

## Health Education and the AIDS Epidemic

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What is known about the biology of AIDS is reviewed, and the social factors which influence disease transmission and public attitudes are considered. After an evaluation of the methods available to control the epidemic, the reasons for the limited success of public health measures thus far undertaken are considered. The ethical debate on public health policy is analysed, and the need for a nationwide educational programme on AIDS is emphasised – one which is responsive to the rights and obligations of citizens in a democratic society.

To meet ethical standards, education about the acquired immune deficiency syndrome (AIDS) should

- (a) provide an accurate account of what is and is not known about the disease
- (b) do so in language understandable to its intended audience
- (c) offer guidelines which, if acted upon, will bring health benefits to individuals, families and communities
- (d) be so constructed as to promote the common good at the least cost to individual freedom.

### The public health problem posed by AIDS

As of July 1988, more than 100 000 cases of AIDS had been reported to the World Health Organization (WHO) from 138 countries; because under-reporting is extensive, WHO estimates the actual cumulative total at about 250 000 cases. By extrapolation from fragmentary data on the population seroprevalence of antibodies to the human immunodeficiency virus (HIV), the number of infected persons has been estimated at between five and ten million. Even at the lower estimate, about one million additional cases of AIDS can be expected to rise during the next five years from among those *already* infected by the virus (Mann & Chin, 1988).

Geographically, there are three distinct patterns of HIV infection. In pattern I (predominant in North America, Western Europe, Australia, New Zealand, and urban areas of Latin America), sexual transmission occurs mainly among homosexual and bisexual men; transmission through blood results mainly from intravenous drug abuse. In pattern II (found in sub-Saharan Africa and the Caribbean), sexual transmission is predominantly heterosexual; transmission through blood transfusions continues

because programmes to screen blood are not yet in place. Perinatal transmission to the newborn is a major problem; in some urban areas, 5–15% of pregnant women are infected by HIV. Pattern III (found in North Africa, the Middle East, Eastern Europe, Asia, and the Pacific) is characterised by relatively low rates of infection, primarily through exposure to imported blood and blood products, or through sexual contact with travellers from pattern I and II areas.

Currently, neither a vaccine for the prevention of the disease nor a drug to cure it is available, nor is either foreseeable in the near term (Institute of Medicine, 1988a). Available treatments are palliative. Hope of intercepting the epidemic rests upon the development of effective health education to change the behaviour which leads to disease transmission. Given the differences in prevalence and predominant modes of transmission, the focus of health education will necessarily vary from country to country.

### The biology of HIV infection

AIDS was first recognised in 1981 because of the temporal conjunction of two unusual disease clusters in young men. The first was made up of cases of pneumonia caused by *Pneumocystis carinii* (Centers for Disease Control, 1981a), a fungus (Edman *et al.*, 1988) which is pathogenic only in individuals debilitated by another disease; the second consisted of Kaposi's sarcoma (Centers for Disease Control, 1981b), a rare skin cancer previously seen almost exclusively in elderly men (Ross *et al.*, 1975). The common feature of these two very different diseases is that 'opportunistic' infections (those which occur only in an immunologically compromised host) and secondary cancers had both been observed in patients receiving treatment with immunosuppressive drugs (Walzer *et al.*, 1974). What was new was their

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occurrence in otherwise healthy young men without an ascertainable cause for suppression of the immune system. Cases fitting the epidemiological definition of AIDS were next discovered among intravenous drug addicts, and recipients of blood transfusions or blood products.

It soon became evident that an epidemic was underway. Whereas the number of AIDS cases reported in the United States did not reach 800 until the end of 1982, it had risen to more than 7200 by the end of 1984, and had more than doubled again by the end of 1985. As of 9 January 1989, the cumulative US total had risen to 83 231; the fatality rate among patients diagnosed in the first three years of the epidemic and followed to the present exceeds 90% (Centers for Disease Control, 1989). AIDS is occurring at disproportionately high rates among minority and poor populations (Friedman *et al*, 1987).

Contact tracing in the gay community, and from transfusion recipients to donors, implicated transmission of a hitherto unknown infectious particle through semen and blood (Allen & Curran, 1988). By 1983, Montagnier's group at the Pasteur Institute in Paris (Barre-Sinoussi *et al*, 1983) had identified, and Gallo's group at the National Institutes of Health in Washington (Gallo *et al*, 1983) had confirmed, a retrovirus, now known as HIV, as the cause of the disease, and had developed antibody tests for the virus which made it possible to detect infection in asymptomatic individuals. Although a few reputable scientists still question HIV as the cause of AIDS (Duesberg, 1988), the vast majority of active investigators regard the evidence for its causal role as clearly established (Blattner *et al*, 1988).

The determinants of the time lag between infection with the virus and the appearance of clinical disease, and of the variability in its clinical manifestations, are still not understood. A minority of HIV-infected persons become immunosuppressed within the first year; about 25% will show overt AIDS and another 25% the AIDS-related complex (ARC) within five years of infection. As follow-up of infected individuals extends beyond five years, new clinical cases continue to arise; the ultimate proportion who will manifest clinical disease is still unknown (Osborn, 1988). The long silent period magnifies the public health problem. Because asymptomatic HIV-infected persons are unaware of their status (and cannot be recognised by partners), unwitting disease transmission persists.

Although promising leads are under investigation, a fully effective treatment for AIDS or ARC continues to be elusive. In a randomised controlled

clinical trial in 1987, zidovudine (azidothymidine, AZT) was shown to produce clinical benefit in patients during a 24-week treatment period; dose reduction or discontinuation was necessitated because of bone marrow toxicity in a number of patients (Fischl *et al*, 1987). As clinical research has continued, zidovudine's initial benefits appear not to be sustainable. Dournon *et al* (1988) have reported, in a consecutive series of 365 treated patients, that most clinical and laboratory indices had reverted to their initial values by six months. Recombinant interferon-alpha has shown promising results in AIDS-related Kaposi's sarcoma, with a major beneficial response in 12 of 26 patients in one trial (DeWit *et al*, 1988), and 8 of 21 in a second (Lane *et al*, 1988). Phase I studies of combined therapy with zidovudine and interferon-alpha are currently underway, as are trials with other putative therapeutic agents.

