AIDS: Law, Ethics, and Public Policy

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Background

Acquired immunodeficiency syndrome, better known as AIDS, has developed in the decade of the 1980s from an unknown, unnamed disease to an epidemic familiar to all. By the end of 1987 there were 48,139 cases known to the U.S. Public Health Service’s Centers for Disease Control (CDC) in Atlanta, where all infectious diseases are reported and nationwide statistics are compiled. The world total at the end of 1987 was 73,670 (a World Health Organization — WHO — figure). This is probably under-reported since accurate surveillance is not possible in such places as Africa, where cases have doubled annually since 1984, and where WHO fears that the numbers reflect only a fraction of existing cases. The Public Health Service has predicted that the number of U.S. AIDS cases could be 270,000 in the early 1990s, just a few years from now.

The AIDS virus is primarily transmitted either sexually or by use of contaminated needles by drug users. Infected persons initially become asymptomatic carriers of the human immunodeficiency virus (HIV), which was first identified in 1983 by French and American scientists when it was known as the HTLV-III/LAV virus. Clusters of persons with Kaposi’s sarcoma, a formerly rare skin cancer, and pneumocystis carinii, a virulent pneumonia, began to be reported to the CDC in 1981, with formal surveillance of the disease beginning the following year. Once the HIV infection becomes a full-blown case of AIDS, there is no known cure; at present AIDS is thought to be uniformly fatal.

Once a person is infected with the virus, he or she can pass it to others via bodily fluids, such as blood or semen. Prior to the development of the ELISA antibody test in 1985, recipients of blood transfusions were at risk. Now all blood and blood products donated in the United States are screened to detect HIV contamination.

As the disease spreads, public concern grows. What was once considered a threat primarily to homosexuals and intravenous drug users is seen as endangering all who are exposed to the blood or semen of infected persons. The epidemiology of the disease in central Africa, for example, clearly demonstrates that AIDS can afflict heterosexual, non-drug-using populations.
Ethical Issues

Ethical issues are involved in all aspects of AIDS. Three notable areas are: (1) clinical treatment for AIDS patients and its funding; (2) protecting the public health and establishing public health policies; and (3) carrying out research aimed at preventing or curing the disease.

Communicability has been an important issue for health care personnel involved in the care of AIDS patients. Those who come into contact with bodily fluids, blood and blood products are at risk for the infection and also constitute a possible source of spreading the virus to their patients who are ill from other causes.

Confidentiality is a major concern for those infected by the AIDS virus as well as those who are tested for antibodies to the disease. Patients and their family members face problems involving the loss of privacy and stigmatization as a result of infection.

Another ethical dilemma arises over the need to decide appropriate treatment when the disease reaches an advanced stage. Decisions include whether to forego life-sustaining treatment in favor of supportive or palliative care; who should make the decisions if the patient becomes incompetent; and, finally, when should a treatment be deemed useless. Care involves both value questions and technical judgments.

Because of the fatal outcome of the disease, AIDS patients must prepare for the time when they become incapacitated and for their eventual death. Advance directives and durable powers-of-attorney may be used by persons who wish to keep decision-making powers in the hands of those who will carry out the patient’s wishes.

Allocation of scarce medical resources and funds also raises ethical questions, since the expenses of life-sustaining technologies will not provide a cure in the fatal course of the disease.

Questions have been raised concerning the obligation of health care personnel to treat AIDS patients. In November 1987 the Council on Ethical and Judicial Affairs of the American Medical Association issued a prepared statement saying that a physician may not refuse to treat patients who are infected with the AIDS virus. It called on physicians who are themselves infected to act in such a manner that transmission of the infection to patients is not possible.

Information Sources

The following are on-going sources of information to the literature of AIDS, and some of them also present developments in research, governmental policy decisions, statistics and other documents pertinent to this epidemic disease.


