Ethical Issues in the Prevention and Treatment of HIV Infection and AIDS

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The epidemic of infection with the human immunodeficiency virus (HIV) and the acquired immunodeficiency syndrome (AIDS) poses a major ethical question: How can we control the epidemic and the harm that it causes without unjustly discriminating against particular social groups and without unnecessarily infringing on the freedom of individuals? This question pertains to three spheres of public policy in the United States: public health, the delivery of health care, and research. In the public health sphere, vigorous educational efforts will be required, as will modified approaches to intravenous drug use, prostitution, and homosexual and bisexual sexual activity. Carefully targeted, voluntary testing and screening programs should be coupled with counseling and with guarantees of confidentiality and nondiscrimination where these are appropriate. Both health care workers and the health care system have a moral obligation to provide care to people with HIV infection, but heroic self-sacrifice should not be required provided that infection control precautions are observed. Patients with neurological involvement and terminally ill patients will benefit from statutes allowing recognition of advance directives about preferred modes of care or nontreatment. There is a moral imperative to perform intensive research directed toward the understanding, treatment, and prevention of HIV infection and AIDS. The research process will raise challenging ethical questions.

AN ADEQUATE ETHICAL FRAMEWORK FOR EVALUATING PUBlic policies regarding infection with the human immunodeficiency virus (HIV) will include the following considerations: (i) the outcomes, often categorized as benefits and harms, of the policies; (ii) the distribution of these outcomes within the population; and (iii) the liberty-rights, or freedoms, of those who are affected by the policies. A recent presidential commission on bioethics called these three considerations well-being, equity, and respect (*1*). In their *Principles of Biomedical Ethics*, Beauchamp and Childress designate these considerations beneficence and nonmaleficence, justice, and respect for autonomy (*2*).

As we and other societies attempt to confront the AIDS epidemic, the central problem we face is the following: How can we control the epidemic and the harm that it causes without unjustly discriminating against particular social groups and without unnecessarily infringing on the freedom of individuals? This formulation accepts the importance of halting the transmission of HIV infection but recognizes that the achievement of that goal may at times be in tension with other moral constraints, namely, constraints based on justice or respect for autonomy. At the same time, however, these three considerations, or moral vectors, may all point in the same direction, for example, if a particular policy is simultaneously counterproductive, discriminatory, and intrusive.

In this article I will indicate how the ethical principles of beneficence, justice, and respect for autonomy relate to the epidemic of HIV infection in the United States (*3*). I will argue that, because these three principles are all of importance, none of them should be ignored in the formulation of public policy. While one principle may predominate in a given situation or sphere, it should not be allowed to overwhelm or displace the other two.

Three types of policies will be considered: public health policies, policies for the delivery of health care to people with HIV infection, and research policies.

Public Health Policies

Public education. Until more effective medical therapies and preventive measures are developed, public education is likely to be one of the most important means for controlling the epidemic. If the education appeals to the rational capacities of the hearer, it respects his or her autonomy. If public education simultaneously leads to risk-reducing behavioral change, it also promotes the health of the hearer and his or her associates.

Imaginative public education will be moral education in the sense that it helps the hearer to see clearly the possible effects of his or her behavior on others. One possible approach to such education involves the use of ethical if-then statements such as the following. "We have discussed the pros and cons of engaging in behavior X. If you choose to do X, then, in order to avoid harming others, you should adopt measures A, B, and C." Fortunately, many of the measures that protect others are also self-protective. Thus, public educators can simultaneously appeal to both the self-interested and altruistic sentiments of their audiences.

While everyone who is at risk of contracting or transmitting HIV infection should be educated, there are strong moral arguments for targeting educational efforts especially toward people who are most likely to engage in risky behaviors—for example, receptive anal intercourse, intravenous (IV) drug use with shared needles, or vaginal intercourse with IV drug users. Such targeted programs can be justified on either or both of two grounds. Intensive coverage of the groups most at risk for infection is likely to be more efficient in controlling the epidemic than general educational programs alone will be. It can also be argued that groups at higher than average risk need, or even deserve, stronger than average warnings of the risks to which they may be exposed (*4*).

