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The Nucleus of a Public Health Strategy to Combat AIDS

Larry Gostin

Since AIDS was first identified in 1981, its rate of spread among a primarily young and vibrant population has chilled the medical and lay communities. Today, the public response is sober and oriented toward the examination of specific policies that could lessen the impact of the disease. After six years' experience it is now feasible to propose a strategy for combatting AIDS. Consensus around the following policies should form the nucleus of the public health strategy to combat AIDS before the intervention of an effective vaccine or treatment.

Prevention: A Comprehensive and Well-Resourced Program of Education

Unprotected sexual intercourse and use of contaminated needles are intentional activities. Voluntary changes in behavior to avoid a high risk of transmission is currently the overriding public policy objective. The first line of defense in controlling AIDS, therefore, is to inform and educate individuals about high-risk behavior and about methods of altering behavior to protect against transmission of the infection.¹

The country has been pulled both ways on early sex education. Some officials at federal and state level have been decidedly squeamish about explicit sex education. Religious and moral beliefs have interfered with critical efforts to disseminate accurate and clear public health information. On the one hand, the U.S. Centers for Disease Control has said that education of the gay and IV drug communities would have to be "judged by a reasonable person to be unoffensive to most educated adults beyond those groups." Several major cities have prevaricated about explicit sex education, with New York City at one point censoring an education film for public schools. The national media have had difficulty accepting paid and public-service advertisements about the use of condoms, despite laboratory evidence that they significantly impede the transfer of HIV.

The surgeon general, C. Everett Koop, has called for this "silence to end," to give way to frank, open discussions about sexual practices—homosexual and heterosexual. Sex education materials must be graphic and appropriate to the target audience. Accordingly, they should be clear in warning that fellatio and unprotected vaginal and anal sex with an infected person has a real probability of transmission of the virus. Information given to drug-dependent people must also be frank in describing the risk of transmission from sharing contaminated needles.

Public health departments must be realistic in understanding that behaviors of an intimate or addicting nature are difficult to alter. Many young men and women will not abstain from sex, prostitution, or drug abuse. They need unambiguous instruction about how to engage in gay or heterosexual relations in a reasonably safe manner. Drug-dependent people require clear information about the use of sterile needles, where they can be obtained or, minimally, how they can be sterilized. Thus, the information must be explicit, understandable, and directly relevant to the target audience. Public health officials cannot concern themselves with morality or even the fact that the behavior is unlawful. The ultimate concern is to secure changes in behavior conducive to the health of the people.

Effective mass communication requires a substantial allocation of resources. Harvey Fineberg, dean of the Harvard School of Public Health, points out that when a new brand of cigarettes is introduced around the world, to make that brand of slow death known to the public, the manufacturer expects to spend more than \$100 million. How much should national and state government be prepared to spend to convey a vital health message to the public?

The British government recently mailed a graphic leaflet to every household in the country to help prevent the spread of AIDS. Britain and several other European

countries have also aired regular prime-time television public health announcements. In these countries the prevalence of the infection is far below that in the United States. Yet the U.S. administration and state public health departments have lagged well behind in their preventive public health strategy.

A Widespread Program of Voluntary Testing

One of the foundations for voluntary alteration of behavior is knowledge about serological status. Individuals can make the best decisions about the health of themselves and significant others if they are tested for HIV antibodies. Knowledge of seropositivity can allow a person to take precautions against transmitting the virus, and to seek early treatment.

Testing for the virus should be widely available to members of high-risk groups. Many states now have "alternative test sites" that provide anonymous screening for the AIDS virus. These sites, however, often have long waiting times, inconvenient locations, and uncertain confidentiality protections. The CDC has recommended widescale testing among high-risk populations.² However, there has been no development of a strategic plan or allocation of adequate resources to implement the recommendation.

Testing programs are more reliable and cost-effective when targeted on populations vulnerable to HIV, or where there is a strong possibility of transmitting the infection (see Barry et al. in this issue). Accordingly, facilities for testing should be located in centers for the treatment of drug dependency and sexually transmitted diseases, and in urban areas with high concentrations of people vulnerable to the virus. Groups representing the interests of gays and IV drug abusers should be closely involved in the planning of testing sites, for the object is to maximize the voluntary use of the facilities.

One of the next great challenges in combatting AIDS is to prevent its spread from infected mothers to their newborn children.³ A mandatory duty could be placed on the treating physician to offer an HIV-antibody test to women considering childbirth, or early in the course of pregnancy. However, no test should be given without the informed consent of the woman. This approach provides a public health benefit without encroaching on the autonomy and dignity of women infected with HIV.

