

AIDS: Social, Legal, and Ethical Issues of the "Third Epidemic"

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The "first" and "second" epidemics of AIDS are considered to be the spread of HIV infection and subsequent development of AIDS cases; what has been termed the "third epidemic" is the widespread economic, social, and cultural reaction to the disease, raising crucial social, humanitarian, and legal issues. This article deals with four questions arising from these issues: (1) What is the best public health approach to people with HIV/AIDS, and what rights should they have? (2) Who should be subjected to mandatory testing? (3) Who has a right to know or be warned if someone has HIV/AIDS? and (4) How can society be protected against people who irresponsibly or deliberately set out to infect others? It is concluded that, as recommended by the World Health Organization, policies which balance concern for public health with respect for individual rights are both the most humane and the most effective ways to control the spread of AIDS.

A nurse in the United States was told she had tested seropositive for the human immunodeficiency virus (HIV) after working on the ward with AIDS patients. She has told her story throughout the country: how she changed her life, and how her life changed. She stopped having any physical contact with her husband or children—she wouldn't even kiss them. She became excessively concerned with personal hygiene and used a separate set of dishes. She found her co-workers, all very sympathetic to her, were wary of working with her in the hospital. Her neighbors treated her with special caution and exaggerated courtesy. She was depressed and angry and very fearful. Her story has a happy ending. She was a false positive. She was not infected. The numerous tests had been wrong. But she has used her experience to educate—the public, health workers,

anyone she can reach—about what it might feel like to be infected with HIV. (In addition, living in the litigious United States, at last report she was considering suing the laboratories that had identified her as seropositive.)

This nurse's experience is not unique. AIDS is now found throughout the world. It is a justifiably frightening disease, appearing invariably fatal. We are all afraid of AIDS, just as we are all afraid of cancer. But, unlike cancer, we can get AIDS from other people. It is a contagious disease in a generation that, at least in the developed world, has become accustomed to living without fear of death from contagion. It is merely human nature, then, to fear contact with a person who might be a "carrier" of this disease.

This fear leads to what Dr. Jonathan Mann, Director of the World Health Organization (WHO) Global Program on AIDS, has termed the "third epidemic":

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The third epidemic closely follows the first two, of HIV infection and AIDS. It is the epidemic of economic, social, political, and

cultural reaction. In the words of Javier Pérez de Cuéllar, Secretary-General of the United Nations, "AIDS raises crucial social, humanitarian, and legal issues, threatening to undermine the fabric of tolerance and understanding upon which our societies function." (1)

This article discusses a few of the more critical social, legal, and ethical issues raised by AIDS. Clearly, however, it is impossible to cover all such issues in a brief article, or to truly analyze the substantial moral questions, about which much has been written by sensitive experts. With this apology for cursory treatment, we will cover essentially the following questions:

1. What is the best public health approach to people with HIV infection and AIDS? What rights should they have?
2. Who should be tested for AIDS on a mandatory basis?
3. Who has the right to know if someone has HIV infection or AIDS? Is there a duty to warn?
4. How can society be protected against people who irresponsibly, perhaps even deliberately, set out to infect others?

All of these questions involve essentially the same analysis. First, where do we draw the line between the rights of the individual and the rights of society? Second, how do we balance those interests? Third, what is the best way to protect individuals at risk and society as a whole against the spread of AIDS? And fourth, what relevant scientific evidence exists regarding transmission, prognosis, treatment, testing, behavior modification, counseling, education, and information transfer?—for ultimately it is science that must determine policy and therefore law.

All these considerations are extremely critical in the case of HIV infection and AIDS, where the scientific evidence points to spread from intimate behavior censured by most societies (homosexual contact, intravenous drug abuse, extensive heterosexual contact). The level of social tolerance or disapproval varies widely from country to country, and every nation also has different traditions governing the strength of individual rights versus those of society at large. There are some absolutes accepted throughout the world, enshrined in human rights conventions and declarations. But those texts leave a lot of room for interpretation. The job of WHO is to define those absolutes from the public health perspective, to elucidate the best way of protecting public health from a scientific standpoint. That is the subject of this paper.