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Modified approaches to IV drug use. Twenty-five percent of clinical AIDS cases involve the illegal use of IV drugs (*5*). The sharing of needles and syringes, sometimes a ritual in settings where multiple drug users self-inject together, seems to be the principal mode of transmission among IV drug users. People who become infected through sharing contaminated needles and syringes may, in turn, infect nondrug-using people through sexual intercourse.

Members of ethnic and racial minority groups are represented in disproportionate numbers among U.S. IV drug users who have AIDS. In AIDS cases involving IV drug use as the sole risk factor, 51% of patients are black and 28% are Hispanic (*5*). Among minority group women, the correlation between IV drugs and AIDS is particularly strong: 70% of black women with AIDS and 83% of Hispanic women with AIDS are either IV drug users or the sexual partners of IV drug users. Two-thirds of black children and three-fourths of Hispanic children with AIDS contracted their infections from mothers who were members of the same two risk groups (*6, 7*).

It is clear that current programs for IV drug users in the United States are failing in many respects and that new and bold measures are needed. These measures may not be politically popular, given the misunderstanding and fear that frequently surround drug use and given our society's traditional neglect of IV drug users. But the initiatives will be essential for controlling the epidemic, for meeting the needs of people who are often stigmatized, and for enabling IV drug users to make autonomous choices about their lives.

The first initiative that should be undertaken is the expansion of drug-treatment programs to accommodate, on a timely basis, all IV drug users who desire treatment. Reports of 3-month waiting lists in U.S. drug-treatment programs are commonplace (*8*, pp. 108–109; *9*). Our failure to provide treatment to people who indicate an interest in discontinuing drug use is both short-sighted and counterproductive. It is encouraging to note that the Presidential Commission on the Human Immunodeficiency Virus Epidemic is making the lack of programs to treat IV drug users one of four major areas for initial study (*10*, pp. 22–23).

A second initiative that will probably be necessary to control the epidemic among IV drug users is the establishment of public programs for the exchange of sterile needles and syringes for used and possibly contaminated equipment. Three countries, the Netherlands, the United Kingdom, and Australia, have experimented with free needle-exchange programs and have reported initially encouraging results—although it is too early to know for certain that the exchange programs actually reduce the rate of infection transmission (*9, 11, 12*). Proposals to initiate needle-exchange programs in the United States have not yet been implemented, in part because they appear to condone or even to encourage IV drug use. Perhaps for this reason U.S. law-enforcement officials have generally opposed such programs (*8*, pp. 109–110; *9*). However, the ethical if-then statements discussed above may also pertain here. Moral and legal prohibitions of IV drug use have not achieved universal acceptance in our society. Given that fact, one seeks to formulate rules of morally responsible drug use: "If you choose to use IV drugs, then you should take steps, including the use of sterile needles and syringes, to minimize the chance of your becoming infected and infecting others with HIV."

If the foregoing measures, coupled with targeted education for IV drug users, are insufficient, more radical initiatives will need to be contemplated. One of the most controversial initiatives, at least among law-enforcement officials, would be the provision of controlled access to injectable drugs by IV drug users in an effort to bring addiction and its social context above ground. Such a policy was endorsed editorially in May 1987 by the British journal *The Lancet* (*13*). Pilot programs of controlled access to injectable drugs, with simultaneous decriminalization of IV drug use, could provide valuable data on the potential effectiveness of this initiative.

Modified approaches to prostitution. Male or female prostitutes who have unprotected intercourse with multiple sexual partners expose themselves to considerable risk of HIV infection in areas of moderate to high seroprevalence. This theoretical risk has been actualized among female prostitutes who have been studied epidemiologically in both the United States and equatorial Africa. For example, a recent cross-sectional survey of female prostitutes in the Newark, New Jersey, area indicated that 51.7% tested positive for antibody to HIV in 1987; in Miami the seroprevalence rate among incarcerated female prostitutes was 18.7% (*14*). A high infection rate among prostitutes imperils not only their own health but also the health of their clients and their clients' other sexual partners.

