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AIDS—PUSHING THE LIMITS OF SCIENTIFIC AND LEGAL THOUGHT

Jane Aiken*

Perhaps one of the greatest challenges to the scientific and legal community confronts us now—not by choice but by tragic happenstance. It has taken the form of a mysterious disease that is striking down its victims at an alarming rate. The disease is AIDS. The scientific community is pushing the limits of medical knowledge in its effort to cure and contain the illness. At the same time the legal community, in the face of scientific uncertainty, must balance the needs of a frightened public and the rights of those persons who are affected by the disease. One thing is clear: it is important for the law to confront these challenges by anticipating needs before they overwhelm us.

I. THE MEDICAL FACTS

In order to understand the legal implications of the disease, one needs to know a little about its medical history and prognosis. Acquired Immunodeficiency Syndrome or AIDS is acquired damage to the immune system. That damage makes the body susceptible to otherwise rare opportunistic infections. The disease was first identified in 1981. At that time approximately 60 cases were identified in the United States. There are now over 20,000 known cases. The figure is expected to double every ten months. To date AIDS is terminal and there is no cure in sight.

AIDS is the diagnosis when the person shows a suppressed immune system

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with one or more of the serious opportunistic infections, such as Kaposi Sarcoma or certain kinds of pneumonia. AIDS-Related Complex or ARC is diagnosed when the person shows signs of immune suppression with a pre-AIDS condition ranging from swollen lymph glands and flu-like symptoms to more serious diseases. It is unclear how many people suffer from ARC. Finally, a third level of diagnosis is a positive test for HTLV-III or AIDS antibody. In March 1985, an experimental test, known as the ELISA test, was approved to screen blood for the presence of the AIDS antibody. Presence of the antibody indicates that the person has been exposed to the AIDS virus, although the immune system may produce the antibody even though the virus is dead. Furthermore, the ELISA test yields a high proportion of false positives—erroneous reports of the antibody's presence. If a person tests positive on the ELISA, a back-up test called a Western Blot is used. It is more expensive but somewhat more accurate. A person carrying the HTLV-III antibody may have absolutely no outward symptoms of AIDS, but it is believed that such an apparently healthy person may nonetheless harbor the virus and thus be capable of transmitting it through their blood or semen.

The Centers for Disease Control estimate that in five years as many as three million people around the world will develop traces of the AIDS antibody and that 20–30 percent of those people will develop the full-blown disease. As a public health menace, the severity of AIDS has been compared to the 1919 influenza epidemic. It is currently the most common cause of death of males between the ages of twenty-one and forty-four.

There is a great deal of confusion about what causes AIDS. Epidemiologists understand how the disease acts in the body. They do not as yet know how to stop it. To date, there is no cure and no vaccine. Most people die within eighteen months of a diagnosis of AIDS. AIDS cannot be contracted through casual contact. It is communicated through blood and semen. Although the virus has been isolated on rare occasions in saliva and tears, medical evidence indicates that the disease cannot be spread through these bodily fluids.[1] There is, for example, no known case of a person getting AIDS from someone else in his or her family or household, in the absence of sexual contact.[2] The virus is not hardy. It appears to require an exchange of blood and/or semen and perhaps a host with an already depressed immune system. In the United States, the majority of those persons with AIDS are homosexual men or intravenous drug users. This does not tell us much about the disease. In Africa, the disease afflicts heterosexual people with no history of intravenous drug use and is spread

[1] *See* Friedland, Saltzman, Rogers, Kahl, Lesser, Mayers, and Klein, *Lack of Transmission of HTLV-III/LAV Infection to Household Contacts of Patients with AIDS or AIDS-Related Complex with Oral Candidiasis*, 314 NEW ENG. J. MED. 344 (1986). *See also Prospective Evaluation of Health Care Workers Exposed via Parental or Mucous-Membrane Routes to Blood and Body Fluids of Patients with Acquired Immunodeficiency Syndrome*, 33 MORBIDITY AND MORTALITY WEEKLY REP. 182 (1984).

[2] The one exception is the transmission of the disease from a pregnant woman to her unborn child.

by sexual contact. The location of the disease in the homosexual community here is apparently happenstance.

Despite the clear evidence that AIDS cannot be communicated through casual contact, much of the public has been blinded by fear of this disease. In a *Los Angeles Times* poll, 51 percent of those polled said that they favored quarantine for persons with AIDS. It is this public fear and misinformation that has given rise to the need for civil libertarian vigilance in coping with the AIDS crisis.

II. THE LEGAL ISSUES

The response to AIDS has come both from the public and private sector. Legislatively, there have been a number of proposals. Some of the legislation has anticipated the problem of discrimination against those persons with AIDS or persons perceived to be at risk of having AIDS. Unfortunately, some of the other legislative and regulatory proposals reflect a misunderstanding of the disease and create a serious threat to civil liberties.