QUESTION 1

What is the best public health approach to people with HIV infection and AIDS? What rights should they have? The best way to protect the health of all the people is to allow people with HIV infection and AIDS to live normal lives to the extent their health permits. Discrimination and stigmatization will hurt, not help, the general public as well as those infected.

The third epidemic has led to some truly horrifying abuses. Adults and children only suspected of being HIV-positive have been denied housing, schooling, employment, and even burial. Health care workers have refused to treat them. Even in the most theoretically enlightened societies, fear has led to hysteria. The home of two hemophiliac boys was burned when they tried to enroll in the local school. Employees have been summarily dismissed. Insurance companies have refused to issue insurance poli-

cies to men living in areas known for homosexual activity. Landlords have evicted tenants who have tested seropositive.

Sometimes these abuses have occurred even though local law made them illegal. In many countries, laws and court precedents prohibit discrimination on the basis of handicap or illness (although few or none of those laws specifically bar discrimination for HIV infection or AIDS). Freedom from discrimination on the basis of handicap is deemed a fundamental human right. Worldwide, this has become the modern view.

International human rights conventions and declarations, which set the standards for human rights around the world, were adopted before it became clear that discrimination based on handicap or illness should be made clearly and specifically illegal. Yet the underlying theory of human rights is that no one should be treated unfairly or unequally because of race, religion, national origin, or *other status* unrelated to qualifications or actions. This sentiment, so strongly held in the modern world, applies to HIV infection and AIDS.

The World Health Organization has taken a very strong stand on this, even though human rights (while implicit in the very *raison d'être* of the international public health agency) do not usually command explicit WHO attention. This strong WHO concern for the right to be free of discrimination is based on more than a general preference for human rights. Experience around the world has shown that the only way to combat an escalated spread of HIV infection depends on public cooperation. Risky behavior must change—particularly risky behavior by people already infected. The changes in behavior involve intimate moments, and there is no way that society can *force* “safe sex” practices without applying unthinkable draconian measures.

(Even the draconian measure of quarantine cannot ensure risk-free behavior.) Moreover, AIDS is an illness, not a punishment or a crime.

WHO experts in public health, epidemiology, infectious diseases, health education, and disease prevention—as well as in law, psychology, and sociology—have exhaustively reviewed the potential policies for preventing and controlling AIDS. These experts have been assembled from every type of culture and from countries in all stages of development. Their reports have been debated in worldwide meetings. The essentially universal conclusion has been that respect for human rights is more than a humane approach, it is the only approach capable of effectively combating AIDS.

The reason is plain enough. If people at risk fear losing their jobs, housing, schooling, and participation in normal activities, besides eventually losing their lives, they will not come forward for testing and counseling. Nor will they be reachable by the public health authorities, who will be unable to warn others of potential exposure through blood transfusions or intimate activity. This is the main public health reason for avoiding discrimination and stigmatization. Fortunately, this conclusion coincides with promises made by virtually all the world's countries to respect individual human rights and to treat all people equally, regardless of status.

WHO's initial position against discrimination was affirmed by the World Summit of Ministers of Health on Programs for AIDS Prevention that was held in London early in 1988 (see pp. 234–236 in this issue). There, delegates from 148 countries representing the vast majority of the world's people declared that “We emphasize the need in AIDS prevention programs to protect human rights and human dignity. Discrimination against, and stigmatization of, HIV-infected peo-

ple and people with AIDS and population groups undermine public health and must be avoided" (2).

The World Health Assembly, the prime WHO governing body comprised of representatives of all the WHO Member States, issued a resolution at its 1988 session that was similarly strong and explicit:

The Forty-first World Health Assembly . . . strongly convinced that respect for human rights and dignity of HIV-infected people and people with AIDS, and of members of population groups, is vital to the success of national AIDS prevention and control programs and of the global strategy:

Urges Member States, particularly in devising and carrying out national programs for the prevention and control of HIV infection and AIDS:

1. To foster a spirit of understanding and compassion for HIV-infected people and people with AIDS through information, education, and social support programs;
2. To protect the human rights and dignity of HIV-infected people and people with AIDS and of members of population groups, and to avoid discriminatory action against and stigmatization of them in the provision of services, employment, and travel;
3. To ensure the confidentiality of HIV testing and to promote the availability of confidential counseling and other support services to HIV-infected people and people with AIDS; . . .