Official policies on prostitution in this country are set by states and localities. In most U.S. jurisdictions the general approach has been to criminalize the practice of prostitution; in some jurisdictions, the patronizing of a prostitute is also a crime. In contrast, many European countries and several counties in Nevada have adopted a licensing or regulatory approach that includes periodic screening of prostitutes for infectious disease (*14*; *15*, p. 2-20).

An ethically appropriate response to prostitution will be based not simply on our evaluation of prostitution as a practice but also on careful assessment of the extent to which alternative public policies on prostitution are compatible with the principles of beneficence, respect for autonomy, and justice. Although the intervening variables are numerous, the available evidence from Nevada and Europe suggests that, compared with the outlaw and arrest approach, the licensing and regulatory approach to prostitution is at least correlated with lower rates of infection with several other sexually transmitted diseases among prostitutes (*14, 16, 17*). At the same time, a licensing and regulatory approach displays greater respect for the autonomy of adult persons to perform acts that affect chiefly the persons themselves, especially if the transmission of disease is prevented through the use of condoms and through regular health examinations.

Again in this case we should be willing to become pragmatic and experimental in our approach to controlling the epidemic. The legal prohibition of prostitution has not been notably successful in preventing a rapid rise in seropositivity among prostitutes, at least in some cities. Pilot studies of less restrictive approaches in selected localities, taken together with evidence from Nevada and Western Europe, might reveal that alternative policies are, on balance, ethically preferable (*18*).

Modified approaches to homosexual and bisexual sexual activity. As of December 1987, 65% of AIDS cases in the United States involve homosexual or bisexual males; an additional 8% of cases involve homosexual or bisexual males who also admit to IV drug use (*5*). Thus, in a substantial fraction of U.S. AIDS cases to date, HIV seems to have been transmitted through sexual intercourse between males. Receptive anal intercourse is one of the principal modes of viral transmission (*19, 20*).

Many homosexual and bisexual males with AIDS or HIV infection became infected before AIDS was described as a clinical syndrome and before the primary modes of transmission were identified. Thus, while they may have known that they were at increased risk for a series of treatable sexually transmitted diseases, for example, gonorrhea or hepatitis B, they could not have known that they were at risk for contracting an infection that might lead to AIDS. Since the facts about HIV transmission have become well known, homosexual and bisexual men have been heavily involved in targeted public education programs and in humane health care programs for people with AIDS. There is also substantial evidence to indicate that considerable numbers of homosexual and bisexual

males have altered their sexual practices to reduce their probability of becoming infected and infecting others with HIV (*21–23*).

It might seem that, short of traditional public health measures such as increased testing and screening, little more can be done to encourage the cooperation of homosexual and bisexual males in controlling the epidemic. However, two public policy initiatives might conceivably have a salutary effect: (i) in jurisdictions that currently outlaw such acts, the decriminalization of private homosexual acts between consenting adults; and (ii) in jurisdictions that currently lack such antidiscrimination statutes, the legal prohibition of discrimination against people who engage in private consensual homosexual acts.

There would be strong moral arguments for these legal changes even in the absence of a major epidemic (*24–27*). However, in the midst of an epidemic that has already affected large numbers of homosexual and bisexual men, the following additional arguments can be advanced. First, decriminalization and antidiscrimination initiatives would encourage homosexual and bisexual males to disclose their patterns of sexual activity to health providers and hospitals without fear that a breach of confidentiality could lead to criminal prosecution. Such open disclosure could, in turn, lead to the discussion of risk-reducing practices such as the use of condoms or the avoidance of anal intercourse. Second, the legal changes could facilitate the gathering of more accurate data on current patterns of sexual activity in the United States—patterns that have not been studied in depth since the research of Alfred Kinsey and associates in the 1940s (*28*). By reducing respondents' fears about being stigmatized, the proposed legal changes could enhance the accuracy of data that would then be used for educational and epidemiological purposes. Third, the proposed legal changes would send a clear signal to homosexuals and bisexuals that heterosexuals intend to treat them with what Ronald Dworkin has termed "equal concern and respect" (*29*). More specifically, these policies would help all of us, regardless of sexual orientation or pattern of sexual practice, jointly to reassess whether the magnitude of our national effort to control the current epidemic has been proportionate to the gravity of the threat posed by the epidemic.