Developing a vaccine against HIV infection has proved to be a difficult task because of the characteristics of the virus and the nature of the host response. To begin with, there is extensive genetic variation among virus isolates; indeed, the virus continues to mutate within the human host, so that multiple new variants appear during the course of infection (Marx, 1988). This extraordinary mutability (at a rate estimated to be a million times that of eukaryotic DNA genomes) may arise from high error rates in the replication of the retroviral genome, because of the low fidelity of HIV encoded reverse transcriptase (Preston *et al*, 1988; Roberts *et al*, 1988). Second, the virus integrates its genetic code into the genome of cells in the human host once infection occurs; thus, infection is life long. Third, although infection results in antibody production, anti-HIV antibodies are relatively ineffective in neutralising the virus. Fourth, there is still no satisfactory animal laboratory model for AIDS (Koff & Hoth, 1988).

Even after promising vaccines have been fabricated in the laboratory, and have been shown to be immunogenic and non-toxic in human volunteers, there are formidable obstacles in the way of controlled epidemiological trials. Because of the long latent period between infection and the appearance of clinical disease, trials will require not less than three to five years to determine whether the vaccine confers effective protection. Recipients of a trial vaccine, once they seroconvert, will need special means of identification to protect them from being mislabelled as infected. To the extent that AIDS education – obviously a public health priority and an ethical obligation to the volunteer participants – succeeds in reducing high-risk behaviour in both the

experimental and the 'placebo' vaccine subjects, it will diminish the likelihood of demonstrating vaccine potency, even if it is present.

### The social dimensions of HIV infection

Because AIDS was first recognised in the US among male homosexuals and, shortly thereafter, among intravenous drug abusers, political conservatives as well as fundamentalist religious leaders interpreted the disease as the physical embodiment of the sufferer's moral defilement. They did not disguise their grim satisfaction at what they considered to be the wages of sin (Eisenberg, 1986), just as, earlier in the century, syphilis had been regarded as a moral problem rather than as a disease warranting a public health response (Brandt, 1988). Yet vulnerability to AIDS does not result from homosexuality *per se*, but from unprotected intercourse with an infected partner. Nor does AIDS result from drug abuse as such. High rates of infection among intravenous drug users stem not from drugs, but from sharing contaminated drug equipment.

Public panic was joined with moral opprobrium when the disease spread to 'innocent victims': recipients of blood transfusions (Curran *et al*, 1984), haemophiliacs dependent on donor-derived factor VIII (Evatt *et al*, 1984), female sexual partners of infected men (Harris *et al*, 1983), babies born to infected mothers (Scott *et al*, 1985), women impregnated by artificial insemination (Stenart *et al*, 1985), and health-care workers accidentally punctured by needles (Centers for Disease Control, 1988a). The reassurance the general public had taken from the apparently low rate of heterosexual transmission eroded with the recognition of an almost 1:1 sex ratio in sub-Saharan Africa. Public demand for action grew. Government authorities were forced to face issues they had been trying to avoid because of their inability to satisfy the claims of all constituencies.

Co-operation between nations was impeded by a dispute about the origins of the disease. African seroprevalence data and the discovery of a simian immune deficiency virus (SIV) endemic among green monkeys led to speculation that SIV was the viral precursor for HIV. Recently reported nucleotide sequence data on SIV (Mulder, 1988) and HIV variants (Smith *et al*, 1988) make SIV an unlikely source for HIV. However, the damage had been done. The hypothesis of an African origin of AIDS was bitterly resented by Africans, who took this as yet another example of 'colonial mentality'. The dispute contributed to a delay in acknowledging the extent of the public health problem in Africa.

Although the reasons for the epidemiological differences between pattern I and pattern II countries are not entirely clear, they are likely to have arisen from accidents of history and culturally determined differences in behaviour. In the US, HIV infection apparently began first among a subset of the homosexual male community (Curran *et al*, 1988). Rapid spread was the tragic but inevitable result of patterns of sexual behaviour which had become prevalent in the 'fast lane' of the gay community in the '60s and '70s: sexual congress with multiple and constantly changing partners in gay establishments (bars, bath houses, and the back rooms of cinemas). It is likely that vulnerability to HIV was enhanced by the high prevalence of other sexually transmitted diseases (STDs) in this subpopulation. Homosexual intravenous drug users unwittingly introduced HIV to the addict population. There it spread very rapidly among users sharing equipment in 'shooting galleries' (underground establishments renting space and equipment to use in shooting up, and sometimes providing 'street doctors' expert in needling collapsed veins). AIDS in women, who account for less than one case in ten in the US, results primarily from drug abuse and/or sexual intercourse with bisexual men or male addicts.

In Africa, in contrast, transmission through homosexual intercourse and intravenous drug use is far less common. There, spread has been fostered by multiple heterosexual partners, a high prevalence of other STDs (Piot *et al*, 1988), widespread female prostitution in urban centres consequent upon massive rural migration, and the transfusion of infected blood, all leading to the nearly 1:1 sex ratio (Simonsen *et al*, 1988).

### Interrupting HIV transmission

The facts thus far established about how HIV is, and is not, transmitted from one person to another provide the scientific foundation for control measures. The three principal modes of transmission are (a) by sexual intercourse with an infected partner; (b) by infected blood and blood products; and (c) by placental passage from infected mother to fetus. HIV is *not* transmitted through casual or even intimate non-sexual interpersonal contacts within families, in the workplace, or at school (Friedland & Klein, 1987). Whether it can be transmitted by orogenital contact, by deep kissing, or breast feeding is not known.