The resolution asks the WHO Director-General to take all measures necessary to advocate the need for this respect for human rights, to cooperate with other relevant organizations in fostering this respect, and to stress to Member States and others "the dangers to the health of everyone of discriminatory action against and stigmatization of HIV-infected people and people with AIDS and members

of population groups." The Director-General is also asked to report annually to the World Health Assembly, starting in May 1989, regarding implementation of the resolution, which means that all countries of the world will be asked to report their social responses regarding AIDS to WHO (3). This resolution represents the most comprehensive and official policy statement possible within the constitutional framework of the World Health Organization.

In July 1988, WHO and the International Labor Organization convened a three-day expert Consultation on AIDS in the Workplace. At this meeting, 36 medical, public health, labor, government, union, and business representatives from 18 countries concluded that "workers with HIV infection who are healthy should be treated the same as any other workers," and that "a worker with HIV-related illness, including AIDS, should be treated like any other worker with an illness." They also stressed the need to avoid discrimination, to educate workers and their families about HIV and AIDS, to provide social security and occupation-related benefits for HIV-infected employees, to provide reasonable alternative working arrangements if a worker's fitness is impaired by HIV-related illness, and to avoid holding HIV infection as a reason for termination of employment (4).

The reason for the importance of this benign policy is that most people with HIV are between the ages of 18 and 45. They are in their economically productive years. They, their families, and society expect them to be financially independent if they are not in school. Losing the ability to hold a job is devastating in almost every society, akin to losing one's life. And speaking realistically, few alternative means of support exist. Few nations have a social security system strong enough to cover people who, although

they have latent disease, may be perfectly able to work for as long as eight to 10 years before they become ill. Moreover, in some countries the prevalence of AIDS is disproportionately high among the most educated young people, whose services the nation can ill afford to lose. Finally, and most crucially, if people know that revelation of HIV infection means job loss, not even those at risk will seek testing, counseling, or information about how to avoid infecting others. Nor will they identify others who should be warned and who may also be infected and spreading the disease.

Regarding pediatric cases, PAHO's 1988 AIDS guidelines state that "children who are infected with HIV should not, in general, be removed from the school system. In special circumstances (poor personal hygiene, behavioral disorders, etc.) an individual decision for attendance should be made by the parents and school medical authorities" (5).

The basic point that bears repeating is as follows: To discriminate against or punish those with HIV or AIDS is bad policy. Besides contravening basic human rights, it seems likely to promote the spread of AIDS.

QUESTION 2

Who should be tested for AIDS on a mandatory basis? The spread of AIDS will not be prevented by mandatory testing of any group, except for blood/tissue/organ donors, but extensive voluntary testing of certain high-risk groups may be justified as a public health measure.

WHO has defined the term "HIV antibody testing or screening" as follows:

Testing is defined as a serologic procedure for detecting HIV antibody (or antigen) from an individual person, whether recommended by a health care provider or requested by an individual.

Screening is defined operationally as the systematic application of HIV testing, whether voluntary or mandatory, to any or all of the following: entire populations; selected target populations; donors of blood/blood products and cells/tissues/organs (6).

Testing may be entirely voluntary, mandatory (necessary for a benefit or service that the individual has voluntarily requested, though the person can theoretically refuse testing by refusing the benefit or service), or compulsory (required by law regardless of the individual's desire). The line between mandatory and compulsory testing may be illusory in some circumstances (for example, in the case of required premarital testing). Generally, the term "mandatory" as used here will refer to both mandatory and compulsory testing.