Testing and screening programs. The moral and legal justification for testing individuals or screening populations for antibody to HIV has been extensively debated (*8*, pp. 112–130; *15*, chap. 2; *30–35*). James Childress has proposed a helpful taxonomy of screening programs (*31*):

Extent of screening	Degree of voluntariness	
	Voluntary	Compulsory
Universal	1	2
Selective	3	4

A recent amendment to the voluntary category in this matrix is "routine" counseling and testing, which is defined in Public Health Service guidelines as "a policy to provide these services to all clients after informing them that testing will be done." The Public Health Service guidelines add that, "Except where testing is required by law, individuals have the right to decline to be tested without being denied health care or other services" (*34*).

There is scant justification and little public support for universal HIV antibody screening programs, whether voluntary or compulsory. The principal arguments against such programs are consequential. The usual screening test has poor predictive value in populations where the prevalence of seropositivity is low; thus, large numbers of people who are in fact antibody-negative would be falsely identified as positive during initial screening (*36*). Further, the cost of universal screening would be high, especially given the fact that screening would need to be repeated at regular intervals to track changes in antibody status. In short, universal screening is incompatible with the principle of beneficence. Mandatory universal screening would involve a massive violation of the respect for autonomy principle, as well.

The crux of the current debate is whether selective screening for HIV antibody should be undertaken and, if so, whether the screening should be compulsory or voluntary. To date, most commentators on the ethics of HIV antibody screening have argued that only carefully targeted, voluntary screening programs are morally justifiable and that such programs are morally justified only if they fulfill three conditions: (i) the programs include adequate counseling of screenees; (ii) they protect the confidentiality of information about individuals, except in carefully specified exceptional circumstances; and (iii) they are conducted in a context that provides guarantees of nondiscrimination to seropositive individuals (*30–34*). Categories of persons often nominated for selective, voluntary screening programs include hemophiliacs, IV drug users, homosexual and bisexual men, prostitutes, patients at clinics for sexually transmitted diseases, heterosexual sexual partners of infected persons, prisoners, military recruits and personnel, applicants for marriage licenses, and hospital patients, especially patients undergoing surgery or hemodialysis.

It is not possible here to discuss each of these population groups (*37*). I will, however, comment on the three conditions for ethically acceptable voluntary screening programs. The provision of face-to-face counseling to all persons participating in a large-scale, voluntary screening program may be infeasible on financial grounds. Thus, it might at first glance seem reasonable to reserve counseling for screenees who are confirmed to be HIV antibody positive. However, if voluntary screening programs are targeted to selected groups with much higher than average prevalence, then the screening context would seem an ideal setting for carefully tailored education regarding risk reduction. Such counseling demonstrates a program's respect for the autonomy of screenees and should help to slow the progress of the epidemic, as well.

The protection of patient confidentiality in all but carefully delineated circumstances also demonstrates respect for the autonomy of screenees (*15*, chap. 4; *38*). Guarantees of confidentiality can be strengthened by statutes that impose criminal sanctions for unauthorized, medically nonindicated disclosure of antibody status. At the same time, however, guarantees of confidentiality should not be absolute. Several commentators have argued, for example, that health care providers have a moral duty to warn known intimate associates of an antibody-positive person who refuses to inform the associates of his or her antibody status and who continues to place those associates at risk (*31, 32, 34, 39*). In this case, the health care provider cannot simultaneously respect the autonomy of both the screenee and the associates.

The level of participation in voluntary screening programs is likely to be higher if legal guarantees against discrimination are provided to antibody-positive persons (*15*, chap. 5; *40*, pp. 347–350; *41*). These guarantees would complement the general guarantees of nondiscrimination discussed above. One formulation of such a guarantee in a major federal bill reads as follows:

> A person may not discriminate against an otherwise qualified individual in employment, housing, public accommodations, or governmental services solely by reason of the fact that such individual is, or is regarded as being, infected with the etiologic agent for acquired immune deficiency syndrome (*42*).