Several recently initiated periodicals can be consulted for the very latest information about AIDS. They are:

- AIDS AND PUBLIC POLICY, published quarterly by University Publishing Group, Inc., 107 E. Church St., Frederick, MD 21701; $95 per year.
- AIDS POLICY & LAW, published twice monthly by Buraff Publications, 2445 M St., N.W., Suite 275, Washington, DC 20037; $387 per year.
- A.T.I.N.: AIDS TARGETED INFORMATION NEWSLETTER, sponsored by the Foundation for AIDS Research; published monthly by Williams & Wilkins, 428 East Preston St., Baltimore, MD 21202. Annotated bibliography of recent literature from clinical, epidemiological, immunologic, legal, ethical and other areas concerned with AIDS.
- NEW FACES OF LIFE, published by the Canadian Public Health Association’s AIDS Education and Awareness Program, 210-1335 Carling Avenue, Ottawa, Ontario K1Z 8N8 CANADA.

Three bibliographical resources are:
A specialized bibliography of the “preclinical, clinical, epidemiological, diagnostic and prevention” literature is available from the National Library of Medicine (NLM) through the U.S. Government Printing Office. From 1983 through 1987 fifteen such bibliographies were prepared and distributed by the NLM’s Reference Section as part of the Literature Search series. Beginning in 1988 the series title has become AIDS Bibliography [GPO List ID: AID88]. The first issue is planned for April 1988. Annual subscriptions for the quarterly updates are $12 ($15 foreign); individual issues are $3 ($3.75 foreign) from: Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402 (1-202-783-3238).

Citations for new publications on ethical, legal and public policy issues raised by AIDS may be obtained by searching BIOETHICSLINE, using “acquired immunodeficiency syndrome (kw)”. For assistance in searching BIOETHICSLINE, call 1-800-MED-ETHX (1-800-633-3849) or 1-202-687-3885. Individual offline searches are available from the National Reference Center for Bioethics Literature, and will be mailed directly from the National Library of Medicine. Any publications listed in this Scope Note or in any BIOETHICSLINE printout which are not available locally can be obtained through the Document Delivery Service of the National Reference Center for Bioethics Literature in compliance with copyright law.

AIDS: ISSUES IN RELIGION, ETHICS, AND CARE, (1988) is an annotated bibliography of materials concerning the religious and moral issues related to AIDS published January 1980 through June 1987. It is available from Park Ridge Center, 1875 Dempster St., Suite 175, Park Ridge, IL 60068; $9.95 plus $1.00 for postage and handling.

Journal Articles


The role of the courts in the protection of individual rights and liberties in response to public health measures enacted concerning AIDS is examined. The history of epidemics and public health regulation, including the landmark 1905 Jacobson v. Massachusetts case, in which the Supreme Court determined guidelines for the constitutionality of public health regulations, is outlined. Concern about the potential infringement of civil liberties is raised, since much regulation affects constitutional rights such as privacy, free association, and property. The author foresees a central role for legislators, but cautions against the promulgation of unnecessarily restrictive public policy.

The author views the public health response to AIDS as particularly difficult given the fact that transmission takes place in the context of intimate, sexual relationships. Our society’s tradition of philosophical individualism, with an emphasis on privacy and individual rights, makes this a difficult problem to address. The problem is whether public intervention is appropriate in cases where private acts have public consequences.


AIDS antibody screening is an important issue, since blood tests are already in use in many settings and broader testing is proposed. New programs for HIV antibody screening should be subjected to ethical analysis, and universal mandatory screening can only be justified when medical or therapeutic intervention is available, or, in the case of a highly infectious pathogen, where the risk to others is great. Voluntary behavior modification is the best course of action to reduce the incidence of AIDS.

The chief workplace issues relating to AIDS are employment, and then access to and benefits from health and life insurance. Rejecting the notion that the AIDS threat is primarily an economic issue, the authors declare it to be a
moral and social problem, which should be reflected in our public policy choices. Following a discussion of blood testing and screening, they conclude that current information does not justify a more restrictive public health policy for persons with AIDS compared to other diseases.

Beauchamp points out the need to (1) broaden our vision of the “common good,” (2) reject legal moralism, and (3) stop using laws to promote standards of public morality, rather than to prevent physical harm. He urges aggressive public education campaigns against AIDS.

The British Medical Association vote that informed consent is not necessarily required prior to testing for HIV infection prompted this editorial about informed consent in the context of AIDS. Noting clinical and ethical opposition to such a policy, it concludes that the law cannot be used to prevent the spread of HIV infection, but can be used to discourage what it calls “reckless” behavior.