The tests generally available as of this writing do not actually detect the HIV virus itself. Rather, they assess the immunologic response by detecting the presence of certain antibodies in the blood. Therefore, there is a "window" of uncertain duration (probably about six months) when the person tested may already be infected, may be able to spread the infection, but will not test positive for the infection. This fact is critical. A seronegative result does not necessarily mean seronegativity.

Besides leaving this window open, the test itself is not always accurate. (Lack of total accuracy is inherent in any laboratory test of this nature.) For that reason, if an initial ELISA test is positive for the presence of HIV antibody, it is recommended in nearly all circumstances that a second ELISA test, followed by a Western blot test, be performed to confirm the subject's seropositivity. While the ELISA tests are generally not costly, the Western blot test is labor-intensive and quite a lot more expensive; but the multiple tests will only be performed if the first test is positive.

Clearly, some truly infected people will be missed because of the window, while others will be missed because they yield false negative results on the first test. The degree of test sensitivity—100% sensitivity means that all true positives are identified—is over 99%; but if a large population is tested, even one false negative result in every hundred tests can add up to a substantial number.

By the same token, the degree of test specificity—100% specificity means that all true negatives are identified—while approaching 99%, will still lead to a number of false positive results (which could lead to the needless sort of devastation suffered by the nurse). False positives become more likely in a low-risk population. Thus, the test cannot guarantee total accuracy, even if correctly done, although it is extremely reliable. (Obviously, if laboratory standards are deficient, the test becomes far less reliable.)

Although other more reliable tests that do test for presence of the virus have been developed, they are quite expensive and are not yet readily available on the international market. Thus, the basic assumption of the WHO recommendations to date on testing and screening is that the HIV antibody test will be performed, leaving the window open to false negative results and recognizing the uncertainties inherent in tests that cannot guarantee 100% sensitivity or specificity. Here the dependence of law and policy on science is clear. If a more accurate test were developed, and if treatment were available, the recommendations might be different.

Are there any circumstances requiring mandatory testing? One answer is obvious. If the state's duty to protect the public health has any meaning at all, governments must seek to insure that the supply of *blood and blood products*, so necessary to modern medicine in every country, is free of disease. Hence, purifi-

cation of the blood supply is a cornerstone of any AIDS prevention program.

In 1987 the World Health Assembly, in endorsing the Global Program on AIDS, reiterated that "information and education on the modes of transmission, as well as the availability and use of safe blood and blood products, and sterile practices in invasive procedures, are still the only measures available that can limit the further spread of AIDS" (7).

Purification of the blood supply is customarily accomplished in two ways: by questioning the donor about high-risk behavior, and by testing the blood units after donation. Many countries have already enacted legislation to require HIV testing (for HIV-1 and/or HIV-2, depending on the nature of the local infection) of all donated blood. At least one country has closed its private blood banks, which had paid donors, because of higher HIV infection rates. Some jurisdictions have closed certain collecting centers for lack of conformity to required testing procedures. Such measures are clearly the most effective. But other countries have not had the means to test all blood units; their laws may only require questioning of donors, or may make it a criminal act to donate blood that is HIV-infected or that comes from a person who has engaged in high-risk behavior. These latter approaches are obviously less effective.

Similar danger to public health is posed by donation of other potentially infected body fluids, tissues, or organs. Where such material is collected, HIV antibody screening is essential, and some countries have already enacted legislation to require it. Fear of infection from such products can be widespread: The director of one respected center for artificial insemination in the United States noted that the first question posed by 90% of the potential recipients was "Have you tested for AIDS?" (8)

Any blood or tissue screening program

(as well as any other testing program) must deal with two ethical issues relating to the very basic human right to privacy, issues intrinsically tied to the traditional ethics of the Hippocratic oath. These issues involve *informed consent* and *confidentiality*.