A. AIDS as a Handicapping Condition

It was generally assumed that persons with AIDS would be considered handicapped under Section 504 of the 1973 Vocational Rehabilitation Act, since the physical debilitating effects of AIDS seem to fit neatly under the statutory definition of handicapped. Indeed, many states have used state laws preventing discrimination on the basis of handicap to protect persons with AIDS, or who are perceived to be at risk of AIDS, from job discrimination and from discrimination in education and insurance. In late June of 1986, the Justice Department's Office of Legal Counsel issued an opinion which recognized that AIDS may be a handicap. Nevertheless, the opinion creates a significant opening for AIDS-related employment discrimination. It says that even though an employer could not fire an employee because he was suffering from the disease, such a firing would not be prohibited by the Vocational Rehabilitation Act if the employer was acting to protect the workplace from contagion even if the fear of contagion was wholly irrational. This opinion affects the federal executive branch, federal contractors, and those in receipt of federal funds. It does not require cities and states with laws protecting the handicapped to import this loophole.

B. Reporting of AIDS Test Results

The Executive Director of the Association of State and Territorial Health Officers urged at a national meeting of that group that there should be mandatory reporting of positive HTLV-III antibody tests and contact tracing of all sexual partners. Many states have instituted mandatory reporting of persons

diagnosed with AIDS and have extended that reporting to those persons who test positive for the HTLV-III antibody. These reporting statutes are generally not supported by parallel statutes that ensure the confidentiality of the test results.

The reason for such mandatory reporting is unclear, particularly when balanced with the potential for discriminatory use. The test results have limited value as a public health measure. Only 10-33 percent of those who repeatedly test positive come down with AIDS. Given the possibility of an extended incubation period, contact tracing is severely hampered as well. The test is flawed by its high false positive rate. While that flaw may be tolerable when the test is employed to exclude the donation of possible infected blood and thus protect the blood supply, other uses present very different questions. For example, some employers have considered using the test to screen job applicants. Other policy makers have considered requiring some workers to carry cards indicating that they are free from AIDS—cards they presumably could not obtain if they tested positive.

Currently, the United States government rejects all new military recruits who test positive for the HTLV-III antibody. The Centers for Disease Control report an incidence of 1.5 per 1,000 applicants for military service with evidence of AIDS infection.[3] The test has just been instituted for all current military personnel. A positive test results in discharge from military service.

The test is not only being considered for use in the employment arena. Insurance companies are alarmed at the high cost of medical care for people with AIDS. Many companies are proposing to test prospective insurance holders for the AIDS antibody and deny coverage or assess higher premiums if the antibody is present. In fact, in a number of cases health insurance has been cancelled simply because the medical record reflected a request by the patient for the HTLV-III test. This does not mean that persons with AIDS do not get medical care. It merely means that such medical care costs are shifted to the state.

Several legislatures are considering a mandatory blood test for the HTLV-III antibody before granting permission to marry. While the requirement may seem analogous to testing for traditional venereal diseases like syphilis, there is an important difference. A person with syphilis can obtain treatment and then marry. But persons exposed to the AIDS virus will test positive for the antibody the rest of their lives, although they may never actually come down with the disease. Such a law would thus create an absolute prohibition on marriage, not only for people with AIDS, but even for some people who are healthy.

Making reportable the names of those persons who test positive for the HTLV-III antibody is likely to have additional unwanted consequences. Many people at risk of AIDS fear that if their names are reported they may be identified and thereby suffer widespread discrimination. Consequently some persons who may be infected with the AIDS virus are avoiding medical treatment (and

[3]*See* The New York Times, June 26, 1986, "Rise in AIDS Virus Infection Is Detected."

the resulting required reporting) until it is absolutely necessary. This delay may hasten the death of the individual. The risk of having one's name associated with the disease may cause people to avoid giving blood for fear that they may be stigmatized. In Tucson, Arizona, the local Red Cross Branch surveyed a cohort of low-risk blood donors to ask if they would be deterred from giving blood if a positive test would be reportable to the state. One hundred percent said they would not continue to give blood out of fear that they would be stigmatized by an incorrect positive result. This could result in a decrease in the nation's blood supply.