Changes in the preparation of factor VIII and other blood products have made those products entirely safe for use. Antibody screening of donated blood has markedly, although not entirely, reduced

the risk of HIV transmission by transfusion wherever screening has been introduced; risk persists, however, because of the 30–90-day time ‘window’ between the onset of HIV infection and the production of antibodies detectable by current screening measures (Ward *et al.*, 1988). Systematic screening of semen donors (freezing the semen until repeat HIV antibody testing on donors initially and after six months has established its safety) has minimised the risk associated with artificial insemination. Precautions have limited, although not abolished, the relatively low risk for health-care workers (Centers for Disease Control, 1988a). There are, however, no fully effective technological remedies for the two most common modes of HIV transmission, sexual intercourse (homosexual or heterosexual) and intravenous drug use, and none at all for perinatal transmission, other than aborting the foetus because of a 40–50% risk of infection.

Although the use of latex condoms (which do not allow HIV to pass the physical barrier they interpose between penis and vagina) plus virucidal spermicides (which contain nonoxynol 9) reduces risk (Feldblum & Fortney, 1988), condoms are not fail-safe, as is evident from their imperfect record as contraceptives; they may be defective in manufacture, they may be torn or slip off during use, and they must be properly applied before each episode of intercourse. Some men are reluctant to use condoms on the grounds that they diminish pleasure in the sexual act, and others because they are contraceptives; in many countries, condoms are not readily accessible.

With intravenous drug use, the danger inheres in the use of shared paraphernalia (needles and syringes). The virus is transmitted by means of the residual blood in the apparatus when it is passed from one individual to another. The interruption of intravenous drug use (the obviously preferable public health solution – were it possible) or the use of sterile needles and syringes will abolish this mode of transmission. Alternatively, because HIV is a relatively fragile virus, the proper use of a diluted solution of household bleach to clean equipment between use can reduce the likelihood of transmission.

#### The level of public knowledge

In view of the extensive media coverage given to the AIDS epidemic in industrialised (pattern I) countries, is there a need for additional health information? Sequential public opinion polls since 1983 reveal growing awareness of AIDS, the risk it poses to health, and some of the facts about infectivity; they also demonstrate that misinformation persists (Fink, 1987). The National Health Interview Survey (Dawson

*et al.*, 1988) interviewed a probability sample of the US civilian non-institutionalised population at regular intervals. A survey of some 3100 persons on knowledge and attitudes about AIDS in September 1987 revealed that almost all had heard of AIDS; 98% knew it to be fatal, 95% believed that it could be transmitted by sexual intercourse, 76% that it was caused by a virus, 68% that it could be transmitted by transfusion. However, substantial numbers were grossly misinformed. A third or more of the respondents thought it was definitely or probably true that AIDS could be contracted by sharing eating utensils, eating in a restaurant where the cook had AIDS, being coughed or sneezed upon by a person with AIDS, using public toilets, or being bitten by insects! A quarter considered that the disease could be acquired by *donating* blood and a sixth by working near, shaking hands with, or going to school with a person with AIDS. Whereas 82% knew condoms could prevent transmission, 13% believed diaphragms to be effective as well.

Anonymous questionnaires distributed to some 600 students at an eastern US university (Landefeld *et al.*, 1988) showed them to be more knowledgeable than the general public; nonetheless, an eighth of the students were concerned about ‘catching’ AIDS in public toilets, a quarter believed that infected persons should not be allowed to live in dormitories, and an eighth that they should not be allowed to attend classes. Less than 20% of the students who reported having multiple sexual partners, whether homosexual or heterosexual, had changed their sexual behaviour because of the danger of HIV infection. In a current San Francisco study (Bass, 1988) of 500 sexually active teenagers, only 2% of the boys and 8% of the girls used condoms consistently; no less disturbing was the finding that 30% engaged in unprotected anal intercourse, the sexual behaviour most closely associated with HIV transmission in the US.

A public opinion survey of social perception of AIDS in France (Moatti *et al.*, 1988) revealed that 37% continue to believe AIDS can be transmitted by blood donation, and 10% by mosquito bites, by drinking from a patient’s glass, or in public lavatories. Those who were the least informed were the most likely to favour mandatory screening for HIV infection and isolation of AIDS patients (as was true in the US university study).

The situation is somewhat different but still far from satisfactory among the two populations in Western countries at greatest risk: sexually active homosexuals and intravenous drug addicts. Among selected (that is, middle-class, highly educated, and self-declared) US gay populations, knowledge of AIDS is greater, and reported reduction in high-risk

behaviour is more extensive (Winkelstein *et al.*, 1987; Martin, 1987). In parallel, there has been a decline in rates of HIV seroconversion and in the prevalence of other STDs among such groups. These changes likely reflect the enormous emotional and social impact AIDS has had on the organised gay community (Fitzgerald, 1986*a,b*). Nonetheless, a significant proportion continue to engage in behaviour they report they know place them at high risk for infection. Moreover, the recently reported increase in rates for syphilis in the US (Centers for Disease Control, 1988*b*), primarily among Blacks and Hispanics, reflects (a) the failure of current efforts to reach minority populations, and (b) the diversion of resources from other STD control programmes to support AIDS control efforts. Among intravenous drug addicts, sharing equipment is widely known to be dangerous; an illegal market in allegedly sterile needles has grown in New York City; yet sharing continues to be the modal behaviour pattern (Friedman *et al.*, 1987).

Thus, there is an urgent need, not only for more, but for more effective, health education.

#### Barriers to AIDS education

AIDS education faces formidable obstacles. Stating information clearly and disseminating it widely in language understandable to target populations are necessary, but not sufficient. Individuals at risk must be motivated to change their actions, and must have the skills to do so; to maintain safer behaviour, continuous social reinforcement is necessary. When the established behaviour involves sexual practices and drug use, change is predictably difficult to effect (Fineberg, 1988). For almost two decades, unprotected sexual intercourse has been the norm among US teenagers, evident in the fact that the US has the highest teenage pregnancy rates, although it does not have the highest rates of pre-marital intercourse, among industrialised nations (Jones *et al.*, 1985). As to intravenous drug use, not only is needle sharing part of its subculture, but addicts made desperate by withdrawal will use whatever equipment they can find. Long-term disease prevention from either mode of transmission demands a sustained change in behaviour (in contrast to the one-time decision to be vaccinated without having to change the rest of one's behavioural repertoire).