Informed consent means that the patient's right to bodily integrity and personal dignity are recognized: Every person has the basic right to make the decisions about his or her body; and so every person ordinarily has the right to refuse to take a medical test. As with all personal rights, however, this right can only be exercised while respecting the rights of others. In the case of blood donation, the respect for others' rights clearly outweighs the individual's normal right to refuse testing. But the principle of informed consent should nevertheless be followed. That is, the potential donor has the right to know (1) that an HIV antibody test will be performed on the donated blood, (2) whether he or she will be told of the results, (3) who else will be informed of the results, and (4) what the results mean.

The second ethical principle is the need to ensure confidentiality. The trust between physician and patient has been sanctified for thousands of years. It is a basic tenet of the doctor-patient relationship. The need for confidentiality is particularly acute in the case of HIV infection and AIDS, because of the unfortunate fear, discrimination, and stigmatization that may ensue. If the results may not be kept confidential, how likely are people to volunteer for testing, and how likely are they to voluntarily donate the blood needed to save lives?

Confidentiality can be ensured in either of two ways. One way is to keep the testing "unlinked," so that the donor is not identified in any way. A blood unit that tests positive for infection is simply discarded, without knowledge of the do-

nor's identity. Alternatively, the testing can be anonymous, as is customary with most laboratory samples. That is, a number is attached to the donated unit, but only a master list can match the number to the donor. The master list is carefully controlled, and the laboratory technicians and other personnel involved in the collection are unaware of the donor's identity.

The advantages and disadvantages of each procedure are fairly obvious. Unlinked testing is simple and ensures absolute confidentiality. Only an initial ELISA test need be performed, since a mere suggestion of positivity will be enough to justify discarding the donated unit. Unlinked testing thus serves the basic purpose of purifying the blood or tissue supply.

Confidential testing poses some risk of exposing the donor's identity. However, this type of confidential handling of blood samples has been practiced for years in most countries. Like unlinked testing, confidential testing purifies the blood supply, and it has one advantage over unlinked testing; that is, the donor who tests positive can be told and counseled, hopefully causing a link in the epidemiologic chain to be broken. There is also a growing belief that people have the right to know the test results, and that respect for people as individual human beings requires that they be told. In practical terms, the main disadvantages of such testing are that a second ELISA test, followed by a Western blot test, must be performed, and that manpower and time are needed to follow up on seropositive results.

WHO has not yet taken a position on whether unlinked or confidential testing should be undertaken. At present, confidential testing seems to be the norm in the developed countries.

Are there other situations in which mandatory testing is a justified public

health measure? Various societies have considered and even legislated requirements for testing such groups as military recruits, prisoners, prostitutes, homosexuals, airline pilots, international travelers, applicants for marriage licenses, all people admitted to hospitals, and all patients at clinics for sexually transmitted disease.

Besides helping to prevent HIV transmission through donated blood, semen, tissues, or organs, such programs can provide epidemiologic data on HIV incidence and prevalence. Despite these advantages, however, screening programs other than serosurveys to determine HIV prevalence appear advisable only in rare cases. In this vein, a WHO meeting of health experts that reviewed screening in 1987 concluded that:

HIV screening programs present broad problems beyond the simple recognition to infected individuals. Because of the extremely restricted modes of spread of HIV, the privacy of the behavior usually involved in transmission, and the current lack of any specific intervention, screening programs must be approached with great caution. Such programs may be intrusive and cost-ineffective, and may divert human, material, and financial resources from education programs that are acknowledged to be the primary and most effective preventive measure available (6).

In short, screening programs are expensive, unlikely to reveal all those infected, and cost-ineffective when applied to low-risk populations. Regarding this latter point, one populous state in the United States decided to require premarital screening. After screening many thousands of marriage applicants for 18 months, fewer than 10 cases of HIV infection were discovered. Where the population group to be screened is at high risk, the argument for screening may be slightly stronger; but screening should

still be considered more or less as a last resort.

WHO has convened consultations of experts to weigh the merits of screening certain groups considered for screening by various countries²—specifically international travelers, prisoners, high-risk groups, and special occupation groups. The WHO experts' recommendations for each of these were as follows:

International Travelers

The 1969 International Health Regulations of WHO, as amended, are designed to provide all the protections appropriate for containing the international spread of infectious diseases. Signatories to the International Regulations are not supposed to require any health documents not required by the regulations. These regulations have not been amended to include AIDS or HIV infection.