In a democratic society, the presumption should be in favor of voluntary rather than mandatory public health programs. This presumption should be overridden only as a last resort, after voluntary alternatives have been vigorously employed and have

failed, and only if there is a reasonable hope that a mandatory program would succeed (*43*). In my judgment, voluntary screening programs that include adequate counseling and appropriate guarantees of confidentiality and nondiscrimination have not yet received a sufficient trial in the United States. Such screening programs, coupled with anonymous testing for those who desire it and with the other public health strategies outlined above, offer us a reasonable hope of bringing the AIDS epidemic under control. Thus, I conclude that mandatory screening programs—other than those involving persons who voluntarily donate blood, semen, or organs—are not morally justifiable at this time (*44*).

Policies for the Delivery of Health Care

Even as public health efforts to prevent the further spread of HIV infection proceed, some of the approximately 1.5 million already-infected people in the United States will experience initial symptoms, become ill, develop full-blown AIDS, or die. As of 7 December 1987, 47,436 infected adults and 703 infected children had been diagnosed as having clinical AIDS; 26,816 (60.3%) of the adults and 419 (59.6%) of the children had died (*5*). HIV infection produces a broad clinical spectrum that includes, at its extremes, asymptomatic status and terminal illness. The health care delivery issue is currently focused on people who are symptomatic as a result of HIV infection and who know that they are infected with HIV. Increasingly, however, people at risk for HIV infection are likely to call on the health care system for help in clarifying their antibody status. Further, the health care system may be able to offer medical interventions to asymptomatic infected people that will prevent, or at least delay, some of the possible sequelae of HIV infection (*45*).

The duty to provide care. This issue can be considered at two levels: the level of the individual health care worker and the level of health-related institutions and the health care system.

Surveys of attitudes toward caring for AIDS patients in one high-prevalence area have revealed considerable anxiety among physicians and nurses. A study conducted at four New York residency programs in 1986 noted that 36% of medical house officers and 17% of pediatric house officers reported needlestick exposure to the blood of AIDS patients. Twenty-five percent of respondents indicated that they "would not continue to care for AIDS patients if given a choice" (*46*). A 1984 survey of nurses at the Westchester (New York) County Hospital found that 39% would ask for a transfer if they had to care for AIDS patients on a regular basis (*47*).

Studies suggest that the probability of infection transmission from patient to health care worker is very low. Yet ten reasonably well-documented cases of seroconversion in health care workers have been reported, with six of these workers having been exposed by accidental needlesticks and the remainder by exposure of the eyes, mouth, or hands and arms to infectious body fluids (*48, 49*). HIV seems to be much less infectious than the hepatitis B virus. Yet this comparison is not entirely pertinent; hepatitis B is not usually a lethal disease, and an effective vaccine against the disease is available. Thus, there remains a very small but nonetheless real probability that health care workers will acquire HIV infection from the blood or other body fluids of people with HIV infection. In an unknown proportion of these workers, the infection will have lethal consequences.

Despite these attitudes and risks, it might seem at first blush that the ethical obligation of health care workers to care for people with HIV infection is clear. The words "profession" and "professional" leap readily to mind, as do images of real or fictional heroines and heroes such as Florence Nightingale, Benjamin Rush, or Bernard Rieux (*50*). Yet the scope of the term health care worker is broad and includes the medical technologist, the phlebotomist, and the person who transports infective waste to the incinerator. Further, the basis for and the extent of the health care worker's obligation to provide care for patients are matters of dispute—despite several vigorous reassertions of the physician's moral duty to treat people with HIV infection (*51*).

A reasonable ethic for health care workers will not require of them heroic self-sacrifice or works of supererogation. Such a requirement would violate both the principles of autonomy and beneficence. On the other hand, a reasonable ethic will not allow people who are in need of care to be refused treatment or abandoned solely because they are infectious. Such refusal and abandonment would violate the principle of beneficence. Universal infection-control precautions such as those suggested by the Centers for Disease Control (CDC) (*49*) are likely to reduce substantially the risks to health care workers; thus, heroic self-sacrifice will not be required. If these measures are insufficient in certain high-risk settings, or if the universal precautions seriously impede patient care, testing of selected categories of patients, for example, surgical patients, may be justifiable. This testing should be carried out only with the prior knowledge and consent of patients and should include counseling for seropositive persons. Patients who decline testing will be presumed to be antibody-positive. Testing measures will seem less threatening to patients when carried out in a social context that respects confidentiality and opposes discrimination.