Business managers are faced with several problems regarding AIDS. Employment discrimination may result if fellow employees refuse to work with those who have AIDS or if an employee with AIDS is dismissed. Education, such as that demonstrated by IBM and Wells Fargo, is viewed as an important management tool. The effect of the AIDS epidemic on the health and life insurance industry is quantified.

The author, a law professor, gives an overview of the issues which have come to dominate the legal debate about AIDS. The rights of individuals with regard to testing, treatment, confidentiality and non-discrimination, as well as access to health care and other services, are discussed. Dickens also focuses on the rights and duties of HIV-infected persons, non-infected persons and health professionals.

Disease surveillance is a traditional and routine public health concern. Compulsory notification to health authorities began around the turn of the century. The AIDS epidemic has brought many of the long-standing, unresolved issues of disease reporting back to a central place in public health policy debates. The author points out that mandatory reporting has never been a purely technical issue, but rather one laden with politics and conflicts of values. Fear of stigmatization and concerns about confidentiality and the uses of information are the primary concerns of gay men in the surveillance of AIDS. The controversy will certainly occupy an important place in public health debates for some time to come.

Focusing on the ethical, legal and economic challenges to Catholic hospitals, this special AIDS report advocates that Catholic and Christian care-givers provide compassionate care to all. Topics include: formulating public policy; recognition of our collective responsibility; financial responsibility for the AIDS epidemic; an examination of Catholic health care and attitudes toward AIDS patients; the role of pastoral counseling, patients’ emotional needs; and legal implications for health- care providers.

Gillon argues that it is wrong to screen for HIV antibodies without a patient’s informed consent, noting that covert testing is unnecessary due to the ease with which consent is normally obtained.

Gostin, Larry, and Curran, William J., AIDS...

Both selective and universal mandatory screening for HIV antibodies is opposed here because it is unlikely to lead to behavioral changes which would impede the spread of the disease, and because of the potential negative impact on such civil liberties as privacy and freedom from discrimination.


Beginning with the 1905 U.S. Supreme Court decision in Jacobson v. Massachusetts, courts have been reluctant to impose limits on the types of measures which authorities could take in dealing with communicable disease. Early public health law cases will not serve as reliable guides to current AIDS cases because of the enormous change in thinking about individual rights and liberties. The authors conclude that public policy makers can be assured of legal and political support for AIDS infection control measures based on scientific findings, not hysterical reaction and vague, undocumented fears.


The authors describe the ethical principles that should form the foundation for public policy when a deadly infectious disease exposes the inherent conflict between public health and individual liberty. These include the moral duties of health care providers, the extent of appropriate care, and the ethical implications of restricting the individual liberties of victims of AIDS to control an infectious disease.


This article looks at the Australian legal and legislative response to AIDS. Kirby describes earlier Australian epidemics and the hysterical reaction to them, and sees a particular tragedy in the fact that just as attitudes toward homosexuals were changing, the AIDS crisis has re-ignited prejudice. The author, an Australian jurist, catalogues the national legislative response ranging from proposals for projections of severe financial strain on the health care delivery system and by extensive media coverage of AIDS, is described. Topics discussed include: the system used to determine eligibility for government help, resource allocation, financial risk to insurers, and the difficulty in addressing public health issues. It says that physicians will occupy a central place due to their influential role in government, in organized medicine, and in direct patient care.
universal testing, quarantine and compulsory detention to mere advocacy of “safe sex” education.


Public concern about the safety of the nation’s blood supply and the fear of its contamination by the AIDS virus has led to a broad debate centering on the public health issue of individual freedom versus the protection of the common good. The authors oppose mass screening of individuals in high risk groups and consider such key ethical issues as: protecting confidentiality, the problem of false negatives and positives, and the implications of public health intervention via restriction of sexual activity.


This review of AIDS-related litigation and legislation covers the legal aspects of public health legislation and regulation, the question of legal liability after AIDS transmission has occurred, and the status of lawsuits related to various forms of AIDS discrimination.