In face of the powerful social and cultural forces which maintain high-risk behaviour, the US federal commitment to AIDS education can only be called paltry. The Institute of Medicine/National Academy of Sciences (1986) called for annual expenditures of a billion dollars for AIDS education and related

public health measures by 1990. The allocation did not reach \$315 million until 1988; the budget proposed by the administration for 1989 is only \$400 million. The Presidential Commission on the Human Immunodeficiency Virus Epidemic (1988), notwithstanding its appointment by the incumbent administration, severely criticised the inadequacy of the federal effort, and called for a far more ambitious undertaking.

The effectiveness of education has been further compromised by reluctance to use explicit terminology. In the first years of the epidemic, US media employed the term 'bodily fluids' as a euphemism for semen or blood. The ambiguous language added to public panic because it was interpreted to include saliva, sweat, and tears. Even the instructions inserted in commercial condom packages require the reading level of a high-school graduate for full comprehension, making the instructions virtually useless for those in most need of them (Richwald *et al.*, 1988).

#### Ethical issues *vis-à-vis* risk reduction

The US effort to control HIV infection has been bedevilled by strongly held differences about what is and is not morally acceptable in public policy. Although the US is a democracy with a constitutionally prescribed separation between church and state, the cultural and ethnic heterogeneity of the US population has resulted in divergent religious and secular viewpoints. Fashioning coherent public policy out of the claims of competing constituencies represents an as yet unsolved political challenge.

The public debate can be most clearly epitomised by contrasting two opposing camps: public health advocates versus moralisers. The former adopt a pragmatic, consequentialist position, one that can be termed 'ethical realism'; the latter base themselves on religious fundamentalism, and claim they are 'the moral majority' in the US. Their morality has been challenged; public opinion polls have demonstrated that they are far from the majority. It is true that some physicians adopt a moralising stance, and some religious leaders accept the urgency of pragmatic measures at the same time that they advocate moral persuasion. Yet this antithesis conveys the essence of the controversy. Each position reflects implicit as well as explicit social values about sexuality, medicine, and disease.

The public health position finds no moral meaning in disease phenomenology. Its goal is the reduction of morbidity and mortality to the minimum achievable by existing means. Advocates specify their goals in operational terms, and rest their case on

empirical evaluation. The question they ask is: does a given measure in fact reduce disease transmission? Their position was eloquently stated by Thomas Sydenham in 1673 (see Temkin, 1949), when he defended his studies of venereal disease treatment against the charge that they contributed to immorality by removing "the fear of future trouble" which "terrifies the unchaste":

"If we reject all cases of affliction which the improvidence of human beings has brought upon themselves, there will be but little room left for the exercise of mutual love and charity. God alone punishes. We, as best we can, must relieve. . . . Hence I will state what I have observed and tried in the disease in question; and that not with the view of making men's minds more immoral, but for the sake of making their bodies sounder. This is the business of the physician."

For the moralisers, the prevention of disease, although desirable in itself, is secondary in value to more fundamental moral precepts about the good life. In the eyes of many fundamentalists, disease itself plays a role in the moral order of the world. Behaviourally transmitted diseases serve a moral function, insofar as fear of contracting them encourages continence. To remove that fear by medical means is to encourage immorality. Thus, Norman Podhoretz (see Dershowitz, 1986), spokesman for the New Right, condemned political leaders who called for a crash programme to develop an AIDS vaccine: "Are they aware," he asked, "that in the name of compassion they are giving social sanction to what can only be described as brutish degradation?"

Earlier in this century, when syphilis was epidemic, the social hygiene movement had insisted that the best way to prevent infection was by adherence to an ethic that restricted sexual relationships to marriage, a goal that was to be achieved through education to encourage abstinence and the repression of prostitution (Brandt, 1988). Measures to prevent syphilis or to treat it, by making sex safer, could only encourage promiscuity. Indeed, a leading American dermatologist (Stokes, 1950), after the remarkable success of penicillin in treating syphilis, felt impelled to write:

"It is a reasonable question, whether by eliminating disease, without commensurate attention to the development of human idealism, self control, and responsibility in sexual life, we are not bringing mankind to its fall instead of its fulfillment."

These contrasting views have been widely voiced in the years since the magnitude of the AIDS epidemic became apparent. They lead to sharply different conclusions about disease containment.

The position of the religious right on homosexuality is based on biblical injunctions interpreted as condemning such behaviour. Whatever his desires and however they arise, the homosexual is deemed capable of the moral choice to renounce his impulses. If he opts for celibacy, he can be forgiven; if he continues on his path, he has rejected salvation. To instruct a sinner on how to maintain his health while continuing to sin is to foster immoral behaviour. To educate children about homosexuality except to condemn it is to place temptation in their way. The only moral way, they contend, indeed, the most effective way, to limit the spread of disease among homosexuals is by demanding that they abandon their 'style of life'. Because, in this view, homosexual behaviour is a wilful choice, AIDS becomes a self-inflicted disease.

The consequentialist position places health outcomes first. Whether the genesis of homosexuality is taken to be biologically determined, socially shaped, or freely chosen is irrelevant; the central facts are its concurrence and the health risks associated with it. The public health goal is education about risk reduction. To do so effectively requires that homosexuals be treated with respect as fellow human beings. The self-proclaimed moralist's fear that telling adolescents the facts about homosexuality will seduce them is a fear without data to support it. Providing all citizens with the facts about disease transmission in order to enable them to modify their behaviour accordingly is the fundamental ethos of the realist.

The moraliser believes that pre-marital and extra-marital sex are sins to be condemned. Although the preservation of life is a *desideratum*, it is secondary in importance to living a moral life. Adherence to morality, so defined, will in itself obviate sexually transmitted diseases. Sex education is the primary responsibility of family and church. If it is to be permitted in schools, moral context must take precedence over physiology. Those who believe that intercourse is licit only when it permits procreation regard instruction about condoms as unacceptable; condoms are contraceptives, even if they are ostensibly used for disease prevention.