At the level of health care institutions and the health care system, the AIDS epidemic has exacerbated already existing problems regarding access to health care. The access problems faced by people with AIDS or HIV infection do not differ qualitatively from those faced by many other U.S. citizens with chronic or terminal illness. However, because people with HIV infection are almost always under 65 years of age, their health care needs graphically illustrate major deficiencies in the current U.S. system for providing health care to the nonelderly.

Even before the AIDS epidemic became a major factor in health care financing, it was almost commonplace to assert that 15 to 17.5% of U.S. residents under age 65 lack both public and private health insurance. These percentages translate into 30 to 35 million Americans (*52*). An additional 10 to 15% of these under age 65 who are insured are not adequately protected against chronic or catastrophic illness (*53*). Of the 150 million Americans under 65 who are privately insured, at least 80% have their health insurance tied to group plans at their place of employment (*54*).

People with HIV infection who are currently employed and who have group health insurance coverage through their employers are in the best position to cope with the medical costs that may result from their infection. However, even for these most well-off people a double threat looms. If they become so ill that they can no longer continue employment, they face the prospect of losing both their source of income and their group health insurance coverage. Although federal legislation enacted in 1985 provides for continuing individual health insurance coverage for 18 months after the termination of employment, the cost of such coverage may be prohibitive for an unemployed person. Other people with HIV infection who become symptomatic—the underinsured, the uninsured, and the unemployed—are likely to rely on Medicaid for assistance, if they can meet complex eligibility requirements. Actuaries from the Health Care Financing Administration estimate that 40% of patients with clinical AIDS are assisted by Medicaid with their direct medical care expenses and that an average of 23% of such expenses are borne by Medicaid. In fiscal year 1987 federal and state Medicaid expenditures for AIDS patients were estimated at $400 million (*15*, p. 6-5).

The future looks bleak, both in terms of costs and in terms of

shortages of needed services for chronically and terminally ill patients. In the cost projections made to date, the estimates of personal medical costs for AIDS patients alone in 1991 range from a low of $3.5 billion to a high of $9.4 billion (in 1984 dollars) (*55*). Already in 1988, there are shortages of nursing home facilities, home care programs, hospice facilities, and counseling services for clinically ill people with HIV infection (*8*, chap. 5; *10*, pp. 19–21; *15*, chaps. 6 and 8).

Divergent views exist about the appropriate role of the private sector in the provision of health care to people infected with HIV, as well as to other people with health care needs (*8*, pp. 162–173; *56*). What is clear, however, is that we as a society cannot expect private hospitals and nursing homes to operate at a loss. Nor can we expect private health insurers or self-insuring employers to ignore the financial impact of an unanticipated epidemic.

The central ethical question confronting the U.S. health care system was evident long before HIV was discovered or named. That question is: Does our society have a moral obligation to provide some level of health care to every one of its members? Several commentators on the ethics of health care allocation have argued that our society does have such an obligation (*57*). They have based their argument on the principles of beneficence (the unpredictability of health care needs and the harms caused by lack of access) and justice (the inequities that result from current differentials in access). They assert that the principle of respect for autonomy must take second place, as those of us who are financially well off are called upon to share in meeting the needs of the less well off, presumably through the payment of increased premiums and taxes.

This judgment seems to me to be correct. If so, the major policy question is no longer whether we should attempt to meet the needs of the medically less well off. Rather, we should address the questions "What constitutes a basic level of care?" and "How can this level best be provided to everyone, including people infected with HIV?"

Neurological involvement and consent to care. An unknown proportion of people with HIV infection experience involvement of the central nervous system, including the brain (*58*). Indeed, the CDC has recently expanded the clinical definition of AIDS to include such neurological complications (*59*). The extent of neurological involvement may range from minor symptoms of cognitive impairment to totally disabling dementia.