Seeking the cooperation of people vulnerable to HIV infection requires sensitive recognition that individuals will not come forward for testing if there is uncertainty as to the accuracy of the result or if the result is not kept completely confidential. As Barry et al. illustrate in this issue, a single enzyme linked immunosorbent assay (ELISA) used to detect antibodies to HIV is likely to register as a false positive in a high proportion of cases,

depending upon the frequency of the infection in the population tested. (The test is more accurate when administered to a high-risk population.) To ensure accuracy, all testing services must utilize the highest quality clinical and laboratory personnel, and must administer corroborative tests (e.g., two or three sequentially positive ELISAs, followed by a Western blot).⁴

Counseling and Rehabilitation Services

Medicine still does not have a full understanding of the natural history of HIV infection (see Mayer in this issue). In this issue, Mueller refers to the considerable proportion of persons infected with HIV who will go on to exhibit some serious manifestations of the infection. Yet there are no reliable indicators as to who will develop symptomatology and what precautions can be taken to reduce the risk of illness.⁵ Given the complexity and uncertainty of test results, it is essential that professional information and counseling services be established as an integral part of a screening program. Counseling is also necessary to assist and support individuals such as drug-dependent people and prostitutes to alter their entrenched patterns of behavior.

Treatment and financial support for persons with drug dependency or sexually transmitted diseases are also an indispensable part of the public health function. At present there are long waiting lists for treatment centers in many American cities with high rates of HIV infection. It simply makes no sense to face an epidemic that is spread by sexual contact and shared use of needles without adequate drug and STD treatment facilities. The law already proscribes prostitution and IV drug abuse. But short of preventive confinement, prostitutes and IV drug abusers will continue to spread the infection unless they are given public support to help free them from physical dependency and the need to make a livelihood. Publicly provided treatment and financial support are necessary health measures in this context.

The Drug-Dependent Population

There has been an alarming rise in the frequency of HIV infection in drug-dependent populations in major cities such as New York (see Ginzburg in this issue). The prospects of improvement look grim in the face of government insistence that drug abuse is a crime that will be dealt with strictly and given the traditional resistance of such populations to behavior change. It is necessary to take a bold step to help drug-dependent people to behave in a safer manner. A comprehensive public health program must include:

- 1) Provision of easier access to cost-free sterile needles;

- 2) Massive and well-directed public education of the dependent population on the health risks;
- 3) Use of intensive and individual group counseling, treatment, and rehabilitation services as an integral part of the program of needle distribution.

This is a politically difficult proposal to accept because it appears both to condone and encourage criminal behavior. However, thoughtful public health programs do not promote drug dependency. The objective is not simply to distribute sterile needles but to ensure safer needle use during the process of education, treatment, and rehabilitation.

Development of a Comprehensive Network of Care and Support

It is estimated that by the end of 1991 there will have been a cumulative total of more than 270,000 cases of AIDS in the United States, with more than 74,000 of those occurring in 1991 alone.⁶ In more than 40 percent of these cases patients will suffer from an AIDS-related dementia that may require psychiatric treatment.⁷

The pattern of services, therefore, must be wide-ranging. Acute hospital services of exceptionally high quality are already provided in most major population centers. Health care for AIDS patients, however, can be both more compassionate and cost-effective through services in the community. The infection is characterized by sometimes frequent and lengthy periods of remission allowing the person to live in individual, group, or nursing homes (see Mayer in this issue).

To accomplish the goal of humane care in a normal environment, services must be made available to individuals in their homes and communities. This can be accomplished by multidisciplinary teams of doctors, nurses, and social workers, providing care where people live and on an out-patient basis. Self-help, support, and advocacy groups can also provide needed assistance. These services are not easy to develop or finance. They require a commitment to careful planning based upon projections of need and a substantial allocation of resources for capital and operational expenditure.

There are two conspicuous problems with care for AIDS patients. First, there are few facilities designed for patients at the closing stages of life. Persons with AIDS can have multidimensional problems, including the need for treatment for drug dependency, sexually transmitted diseases, acute medical problems, and psychiatric disorders. Nursing home and hospice staff are often not trained to meet all these diverse needs.

There also has been insufficient thought and planning for procedures to ensure respect for the person's autonomy and dignity should he or she decide not to accept life-prolonging treatment or resuscitation. Persons

with AIDS need legal advice and encouragement to make living wills or to designate durable powers of attorney to help health care facilities respect their wishes at the final stages of life. Health care facilities should also develop thoughtful protocols for sensitively handling such cases.

Second, the psychological impact of HIV infection can be severe. The organic brain syndrome is associated with marked progressive mental deterioration and disintegration in cognition, emotion, and behavior. There are also non-organic causes of psychological symptoms, particularly depression and anxiety. Knowledge that a person has a precursor to, or a fully diagnosed, disease that is almost invariably fatal and that can bring social rejection, discrimination, and financial ruination understandably causes distress. The mental health services have not developed the capacity to provide the breadth of services required to meet the needs of this population.