The consequentialist position on sexuality begins with the recognition that pre-marital experimentation is widespread in contemporary society. Whether it be taken to be a component of normal sexual development or a deviation from mature sexuality, it will not be changed by exhortation. Because ignorance about sex not only fails to delay sexual expression but transmutes it into a high-risk activity, public health advocates focus on what is feasible; namely, the provision of full information about how

disease transmission can be minimised, and ready access to condoms to increase their use when intercourse does occur.

Ethical realists no less than moralisers view intravenous drug abuse as inherently self-destructive. Where the two differ is in the stance they take on how it can be controlled, and on measures to limit the disease transmission associated with it. Whereas the medical viewpoint is compatible with a variety of control measures extending from strict legal interdiction through methadone maintenance to drug-free treatment programmes (to the extent that their effectiveness is supported by empirical evidence), the moraliser accepts only strict interdiction, and rejects methadone maintenance as substituting addiction to one drug for another. There is a further contrast. Those who focus on health outcomes point to the obvious failure of law enforcement to control the drug trade, the unwillingness of many addicts to accept treatment, and the high recidivism rate among those addicts who do enter treatment programmes. In view of these demonstrable facts, although consequentialists support augmented treatment efforts, they simultaneously advocate educating addicts about health risks and making sterile injection equipment available in order to minimise disease transmission. To the religious moraliser, making drug use safer is to condone it, and thus to contribute to its prevalence. No less dismayed by the spread of AIDS, particularly when it is transmitted to unknowing spouses and to offspring, they insist that stricter law enforcement and stronger penalties are the appropriate public response.

Pre-marital sexual continence, sexual fidelity in marriage and cessation of intravenous drug abuse, the propositions put forth by the moralisers, would indeed halt HIV transmission. Because none of these goals has even the most remote chance of being attained, public health advocates promote pragmatic policies, admittedly partial and imperfect, to control disease. They cite the modest but persuasive evidence for effectiveness. That evidence is dismissed by the religious right as irrelevant to what matters most: public morality. The result of the controversy has been to require compromise in, but not to halt, educational campaigns.

#### **Science, human rights, and AIDS policy**

To attain the goal of interrupting disease transmission, AIDS education must increase public understanding of the technical questions and the human rights issues which underlie public policy. This is a formidable challenge. Public education about the scientific method is lamentably inadequate; scepticism about

science and scientists is widespread (Eisenberg, 1986). Few understand that 'safety' can never be absolute and that 'risk' is always relative. Research on the factors influencing choice in the face of uncertainty has shown that the way the alternatives are presented can influence subjective assessment even when the two presentations are mathematically equivalent (Tversky & Kahneman, 1981).

In the debate about mandatory screening for HIV infection, the dispute is between those who assert a public 'right to know' and who claim that mandatory testing is necessary to prevent 'ignorant transmission' of the virus, and those who give greater weight to individual rights and assert on pragmatic grounds that voluntary testing is far more likely to succeed.

Advocates of mandatory testing allege that it would benefit the community at large by providing accurate epidemiological data, and by opening avenues (including quarantine) to control the behaviour of infected persons. The victims themselves, they contend, would benefit from the counselling that would be provided, and by being informed of (or even required by law to accept) such treatment measures as are available at a given time. Advocates differ as to how far they would carry mandatory HIV testing. Some insist it be universal, others would make it a condition for marriage licensure and hospital admission, and still others would limit its application to persons known to be engaging in high-risk behaviour.

Opponents dispute these claims on both civil libertarian and pragmatic grounds. To begin with, compulsory testing violates the right of privacy. Because of the social stigma associated with HIV infection, persons identified as seropositive will be exposed to the risk of losing jobs, being evicted from rented accommodation, being barred from school, being denied health and life insurance, and being rejected by family and friends, events that continue to be everyday occurrences. Confidentiality of medical information is easier to promise than to guarantee. Although opponents of mandatory testing acknowledge the importance of better epidemiological data, they contend that such information can be gathered by anonymous testing in hospitals, clinics, and volunteer test sites. The failure to make assurance of confidentiality credible by additional legal protection currently impairs voluntary test programmes (Presidential Commission on the Human Immunodeficiency Virus Epidemic, 1988).

In a recent study in Oregon (Fehrs *et al.*, 1988) which compared an anonymous test site with one that required names but promised confidentiality, usage doubled at the anonymous site; many more infected persons obtained counselling. The Japanese Ministry

of Health and Welfare has proposed an AIDS Prevention Bill to make reporting HIV carriers to prefectural authorities mandatory. To examine the effects of official notification on willingness to be tested, Ohi *et al* (1988) queried large groups of Japanese workers, students, male homosexuals, and female prostitutes on their willingness to accept testing under such a circumstance. Their findings indicate a sizeable decline in compliance, were the bill to become law, especially among the at-risk groups (homosexuals and prostitutes). They conclude that "the effect of the bill might be the opposite of what is intended".

Mandatory HIV testing as a requirement for employment in occupations where public safety is at stake (e.g. in mass transportation) has been proposed in several countries. Although screening is rationalised as preventing the potential danger posed by an impaired airline pilot or air-traffic controller, it is also clear that industry has a major financial stake in screening new workers at risk for illness or premature death, in order to avoid low returns on the investment in job training and higher insurance costs. These facts do not in themselves gainsay the importance of examining implications for public safety, but do suggest caution in accepting such claims at face value. What is the evidence?

Autopsy data have revealed that extensive infection of the central nervous system is frequent in advanced stages of AIDS; such patients exhibit severe cognitive and emotional neuropsychiatric disorders termed the AIDS dementia complex (ADC) (Navia *et al*, 1986). ADC can appear well before the terminal stages of AIDS (Navia and Price, 1987), but is rare in the absence of other clinical signs and symptoms (Price *et al*, 1988). In a carefully controlled study of cognitive function in a cohort of gay volunteers evaluated before and after their HIV serostatus was determined, Kessler *et al* (1988) found no significant differences between seropositive and seronegative subjects *before* they knew their status. However, psychometric test performance of seropositive individuals declined significantly *after* they had been informed; that is, observed post-test deterioration in HIV positive individuals resulted from psychosocial stress rather than HIV infection *per se*.