Brain involvement resulting from HIV infection, like brain involvement due to other causes, inevitably complicates the relation between patient and health provider. Two methods of extending patient autonomy forward in time have proved helpful in other health care settings and may also be beneficial in the treatment of HIV-infected patients with early symptoms of neurological deterioration. Advance directives about preferred modes of care or nontreatment are now expressly recognized by the statutes of 38 states and the District of Columbia (*60*). In addition, 18 states make legal provision for a patient's appointment of a spokesperson with durable power of attorney, who can express the patient's wishes if the patient should become incapacitated or be adjudged legally incompetent (*61*). The patient's spokesperson is usually a trusted friend or family member. Both modes of anticipatory decision-making were strongly endorsed by the President's Commission on Bioethics in 1983 (*62*) and both seem well adapted to the needs of HIV-infected patients with neurological symptoms (*63*).

The care of dying AIDS patients. When treatment fails and death within a few months becomes inevitable, people with AIDS deserve compassion and support. Individual patient preferences vary, but many terminally ill patients have expressed a desire to die at home in the company of friends or in a hospice-like institutional setting. These alternatives should be provided by an upgraded system of care for all terminally ill patients.

A central role in patient management should be played by the patient's own directives and, if the patient becomes mentally incapacitated, by the patient-designated proxy. If at all possible, future decisions about resuscitation and the use of artificial nutrition and hydration measures should be explicitly discussed with the competent AIDS patient (*64*). Like other terminally ill patients who face the probability of severe physical deterioration and the possibility of a painful death, some AIDS patients will also want to discuss the options of suicide or voluntary active euthanasia. Both of these topics have received intensive study, especially in the Netherlands, the United Kingdom, and the United States (*65*). Respect for the autonomy of terminally ill patients would seem to require us to place these difficult issues on the agenda for sustained local and national discussion.

Research Policies

In the long term, the best hope for controlling the AIDS epidemic lies in biomedical research. A vaccine against HIV would seem to be the ideal solution but if immunization strategies prove to be infeasible, chemoprophylactic measures may succeed. For people already infected with HIV, new interventions are under development, but progress has been slow. Epidemiological, social-scientific, educational, and social-intervention studies will also be key elements in an overall research strategy.

A general question that has been raised about the U.S. research effort is whether it has been proportionate to the gravity of the threat posed by the current epidemic. A 1986 report from the Institute of Medicine and the National Academy of Sciences concluded that at that time the response was inadequate (*8*, pp. 28 and 238–249). A less than adequate response to the epidemic violates both the principle of beneficence and the principle of justice. It fails to prevent avoidable harm to thousands if not millions of people, and it conveys the impression that policy-makers do not care about the welfare of the groups most at risk. Even in the best of times, members of several groups at increased risk for HIV infection experience neglect or even stigmatization by many of their fellow-citizens. These are not the best of times.

Clinical trials of various treatments are being conducted in asymptomatic and symptomatic people with HIV infection as well as in patients with clinical AIDS. The usual practice in early trials is to use a placebo-controlled design with each subgroup of people until an effective therapy for that group is discovered. When the efficacy of an agent has been demonstrated, placebos are no longer given; rather, various dosages of the effective agent are compared, or a new candidate therapy is compared against the older, effective therapy.

Some critics have questioned whether it is ethical to conduct placebo-controlled trials with HIV-infected patients. Some have suggested that all symptomatic people with HIV infection should be given immediate access to potentially promising therapies that have not been validated in randomized controlled trials (*66*). Here one can, in my view, make a justice-based argument for subjecting potential treatments for HIV infection to the same kind of rigorous study that other new treatments must undergo. Further, from the perspective of beneficence, unnecessary suffering would be visited on people with HIV infection if they were provided immediate access to ineffective "therapies" or treatments with toxic effects that far outweigh their therapeutic benefits.

The testing of vaccines for the prevention of HIV infection will also raise important ethical questions. For example, it will be necessary for uninfected volunteers to be exposed to inoculations

that will make them antibody-positive by ELISA and Western blot tests. Further, research subjects who participate in unsuccessful vaccine trials may thereby be made more susceptible to HIV or other infections than they would have been had they not taken part in the trials. Equally disturbing is the possibility that some subjects, having received an ineffective vaccine, may be rendered incapable of being immunized by subsequently developed effective vaccines. Because the numbers of participants in early trials may reach into the thousands or tens of thousands, they could constitute a serious additional public health problem for society.