Statutes Designed to Protect Confidentiality

Persons with HIV infection have good reason to seek protection of the confidentiality of health care information. High-risk groups are associated with IV drug abuse or sexual behavior, both of which are traditionally considered sensitive and personal. Persons with HIV infection, moreover, may be rejected by family and friends, and may be discriminated against by employers, insurers, and landlords.

The need to protect persons with HIV infection by maintaining the confidentiality of health care information is mandated by considerations of humanity and equity. But there are also good reasons for confidentiality on public health grounds alone. Ensuring confidentiality for persons with HIV infection will foster their cooperation in seeking testing and early treatment for HIV-related conditions; in utilizing treatment centers for drug or alcohol dependency, or sexually transmitted diseases; in participating in counseling programs; and in voluntarily informing their past, present, and future intimate partners of the risk of infection.

A few jurisdictions, such as San Francisco, New York City, and Massachusetts, have enacted statutes that expressly require that information about HIV infection and AIDS be held strictly confidential.⁸ Similar statutes enacted across the country would be just, and advantageous to the public health.

Anti-Discrimination Statutes

People with HIV infection have been penalized for their illness by losing their jobs, their life and health insurance, and even their homes. This is a form of discrimination potentially as troublesome as discrimination on other morally irrelevant grounds such as race or gender.

There are no valid public health or social grounds for excluding persons with HIV infection from a school, a job, or a home, since there is no meaningful risk of transfer of infection in these settings (see Mueller in this issue). Where discrimination is based upon irrational fear or prejudice, it should be unlawful.

Whether unjustified discrimination against a person with HIV infection is in fact unlawful remains an open question. There are statutory provisions at the federal and state level proscribing discrimination against the handicapped. The major provision is section 504 of the federal Rehabilitation Act of 1973. The U.S. Supreme Court has recently supported the view that discrimination against a person with an infectious disease could trigger the protection of section 504 and that public health officials must base their decisions on reliable scientific evidence.⁹

The U.S. Justice Department, however, has argued that "an individual's [real or perceived] ability to transmit AIDS to others is not a handicap . . . and, therefore, does not fall within section 504."¹⁰ This opinion has produced confusion and uncertainty as to the protection afforded to persons with HIV infection.

Any discrimination based on the fear of transmission in a non-intimate setting has no reasonable scientific justification and should be unlawful. Several jurisdictions have enacted strong statutes that expressly prohibit discrimination against persons with HIV infection.¹¹ Given the potential for punitive action within a climate of misunderstanding and fear, every jurisdiction should give serious consideration to enacting AIDS-specific anti-discrimination statutes.

Insurance

When a person develops an HIV-related disease his or her needs for high-quality health care become obvious. Yet this is just the time when there can be doubts about the person's ability to maintain health insurance needed to pay for this care. As the number of AIDS cases and the cost of treatment increase, there is growing pressure on insurers to test for HIV antibodies and to exclude carriers from coverage. On its face, this policy is reasonable and based upon standard actuarial assumptions made throughout the insurance industry. Insurance companies quite lawfully use such factors as high blood pressure and smoking in determining insurance premiums and coverage. HIV infection has become at least as good a predictor of ill health as these factors. The insurance industry is asking, "Why should we be prohibited from using HIV as a statistical predictor of health in the same way as for other reliable medical indicators?"

Once society accepts these actuarial assumptions to determine who can and cannot be financially protected

against potentially catastrophic illness, it is virtually impossible to plead a special case on behalf of persons with HIV. The main policy focus, however, should not be on sterile statistics but on avoiding the catastrophic consequences of a terminally ill person having to pay the costs of health care. At present, an AIDS patient without adequate insurance has to pauperize him or herself before being eligible for state benefits.

The solution to this problem must recognize the person's need for treatment, together with the insurer's need for financial stability. There are several possible solutions. First, the states could create a pool for medically high-risk individuals. This could be financed from the tax base or from an insurance surcharge. A similar kind of mechanism would be for the states to require insurers to cover persons with HIV infection. In order to avoid an unfair burden on any single carrier, the state would fairly distribute the burden among all insurers. A second possible solution would be to develop a scheme analogous to Medicare End Stage Renal Disease coverage, specifically for HIV-related conditions. A third possible solution would involve the federal government in developing proposals for catastrophic health insurance. A limited proposal to assist the elderly population is currently reverberating around the federal government. Notably, this proposal has not even considered the highly publicized insurance needs of persons with HIV infection.

Conclusion

Persons with AIDS are gripped by a devastating disease process. In addition to coping physically and psychologically with the disease, they may have had to face rejection, alienation, discrimination, and financial ruination. The challenges ahead will test society—its fairness, compassion, and expertise in law, medicine, and public health. We are at a pivotal moment in the epidemic. Federal and state governments must act now to devise the policies and allocate the resources necessary to combat AIDS. Failure to devise and implement strong policies will cost the country its most vital resource—the health and well-being of a predominantly young and vigorous population.

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