The WHO Consultation on International Travel came to conclusions markedly similar to those of the experts who reviewed screening in general. They said:

The diversion of resources towards HIV screening of international travelers and away from education programs, protection of the blood supply, and other measures to prevent parenteral and perinatal transmission will be difficult to justify in view of the epidemiologic, legal, economic, political, cultural, and ethical factors mitigating against adoption of such a policy. No

²References in this article to practices and laws adopted by various countries and jurisdictions are based on the excellent summaries prepared on a periodic basis by Mr. Sev Fluss of the WHO Health Legislation Unit entitled "Tabular Information on Legal Instruments Dealing with AIDS and HIV Infection, Part 1. Countries and Jurisdictions Other Than the USA," and "Part 2. United States of America (Including States and District of Columbia)." These summaries are available from WHO, Geneva.

screening program can *prevent* the introduction and spread of HIV infection. Therefore the consultation concludes that HIV screening programs for international travelers would, at best and at *great cost*, retard *only briefly* the dissemination of HIV globally and with respect to any particular country (9).

Nevertheless, a number of countries have adopted some form of HIV screening of international travelers, most commonly of foreigners who are seeking to enter the country as immigrants or for extensive periods of time as students or workers. Such screening has not prevented the spread of HIV into these countries.

One motive behind these screening laws has been a desire to avoid the cost of treating AIDS patients from outside the country. Long-standing precedents exist for refusing to allow long-term entry on medical grounds. One of the most sensible policies dealing with this question of costs has been adopted by the United Kingdom. Unlike other nations, the UK does not require an HIV certificate. Instead, the immigration officer has the discretionary authority to order an HIV test. The National Health System, offering free care to all UK residents, will require payment for certain services supplied to foreigners, including treatment for AIDS under this policy. Free health care to non-resident foreigners with AIDS will only cover testing and counseling. The immigration officer may also require proof of a person's ability to pay for other AIDS medical care before allowing entry into the country. Otherwise, the traveler's status with respect to HIV infection and AIDS symptoms will not influence his or her freedom to enter the country.

Prisoners

In some countries, prisoners are considered to be a high-risk group because of

homosexual practices within prisons and the high rate of prior intravenous drug abuse found in the prison population. Despite this, the World Health Organization Consultation on AIDS in Prisons concluded that mass involuntary screening of prisoners for HIV infection should not be recommended for the following reasons:

- Prison administrators have the duty to minimize AIDS transmission in prison.
- Prisoners should be treated with the same principles that apply to other HIV-infected persons—including education, testing, confidentiality, health services, and treatment.
- Discriminatory practices, including segregation or isolation, should be avoided, except when necessary to protect the prisoner's own well-being.
- Compassionate early release should be considered for prisoners with AIDS (10).

WHO has not collected any systematic information on the implementation of this recommendation, but it is evident that involuntary screening and segregation of HIV-infected prisoners has occurred in some countries.

High-Risk Behavior Groups

Who is at high risk in any country depends on the epidemiologic pattern prevailing there. Male homosexuals and bisexuals, intravenous drug abusers, their sex partners, and male and female prostitutes generally constitute high-risk behavior groups. Evidence is increasing that people with other sexually transmitted diseases may also be at higher risk, either due to underlying sexual behavior or to increased susceptibility to HIV in-

fection conferred by the sexually transmitted disease itself. Whether perinatal transmission places newborns at high risk depends almost entirely on the epidemiologic pattern found in the specific locality involved.

WHO has not taken a firm position on the screening of high-risk behavior groups, other than to point out the tests' lack of definitiveness; the ethical issues relating to confidentiality and informed consent; and the critical need to avoid diverting resources from the matters of primary concern: education and provision of a clean blood supply (11). Some countries, according to informal information, have adopted policies of screening certain high-risk behavior groups—especially prostitutes, pregnant partners of male bisexuals or intravenous drug abusers, and patients at clinics for sexually transmitted diseases.