Although negative findings even in a relatively large cohort cannot completely exclude the possibility of rare instances of cognitive impairment in seropositive but otherwise clinically well individuals, this risk must be assessed in relation to other far more common hazards; for example, impairment resulting from alcohol or illicit drugs (Rose *et al*, 1978), minor tranquilisers (Skegg *et al*, 1979), disruption of

circadian rhythm caused by journeys across multiple time zones (Graeber, 1986), and other diseases (Institute of Medicine, 1981; Torsvall & Akerstedt, 1987).

Protecting public safety in mass transport is best assured by efforts to develop more sensitive methods for early detection of significant deterioration of function, whatever its cause (Doege, 1979; Green, 1983). Thus, the WHO Global Programme on AIDS Consultation on the Neuropsychiatric Aspects of HIV Infection (1988) concluded that there is *at present* "no evidence for an increase of clinically significant neuropsychiatric abnormalities" in *otherwise asymptomatic* HIV seropositive persons and "no justification for . . . screening as a strategy".

Mandatory testing involves disproportionate costs for meagre results. The predictive value of a positive finding on a screening test depends not only on the accuracy of the method but also on the prevalence of the disease in the population being tested. The nature of the problem can be illustrated by the following two examples. Although they are 'thought experiments', they are based on realistic field conditions. In the first, screening is applied to a population with low seroprevalence, in the second, to one with a very high rate.

Consider the results when a screening test, the enzyme immunoassay (EIA), is applied to 100 000 persons with a true seroprevalence of 0.5% (approximately that estimated for the US population as a whole). When performed under optimal conditions, the EIA is remarkably accurate. It has a sensitivity (the proportion of infected persons who test positive) of about 98%, and a specificity (the proportion of *uninfected* persons who test negative) of somewhat better than 99%. Yet, when the EIA for HIV antibodies is applied to this study population, it will generate the findings presented in Table I.

The test will yield 995 false positives (i.e., a positive result in the absence of infection) for the 490 true positives it identified, a true-positive:false-positive ratio of more than 2:1! The predictive power of a positive test would be 33%. Almost 1000 persons

TABLE I  
EIA results in a population of 100 000 with a true seroprevalence rate of 0.5%

	HIV infection	No HIV infection	Total
EIA positive	490	995	1485
EIA negative	10	98 505	98 515
Total	500	99 500	100 000



TABLE II  
Western blot confirmation of infection in a population of 100 000 with a true seroprevalence rate of 0.5%

	HIV infection	No HIV infection	Total
WB positive	451	50	501
WB negative	39	945	984
Not tested	10	98 505	98 515
Total	500	99 900	100 000

(1%) of the population tested) would be exposed to the devastating consequences of being told they are infected by HIV, when in fact they are not. Clearly, it would be imperative to carry out confirmatory tests by the closest there is to a gold standard, the Western blot (WB). On pre-screened sera, the WB has a sensitivity of 92% and a specificity of 95%. If it were applied to EIA test-positive sera (the negatives, including ten false negatives, not being subject to retest), the findings would be those in Table II. The final result is now 451 true positives detected, 49 missed, and 50 false positives still misidentified.

If the EIA were to be applied to a population of 100 000 with a true seroprevalence of 50% (a rate approximating that among sexually active San Francisco gays and intravenous drug addict sub-populations in Newark and New York City), the reliability of positive test findings would change dramatically. This situation is illustrated in Table III. Testing would yield one false positive for each 98 true positives. The predictive power of a positive test would be 99%. There would, of course, still be the necessity for WB confirmatory testing (Table IV). The net result would be 45 080 true positives

TABLE III  
EIA results in a population of 100 000 with a true seroprevalence rate of 50%

	HIV infection	No HIV infection	Total
EIA positive	49 000	500	49 500
EIA negative	1000	49 500	50 500
Total	50 000	50 000	100 000

TABLE IV  
Western blot confirmation of infection in a population of 100 000 with a true seroprevalence rate of 50%

	HIV infection	No HIV infection	Total
WB positive	45 080	25	45 105
WB negative	3920	475	4395
Not tested	1000	49 500	50 500
Total	50 000	50 500	100 000

identified at the cost of 3920 missed (7.8%), but only 25 persons out of the original population (0.025%) falsely labelled as infected. Despite the quite extraordinary accuracy of these tests (far beyond that of most tests in common use), both false-negative and false-positive results are inescapable – with all the human costs they entail.

Cleary *et al* (1987) undertook a careful quantitative analysis of the findings to be expected if mandatory pre-marital screening were to be enforced in the US. Their calculations were more precise than those exemplified in the preceding tables, because they took into account known variations in seropositivity by gender and age, and more precise figures for EIA and WB sensitivity and specificity. Pre-marital screening would detect fewer than 0.1% of those tested as HIV infected, would mislabel more than 450 (100 as false negative and 350 as false positive), and would entail the expenditure of well over \$100 million. If mandatory testing were to be instituted nationwide, the fiscal costs and negative social consequences would be more than 100-fold greater. The funds expended would yield far greater benefits if applied to public education and voluntary testing. Experience in one state (Illinois) with a mandatory testing programme has led even its proponents to consider repeal of the legislation: state marriage rates dropped (many couples went to neighbouring states to escape the requirement), test facilities were swamped, and very few new cases were uncovered (Wilkerson, 1988; Associated Press, 1988). Among the first 45 000 persons tested, five were positive; the cost for each identified case of HIV infection (Byrne, 1988) was about \$715 000!

The WHO Global Programme on AIDS convened a meeting of international experts to consider criteria for HIV screening programmes in May 1987 (World Health Organization, 1987). The participants concluded that:

“readily accessible counselling and testing for antibody to HIV, provided on a voluntary basis, are more likely to result in behavior changes that contribute to the public health goal of reducing spread of HIV than are mandatory screening initiatives. . . . Epidemiological surveillance data can be obtained, as needed, by methods that do not compromise human rights. The complexity of logistic, technical, personal, social, legal and ethical issues generated by mandatory screening of targeted populations must be recognized.”

