis. JAMA 1988; 259:1360-61
31 Annas GJ. Not saints, but healers: the legal duties of health care professionals in the AIDS epidemic. AJPH 1986; 76:844-49
34 Merz B. Treatment INDS: promising, problematic. JAMA 1988; 259:1607-08