The AIDS epidemic is viewed as posing the most serious constitutional law/public health issues since the U.S. Supreme Court upheld compulsory immunization in 1905 (*Jacobson v. Massachusetts*). The authors assert that any restraints which may be imposed on civil liberties and personal freedom should be commensurate with the social costs imposed by the disease.


The author maintains that “state-mandated” discrimination exists against AIDS victims, as evidenced, for example, by the armed forces’ mandatory screening policy. The issue of state paternalism is discussed and a distinction between harm to oneself and harm to others is made. A paternalistic position cannot be justified when the risk of harm to others is not great.


Can we provide adequate health care to all those who need it, and maintain the financial integrity of our private health insurance industry? Is it ethical for insurance companies to screen and eliminate poor risks? This article deals with these and other fundamental issues in health care resource allocation and the conflict between the values of efficiency and equity. The uncertainty about the ultimate effect of the AIDS epidemic on the consumption of health care resources has added urgency to the debate on national health insurance.


The improbability of effectively combatting the AIDS virus with existing knowledge is accompanied by an official reticence to discuss the types of sexual behavior which are thought to contribute to the spread of AIDS. At the present time, prevention is the most appropriate course to follow. Osborn concludes that impressive technical advances (e.g., the rapid development of the HIV antibody assay) have outdistanced society’s ability to deal with the social and behavioral issues involved.


Basic biomedical research is crucial to understanding and ultimately eliminating the threat of the AIDS virus. The contentious aspects of the public debate center around the adequacy of research funding and the direction such research should take. The author, a virologist, describes the history of AIDS research and urges more effective planning of
research dealing with unexpected health emergencies.


The focus here is the problems and legal rights of low-income persons with AIDS, a group that has been disproportionately affected by the disease. Legal services attorneys can help such low-income clients, who are particularly vulnerable to discrimination in health care delivery, gain equal access to high quality health care.


The public health crisis surrounding AIDS is viewed as being inextricably interwoven with society’s values and attitudes. Social institutions, such as mass communications, combined with the population’s easy mobility, complicate the discovery and treatment of AIDS. Concern for medical confidentiality, civil liberties, discrimination and sexual identity contribute to the complexity of dealing with the disease. Also considered are the constitutional and public health issues involved in the debate over the 1984 closing of gay bathhouses in San Francisco.


Is it ethical to recommend supportive care over life-sustaining care when the average survival time following hospitalization for opportunistic infection is 8 months? This question, as well as the use of advance directives, durable powers-of-attorney, and the need to plan for the patient’s incompetence are addressed. A distinction is drawn between cessation of treatment for reasons of medical futility versus resource issues. Value judgments, not merely technical decisions, are made in such circumstances.


Homosexual men at outpatient AIDS clinics in San Francisco participated in this survey. Attitudes toward the use of advance directives and proxy decision-making were examined and it was found that homosexual AIDS patients often prefer that partners or friends exercise such powers. Patients tended to overestimate the effectiveness of life-sustaining treatment. It is suggested that doctors and health-care professionals counsel patients on the use of advance directives for terminal care and discuss the efficacy of life-sustaining treatment in the context of this fatal, progressive illness.


The authors discuss personal risk to physicians and the need for physicians to confront their biases about occupational risks in making health care decisions. Since the HIV virus may affect brain tissue, the competency of AIDS patients to give consent is questioned. Also discussed is the problem of apportioning costs involved in therapeutic AIDS research and the ethics of controlled clinical trials.


Walters thinks the major ethical question posed by the AIDS epidemic is how to control the epidemic while protecting individual freedom and preventing unjust discrimination against particular social groups. He surveys the implications for public health policies, delivery of health care, and research.

Books and Reports


This broad social and political analysis of the AIDS epidemic gives particular attention to the non-medical aspects of the disease (particularly the conceptualization of AIDS as a “gay
disease”), and to the initially sluggish response on the part of the government in confronting the epidemic.


Written to help managers respond to issues relating to AIDS in the workplace, this booklet addresses: how to respond to rumors and co-worker concerns, legal issues, legal implications for managers, and relevant laws.


AIDS articles (previously published in the *Journal of the American Medical Association*) covering clinical, historical, and research issues offer an excellent overview of scientific, social and ethical aspects.