Data on HIV seroprevalence in the population can be obtained without putting confidentiality at risk, and without depending on voluntary assent by testing blood specimens obtained for routine medical uses after removing identifying personal information. Such studies are most easily done in hospitals or out-patient clinics by screening residual blood in

specimens taken for other purposes. From an epidemiological standpoint, the findings will not be representative of a random population sample, since the test sera derive from persons who are seeking medical care. However, for particular purposes, testing anonymous specimens can be fully informative; for example, in blood drawn from pregnant women at term, since virtually all urban births are in hospital. Such data represent accurately the status of the population served by specific hospitals (Landesman *et al*, 1987; Hoff *et al*, 1988).

Although anonymous testing of residual blood specimens does not jeopardise confidentiality, the procedure has been criticised on the grounds that a patient's blood cannot ethically be used for any purpose other than that specified when the patient agreed to have it drawn. This objection has not been persuasive to the US Institutional Review Boards when they have been asked to rule on the matter; the residual blood would otherwise simply be discarded as waste matter; testing provides information of use to the community (and, therefore, to the patient as a member of the community). The method does carry a liability: once personal identifiers have been removed from blood specimens, there is no way to notify seropositive persons of their status.

Even if one agrees that voluntary testing and anonymous sampling are preferable to mandatory screening under present circumstances, would the same judgement be warranted (a) if test error were to be significantly reduced, and (b) if means to eliminate infectivity were to become available at some time in the future? Let us consider each in turn.

Error rates can be, and are being, minimised by more exacting confirmatory Western blot standards (Burke *et al*, 1988). New test methods are under development in research laboratories. They are based upon the use of the polymerase chain reaction to amplify specific segments of the HIV genome (Mullis *et al*, 1986), and permit direct detection of infection independent of antibody response (Loche & Mach, 1988; Laure *et al*, 1988). However, reduction of test error rates alone does not suffice to establish the public health utility of mass screening, as Weiss & Thier (1988) have shown in an editorial pointedly entitled "HIV testing is the answer - what's the question?" In the absence of a cure for AIDS, the purpose of testing is to reduce transmission by changing the behaviour of infected persons. Evidence of behavioural change among individuals who choose to be tested on a voluntary basis cannot be generalised to those who are given information they have not sought.

The New York Blood Bank urges donors not to give blood for transfusion if they have engaged in high-risk behaviour; it provides a confidential form

on which potential donors can designate their blood 'for studies only' if they are in a risk category. Nonetheless, such individuals continue to give blood for transfusion (Cleary *et al*, 1988). When notified of their seropositivity and reinterviewed, 90% acknowledged that they fell into a risk class (although only 10% 'believed' they would test positive). Moreover, even after counselling, some infected persons persist in high-risk behaviour (Cleary, pers. comm.). Without more effective means of bringing about behavioural change among those notified of their serostatus, improved precision in screening will not in itself justify mandatory screening.

Suppose, however, that research yields a drug capable of suppressing infection and, more to the point of the present discussion, of abolishing infectivity. Under such a circumstance, identifying infected persons through screening would not only make possible direct benefit to them, but it would also provide the means to halt the spread of infection in the community. Mandatory screening would then appear in a new light. While it seems probable that almost all seropositive persons would seek treatment in view of their almost inevitable progression to severe disease, debate about public policy would soon shift to the question of mandatory treatment for those who refused to accept it voluntarily and thus continued to put others in jeopardy. There are public health precedents for compulsory treatment: in many jurisdictions, individuals with active tuberculosis who refuse care can be confined to sanatoria by court order. Given the far greater lethality of AIDS, one can anticipate that the vast majority of the public would support mandatory screening and mandatory treatment, were such a drug to become available.

The matter will almost certainly not be so simple from a medical standpoint, as the preceding discussion suggests. It is highly unlikely that an agent will be discovered that is both completely effective in suppressing infectivity and altogether without toxicity; thus far, every promising drug has had major side-effects. However persuasive the argument to be constructed for compulsory treatment by a 'fully effective' and 'completely benign' drug, the less certain its therapeutic potential and the greater its toxicity, the more difficult will be the resolution of the trade-off between individual autonomy and the community interest in halting the epidemic.

#### What is to be done?

Despite the absence of a vaccine capable of preventing HIV infection or a treatment able to cure it, what is known about its modes of transmission makes control of the HIV epidemic a feasible goal, but only if citizens are effectively informed about

what is (and is not) known, and what they can do individually and collectively to promote health among those currently well, and to provide care for those who have already been infected. Citizens need to understand not only what modifications they need to make in their own behaviour as individuals, but must also be thoroughly familiar with the issues at stake in formulating public health policy.

There can be no question of withholding facts (such as the inability to assure complete safety of the blood supply), but scientific presentations and media reports on those presentations should take care to put them in context (e.g. compare the risk of infection from transfusion with the hazard of refusing it when it is medically necessary). The specificity of the information provided and the explicitness of the language used should be tailored to the groups at whom the campaign is targeted. Thus, the details of gay sexual behaviour and 'eroticising' safe sex will be of little relevance for the general population, but crucial in enabling homosexuals to avoid disease. A level of explicitness which may be deemed offensive to the population at large is nevertheless essential for reaching specific groups; it can be provided through channels other than mass media. Gay self-help groups have prepared pamphlets, made video tapes, and organised group discussions for their own constituencies. Detached street workers, often former drug addicts employed by health departments, have been able to contact intravenous drug users who need graphic demonstration on how to sterilise equipment. The credibility of the individuals providing the information is a crucial determinant of whether it will be believed (Chelimsky, 1988).

The success (Winkelstein *et al*, 1987; Martin, 1989) of safe-sex educational programmes produced and sponsored by gay organisations has been nothing short of remarkable: seroconversion rates in annual probability samples of homosexual men in San Francisco have fallen from 18.4% before 1984 to 4.2% in 1986, and to 0.7% (Winkelstein *et al*, 1988) in the second half of 1987! But this has been limited to the primarily middle-class, educated, mostly white men who openly acknowledge a gay self-identification. There is little evidence the message reaches 'closet' gays, members of ethnic minority groups, and bisexuals who do not identify themselves as homosexual. The complexity of the issue is illustrated by Brazilian culture, where the ideology of machismo is prominent. The notion of a gay identity is a recent 'import' from North America, and is applied only to those who are the passive or recipient partners in homosexual pairs (Parker, 1987). Men who are the active or 'masculine' partners (i.e., those who insert the phallus) in homosexual

intercourse are by definition not gay, a category which they regard as invidious. Thus, were HIV educational efforts to be directed at 'gays' in Brazil, they would necessarily fail to reach key links in the disease transmission chain.