Special Occupation Groups

Certain occupation groups have been singled out for HIV testing, either because of potential exposure to needlestick-type injuries or because they are directly responsible for the lives of many others. Higher-risk occupational categories are customarily considered to include health care workers, emergency workers (policemen and firemen), morticians, and people caring for infected infants, who may be extensively exposed to infected bodily fluids. Scientific evidence has shown clearly that the risk of needlestick-type injuries is extremely low. WHO has not taken a formal position on this issue, but is expected to hold a consultation jointly with the International Labor Organization on policies toward health care workers. Currently, extensive voluntary testing seems to have become the approach of choice.

The rationale behind proposals to screen the second occupational group—

primarily airline pilots and railroad engineers—is based on fear of the AIDS dementia complex, whose effects are still not clearly known. (These effects seem to be both cognitive and affective, potentially altering judgment and perception of spatial relations.)

The concern is that a pilot or engineer might be physically asymptomatic while suffering from neurologic damage that could result in harm to others. If this were remotely likely, it would justify testing. However, a WHO interdisciplinary consultative group has concluded that there is no evidence of judgment being affected in physically asymptomatic individuals (12). Hence, the usual periodic medical examinations required for licensing of pilots and engineers should suffice to discover early signs of HIV infection, and the public health judgment is that screening of these low-risk groups is unnecessary.

One other special low-risk group, military recruits and personnel, has been considered for mandatory screening. Two reasons are commonly given for such screening: military personnel must be free from any potential disability, and all military personnel are "walking blood banks." A number of countries have adopted this type of mandatory screening. WHO has not made any recommendation on screening military personnel.

The ethical issues involved in any screening program are essentially the same. Is there protection of confidentiality? Is the test as reliable as possible? Is the person notified of the results in a humane way and provided with education and counseling? Are the human and economic costs of the testing program far outweighed by the potential benefits to the tested person and to society? What are the consequences of false positive and negative results? Are those consequences also justified by the potential benefits? What health care or socially use-

ful activities will be deprived of resources by the testing program? And do the potential benefits justify this allocation of scarce resources?

QUESTION 3

Who has the right to know if someone has HIV or AIDS? Is there a duty to warn? The infected person may have a right to know. Health personnel treating the patient have the right to know, as do public health authorities. Also, identifiable people at significant risk have the right to be warned.

WHO has strongly urged its member countries to make AIDS a reportable disease. Most countries have complied, adopting either the WHO or the CDC definition of clinical AIDS. However, few countries have made HIV positivity reportable for epidemiologic surveillance. Reporting is either anonymous (citing the number of cases detected) or confidential (citing the infected person's name but providing restricted access). WHO has not taken a position as to which practice is preferable, and most nations have followed their customary practice for dealing with sexually transmitted diseases. It seems clear, however, that confidentiality must be maintained under any circumstances.

Similarly, WHO does not appear to have a clear position on who, if anyone, has the right to be warned of potential exposure. Few countries have addressed in legislation the issue of contact tracing. The most commonly notified third party is a known sex partner of the HIV seropositive person. If the HIV seropositive person cooperates by naming partners, providing their addresses, and consenting to their being contacted, no ethical problems are posed (assuming confidentiality is maintained). In that case the only remaining question is who has the duty to make the contact: the person

tested, the physician, or the public health authorities.

Where the seropositive individual will not consent, however, the conflict between ethical and public health concerns is sharp, and it becomes necessary to ask when the individual's right to privacy (as well as the clear practical need to encourage people to come in for testing) gets overpowered by the need to protect others.

The infected person has a clear moral duty to cooperate with public health authorities and to inform people who may be infected as a result of his or her behavior. While the author is unaware of any WHO guidance on the subject, the position of PAHO's staff on contact tracing is as follows:

Individuals who are infected should be encouraged to refer their sexual partners and/or drug-sharing partners for evaluation and testing. It is not possible to trace the contacts of large numbers of individuals. However, under certain circumstances, such as clients of infected prostitutes and interstate contacts, contact tracing may be desirable. Confidentiality must be preserved in all cases. (5)

In cases where the infected person will not consent, some countries are moving toward the position that the physician is obliged to inform a known sex partner. (The American Medical Association has adopted this viewpoint, for instance. Its position is based on ethical and public health principles. But a physician in the United States may also be held legally liable for failure to warn a third party of substantial and direct potential for harm to health under the Tarasoff principle.)