With funding from the U.S. Public Health Service, the Project prepared these reports to assist state governments in developing and implementing AIDS policies. The first volume guides the reader through the complex administrative procedures involved in managing AIDS programs at the state level; the second volume is a guide to financing AIDS programs and services; and the third is a resource manual to AIDS literature and services.


Issues ranging from job discrimination to informed consent in antibody screening are discussed in this compendium of national legislative reaction to the AIDS epidemic. This summary of 1986 state legislation includes both laws and a synopsis of legislation which was introduced but failed to become law during the same period.


Aimed primarily at persons involved in making and implementing policy in correctional facilities, this report is intended to assist personnel in understanding the complex issues which AIDS raises in prisons. It provides an overview of the causes, transmission and incidence of AIDS, as well as HIV antibody screening and concludes with a discussion of the medical, legal and correctional management issues.


Various AIDS-related issues are considered from a legal perspective, such as treatment refusal by a hospital, the rights of hospital employees with AIDS (as well as the right of a hospital to know of an employee’s illness with AIDS), and the status of AIDS antibody testing and confidentiality requirements.


This companion volume to **MOBILIZING AGAINST AIDS** describes in stark terms the potential of the AIDS epidemic, foresees catastrophe if the course of the epidemic is not checked, and recommends broad measures, including substantially-increased funding for research ($1 billion by the end of this decade). In addition to stepped-up research efforts, the panel recommends a massive educational program to increase public awareness about ways to prevent transmission of the AIDS virus. The report recommends on-going monitoring of the disease because of the rapid pace of infection and the efforts to combat it. To this end, the panel proposes the creation of a National Commission on AIDS as an advisory
body to Congress and the President.


The October 1985 annual meeting of the Institute of Medicine was devoted to the topic of AIDS. This non-technical volume of the proceedings of that meeting presents the then-current state (1985) of medical knowledge about the disease, and summarizes the range of current issues about AIDS. It describes the discovery of the HIV virus and attributes the rapid identification of the AIDS pathogen to major advances in molecular biology and virology over the past generation. Appendices include the Center for Disease Control’s definition of AIDS and the Public Health Service’s guidelines for preventing its transmission.


The Commission plans to investigate the following before issuing its final report, due June 24, 1988: the lack of drugs to treat AIDS patients, the lack of information concerning the spread of the disease, the need for health care programs out of hospitals, and the need for programs to treat drug users.


The response of the clergy and laity to AIDS is examined. Special attention is paid to the responsibilities of religious bodies.


C. Everett Koop, Surgeon General of the United States, has become an important spokesman in the national debate on AIDS. The report has generated considerable controversy because of its frank discussion of sexual practices thought to play a role in the transmission of AIDS, and because of Koop’s advocacy of the use of condoms to prevent transmission of the disease. Koop stresses that national efforts must be aimed at fighting AIDS as a disease, not those who have it. Koop opposes routine compulsory blood testing of individuals, and he thinks that AIDS can be controlled and prevented by adequate education and behavior modification.


The Justice Department concludes that discrimination against persons based on the disabling effects of AIDS is unlawful under Section 504 of the Rehabilitation Act, but finds that discrimination based on a person’s real or perceived ability to transmit the virus is legitimate and cannot be considered a handicap under the Act. Thus, this memorandum sanctions actions which are taken by persons to prevent the transmission of the virus, even if the perceived threat seems unlikely to cause harm.

Court Decisions


The City of New York presented evidence that sexual activity with a high risk of spreading the AIDS virus took place at a gay public bathhouse and ordered it closed. The New York State Supreme Court found that this closing did not violate patrons’ First Amendment rights of association and privacy.


The Court held in a 7-to-2 decision that a person suffering from a contagious disease (in this case tuberculosis) was a “handicapped individual” within the intended meaning of the Rehabilitation Act of 1973, which prohibits recipients of federal funds from discrimination based solely on their handicap. This decision,
with its clear implications for persons with AIDS, calls into question the Department of Justice ruling mentioned above.

Additional Readings


Miller, David; Jeffries, Don J.; Green, John; Harris, J.R. Willie; and Pinching, Anthony J. “HTLV-III: Should Testing Ever Be Routine?”


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