AIDS education for addicts has hardly begun, and is still not routinely incorporated into drug treatment programmes. There has been a two-and-a-half-fold increase in deaths among intravenous drug users in New York City coincident with the AIDS epidemic, despite no discernible change in the number of users. About a third of the excess deaths have been directly attributed to AIDS. However, Stoneburner *et al* (1988) conclude that AIDS accounts for many more of the excess deaths because autopsy data reveal the presence of infections and other diseases associated with HIV infection. Because such deaths occur disproportionately among black and hispanic intravenous drug users, current data underestimate the impact of AIDS in minority communities. Clearly, such individuals are not being reached by drug treatment programmes and by education about the importance of clean syringes.

The limited success associated with health education for the population at large makes evident the need for experimentation with new approaches. As Warwick *et al* (1988) point out, broadcasting the 'scientific facts' to passive recipients is insufficient to produce change in health-related behaviour. Educational planning must begin by discovering through ethnographic methods what it is particular groups (e.g. teenagers) believe and what worries them, in order to design interactive formats to promote behavioural change. Enthusiasm and good intentions cannot substitute for evidence of effectiveness. The imperative is for a major commitment to evaluation research, thus far sadly lacking.

In late May 1988, at a cost of \$17.4 million, 106 million copies of the Surgeon General's brochure *Understanding AIDS* were distributed to all US household, post-office box holders, and all territories, with a Spanish version for Puerto Rico. What, if any, change in knowledge, attitude, or behaviour resulted from this massive and much-applauded effort? The brochure did elicit 250 000 calls to a special telephone hot-line. However, according to a Gallup Poll, 51% of a population sample queried said they had not read the report, either because they had no recollection of its arrival or because they chose not to read it when they saw it (Blendon & Donelan, 1988). A national health interview survey undertaken in May and June 1988 revealed marginal gains in accurate information, and marginal reductions in misinformation about AIDS in June as compared with May after mass distribution of the brochure

(Dawson, 1988). Public funding for educational projects must include a mandatory set-aside for evaluation of outcome (Chelimsky, 1988), lest we continue to invest in ineffective methods.

Although the prevalence of HIV infection among heterosexuals in the US and Western Europe has remained relatively low; the 1:1 sex ratio in Africa gives reason for concern that current rates may increase if preventive measures are not undertaken. Therefore, education about sexuality and STD transmission must be "part of a comprehensive health education plan" in public schools, as stated by the US Committee on School Health of the American Academy of Pediatrics (1988). The Committee recommends that concepts of health and disease, including the role of micro-organisms, and the importance of cleanliness, should be the focus from kindergarten to third grade. From grades 4 to 6, the nature of AIDS and its modes of transmission should be included; myths of insect vectors and casual spread should be dispelled. Because risk behaviour is likely to begin at about grade 7, the Committee calls for an intensive secondary-school curriculum with emphasis on AIDS as an STD, the nature of HIV infection and the immune response, modes of transmission (including intravenous drug use), the prevention and treatment of the disease, and discussion of its social and psychological aspects.

The Academy Committee (1988) cautioned that "candid discussion of all aspects of sexual transmission must occur in an age-appropriate and culturally sensitive fashion". The recommendations, while correct and straightforward in concept, are broad and general; their translation into specific educational content is key to the success of the effort. Care will be required to avoid identifying sex so closely with disease as to impair normal sexual development. The literature on health education provides abundant evidence that presenting the facts is not enough (Becker & Joseph, 1988). Teenagers must be motivated to act, and be equipped with the skills to do so. A promising lead is provided by the success of classroom training programmes designed to augment behavioural skills in resisting the social pressure to conform with peer solicitations to begin smoking (Schinke *et al*, 1985; Best *et al*, 1988).

Given the number of hours most citizens of the US and Western European countries spend watching it, television could become a highly effective way to reach the general population. Thus far, concern about offending the moral sensibility of some viewers has limited television messages to general, non-specific presentations during other than prime-time hours. Television networks, which have few reservations about soap operas which celebrate clandestine sex, demur at showing the ways sex can

be made safer (e.g. by displaying the proper way to use a condom). A state-supported television campaign in the Dominican Republic has demonstrated that explicit programming about condom application lends to greater public knowledge and increased use (Foreman, 1988).

As emphasised from the beginning of this review, the problem of HIV infection transcends national boundaries. The epidemiology of AIDS differs between countries; control measures will have to take these differences into account; their effectiveness will depend on their sensitivity to unique features of culture and social matrix; the way ethical issues are resolved will differ by country, but they are everywhere paramount. No country can isolate itself from the danger by instituting mandatory screening at its borders (as some have proposed doing). Effective actions require international co-operation (World Health Organization, 1987). The World Summit of Ministers of Health on Programs for AIDS Prevention, meeting in London in January 1988, declared that:

"The single most important component of national AIDS programs is information and education because HIV transmission can be prevented through informed and responsible behavior. . . . [Such programs] should take full account of social and cultural patterns, different life styles, and human and spiritual values. . . . We emphasize the need in AIDS prevention programs to protect human rights and human dignity. Discrimination against, and stigmatization of, HIV infected people and people with AIDS and population groups undermine public health and must be avoided." (World Summit of Ministers of Health, 1988)

In similar terms, the 41st World Health Assembly, held in Geneva on 13 May 1988, resolved that member states be urged:

"To foster a spirit of understanding and compassion . . . and to protect the human rights and dignity of HIV-infected people . . . and to insure the confidentiality of HIV testing and to promote the availability of confidential counselling and other support services." (World Health Assembly, 1988)

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