C. More Extreme Measures Such as Quarantine

Along with reporting statutes, some states have invoked the public health quarantine power. New York State's Public Health Council has used its quarantine power to authorize the permanent closure of gay men's baths. In November of 1986, the voters of California will consider a referendum placed on the ballot by the supporters of Lyndon LaRouche that would require quarantining of all persons with AIDS or indication of the AIDS antibody. The use of the quarantine power raises fundamental issues concerning the exercise of police power and protection of individual liberty. Most state quarantine laws are broad in coverage and are given great deference by the courts. Generally, the power to quarantine has only been deemed necessary when the disease was communicable by casual contact. Given the fact that AIDS is a blood-borne disease transmitted only through the exchange of semen or blood, the use of quarantine power appears inappropriate, yet states continue to add AIDS to the list of quarantinable diseases.

Perhaps one of the reasons that such repressive legislation is being considered is that, at least in this country, the heterosexual population has not seen itself at significant risk of contracting AIDS. Since AIDS has been identified with the gay community, much of the legislation targets this discrete and insular minority. In Indiana, it appears that the state health director considered closing all public establishments where gay men congregate regardless of whether any sexual activity occurs there, on the theory that this will curb the spread of HTLV-III. The New Jersey legislature considered a proposal to regulate gay bookstores by requiring them to maintain registries of their customers and making the bookstore liable if any patron contracts AIDS. Two New Mexico state legislators plan to introduce a bill to recriminalize consensual sodomy which was decriminalized in 1976. They claim the bill is necessary to prevent the spread of AIDS. Indeed, fear of AIDS may well have contributed to the recent Supreme Court opinion in *Bowers v. Hardwick*, which upheld the application of laws prohibiting consensual sodomy to homosexuals.

D. AIDS in Schools and Prisons

The problem of balancing public concern about the spread of the disease against protection of those with the disease also arises in the school and prison context. In the fall of 1985, the debate about AIDS intensified. Parents concerned about their children's vulnerability to this life-threatening disease placed considerable pressure on school boards to prevent children with AIDS from going to school. Such children typically contracted the disease after being transfused with infected blood. The issue was addressed in seven states and the District of Columbia. Only two of those states permitted children with AIDS to remain in school. Since that time the Centers for Disease Control have issued guidelines that indicate that children with AIDS should be allowed into school unless they have open sores. Of course, this has not quieted many parents' fears and leaves open many questions on how such guidelines should be enforced. As the number of children with AIDS increases, the pressure on our educational institutions rises.

Dealing with AIDS in prison creates the same tension as in the school context, with the same necessity for government response. It is estimated that as much as 80 percent of the entire New York State prison population would test positive for the AIDS antibody. Inmates who fear contracting AIDS in prison are calling for mandatory screening and segregation of people who test positive or are diagnosed as having AIDS. Those prisoners with AIDS are fighting the use of isolation and the restrictive conditions that flow from segregation. Medical care in prison is often inadequate and diagnosis of AIDS is often delayed, resulting in early deaths due to a lack of understanding of how the disease progresses. Prison personnel are concerned about the risk of exposure to the AIDS virus, and many are unwilling to have any contact with an inmate with AIDS. Prison administrators argue that isolation is necessary to protect the life and safety of the inmate who is diagnosed with AIDS. They also note that spread of the disease is likely, given the incidence of both consensual and nonconsensual sex in prison. There have been proposals to set up an "AIDS colony"—a specific prison designated for inmates with AIDS. Civil libertarians are troubled by the pitting of the rights of the inmate with AIDS against the rights of the inmate population concerned about the transmission of AIDS.

E. Prevention

Doctors knowledgeable in the research concerning AIDS have urged that the best way to prevent the spread of the disease is to educate the public about unsafe sex practices and hygienic needle use. Many state health departments have been approached by groups who are willing to produce brochures and other educational devices concerning ways to prevent the spread of AIDS. These departments have been reluctant to assist financially or otherwise in the production and distribution, on the theory that the government should not assist

in criminal acts, i.e., sodomy and illicit drug use. Despite the evidence that education is the most effective means to curb the spread of AIDS, the Centers for Disease Control have held up publication of educational materials on AIDS out of concern that the government may be producing pornographic materials. In fact, before any federal money can be used for the production of educational materials, a five-person review panel chosen from non-target groups in the local community must pass on the materials. The federal guidelines instruct this review board not to allow materials that are too explicit and show the anal or genital area. The scientific literature indicates, however, that the more detailed and explicit the educational material is, the more likely it is to effect significant behavior changes. Unfortunately, the politics of AIDS may be hampering effective strategies for coping with the disease.

No matter what one's views are about the phenomenon of AIDS, we are not able to avoid its impact. In the near future, we will see an ever expanding number of people coming down with the disease and more and more legislation that attempts to cope with the myriad problems AIDS poses for us as a society. We must avoid both the urge to ignore it in hopes that it will go away and the urge to separate ourselves from the victims and punish them for the disease, as if such punishment will keep us safe. It is essential that we respond to AIDS with knowledge and compassion.