Other countries have a strong tradition of contact tracing by public health officials, whereby the infected person is asked to name sexual partners. In the case of HIV exposure, a public health official contacts those partners, tells them

they may have been exposed to HIV (without naming the seropositive person), suggests that they be tested, and gives them AIDS education and counseling. This procedure is very labor-intensive and is not to be recommended solely for HIV, as skilled personnel experienced with sexually transmitted disease prevention and control must be used in order for the program to succeed.

QUESTION 4

How can society be protected against people who irresponsibly, perhaps even deliberately, set out to infect others? Isolation and quarantine of HIV patients is not recommended, but criminal sanctions may be applied against a person who intentionally transmits or clearly intends to transmit HIV to others.

Isolation of AIDS patients in a hospital or other health care facility is a common practice. In this situation AIDS is treated as an infectious disease, and a contamination-free environment is sought to prevent secondary infection of the immune-damaged patient. Isolation and quarantine of individuals infected with sexually transmitted diseases have never been effective in preventing the transmission of infection. Therefore, isolation of an asymptomatic individual, solely on the basis of HIV seropositivity, has been strongly discouraged by WHO. For example, the official statement on Social Aspects of AIDS Prevention and Control by the WHO Global Program on AIDS asserts that

There is no public health rationale to justify isolation, quarantine, or any discriminatory measures based solely on the fact that a person is suspected or known to be HIV-infected . . . Persons suspected or known to be HIV-infected should remain integrated within society to the maximum possible extent and be helped to assume responsibility

for preventing HIV transmission to others. Exclusion of persons suspected or known to be HIV-infected would be unjustified in public health terms and would seriously jeopardize educational and other efforts to prevent the spread of HIV (13).

Very few reports of quarantine or isolation based on asymptomatic HIV status alone have been received. Such a practice is not a means of preventing HIV spread because of the inaccuracies of the tests for HIV conversion and the difficulty of policing behavior even in institutional settings. Mandatory screening of virtually the entire population, or at least those identified as being at high risk, would be necessary; and some would inevitably be missed. Also, it is clear that if HIV seropositivity produced total deprivation of liberty, no sane person would voluntarily come forth to be tested. Moreover, unlike the "old" infectious diseases for which quarantine was customary, AIDS has a very long incubation period. So the quarantined person might have to be held eight to 10 years, during which time he or she might be entirely asymptomatic, i.e., apparently healthy.

Quarantine of people with AIDS is no more effective. By the time someone is diagnosed as having AIDS, he or she will be very ill. It is unlikely that further spread of the infection will result from his or her behavior. Therefore, quarantine makes little sense from any public health standpoint. It is a draconian measure, an inappropriate use of the state's police power, and an unwarranted restriction of liberty since it is not needed to protect society from harm.

This situation changes if there is clear evidence that an infected person is one of those rare individuals inclined to recklessly or intentionally infect others. In this case, the presumption that every human being cares for others does not apply, and society is justified in punishing such irresponsible and dangerous behav-

ior, as well as in protecting itself from predictable harm. In this connection, in a few countries prosecutions have been brought for intentional transmission of AIDS, but in most cases the results are not yet known.

In general, however, it is important to note that such cases will be extremely rare. Few human beings set out intentionally, in essence, to kill another human being. Hence, to assume that HIV-infected individuals will act irresponsibly is not only morally wrong, it is factually incorrect. Moreover, the most important point, that has been emphasized repeatedly in this article and by WHO, is that voluntary compliance, voluntary control, voluntary behavior change, and voluntary testing must be the policy to control the spread of AIDS. This approach has been effective. It must be continued.

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