The risks associated with vaccine trials have prompted some researchers to consider testing vaccines against HIV in countries of equatorial Africa, where the prevalence of infection is known to be higher than in the United States and where the number of trial participants could therefore be lower. In addition, the risk of litigation for research-related injury might be reduced in a non-U.S. setting. However, the proposal to export research risks raises questions of fairness in its own right.

Partial solutions to the ethical quandaries presented by vaccine trials can be found in policies that exemplify the principles of respect for autonomy, beneficence, and justice. The autonomy of participants in vaccine trials will be respected if they are warned clearly and in advance of the potential physical and social harms to which they will be exposed. The careful planning and foresight of researchers can also reduce the harms associated with vaccine-induced seropositivity. For example, in a vaccine trial sponsored by the National Institutes of Health, volunteers will be provided with official documentation certifying that their antibody status had been negative before they participated in a vaccine trial (*67*). Nonetheless, if participants in vaccine trials are injured as a result of their participation, they may have a legitimate claim to compensation for disabilities incurred in a publicly declared war on a major disease. Indeed, the principle of justice may require the establishment of a compensation program for research-related injuries (*8*, pp. 228–229; *68*).

Other types of research. Epidemiologic research will provide a scientific basis for policies in public health and health care delivery. Longitudinal studies among members of at-risk groups will help to clarify the natural history of HIV infection and the role of cofactors in the development of clinical symptoms. Homosexual and bisexual men, in particular, have been active participants in published longitudinal studies (*23, 69*). Cross-sectional studies of demographic groups—newborn infants, patients in "sentinel" hospitals, and residents in selected metropolitan areas—will facilitate more refined estimates of the number of people infected with HIV (*70*). One of the major ethical questions in cross-sectional studies has been whether to retain the identifying links between blood samples and the individuals from whom the samples were taken. Anonymous, unlinked testing without consent seems to be emerging as the method of choice, in part because a recent interview survey indicated a likely refusal rate of about 30% among adult Americans if they were invited to be tested in a national seroprevalence study (*71*). The advantages of anonymous epidemiologic studies are that no identifiable subjects are placed at risk and that the research results are not skewed by refusals. The disadvantage is that seropositive individuals cannot be identified, notified, and counseled.

Other types of research can also play important roles in understanding and coping with the current epidemic. Social science and behavioral research will help to elucidate such questions as the extent of homosexual sexual activity among U.S. adults—a topic that has not been studied in large, rigorously selected samples since the 1940s. Educational research will assist public health officials and counselors in communicating more effectively about lifesaving alternatives in the most intimate realms of human behavior (*8*, pp. 230–238; *72*). Finally, social-intervention research can provide public policy-makers with essential information about the effects of innovative approaches to social practices such as IV drug use and prostitution (*73*).

Conclusion

At the beginning of this article I mentioned three ethical principles that are thought to be of central importance in contemporary biomedical ethics: beneficence, justice, and respect for autonomy. These principles have informed the preceding analysis. However, as I have reflected on the complexities of the current epidemic, it has occurred to me that a fourth ethical principle may be required to guide our actions and policies in response to this major threat to the public health. I do not have a precise name for this additional principle, but I will venture to suggest some first approximations: mutuality, solidarity, or community (*74*).

REFERENCES AND NOTES

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74. I thank M. Stanley and C. Williams for assistance in manuscript preparation and E. Meslin, S. Meinke, P. M. McCarrick for bibliographic assistance. I also thank the following people for helpful comments: L. B. Andrews, T. L. Beauchamp, J. F. Childress, R. M. Cook-Deegan, M. A. G. Cutter, B. M. Dickens, R. R. Faden, E. Locke, A. R. Jonsen, C. R. McCarthy, E. Meslin, J. Porter, E. E. Shelp, R. M. Veatch, and three anonymous reviewers for *Science*. This article is dedicated with gratitude to Jane M. Walters, my wife, who died on 15 January 1988 after open heart surgery.