

AIDS & ETHICS

Facing dilemmas of the AIDS crisis, including

Mandatory HIV testing

Education

Legal issues

Human subjects research

Doctor-patient relationships

Civil liberties and privacy

Health insurance

Militant AIDS activism

and other controversial concerns

EDITED BY

FREDERIC G. REAMER

AIDS & ETHICS

FREDERIC G. REAMER
EDITOR



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For Deborah and Emma

■ Preface

ACQUIRED IMMUNE DEFICIENCY SYNDROME (hereafter AIDS) has given new meaning to the term *crisis*. The numbers alone are staggering, each new set of infection and mortality data often being outdated by the time they are printed.

But the AIDS crisis is exacting more than a death toll. It is also imposing disturbingly novel and provocative ethical questions. Under what circumstances is mandatory screening for this infectious disease warranted? What access should AIDS patients have to nonapproved therapies? Should pregnant AIDS patients be permitted to participate in randomized clinical trials? Should insurance companies be required to insure individuals who are seropositive? What are the limits of AIDS patients' right to confidentiality? Do physicians and other health care professionals have an obligation to treat AIDS patients?

By now, as we bring to a close the first decade of the disease's history, we have a good grasp of the most troubling and troublesome ethical questions. With respect to some, consensus on the answers is beginning to emerge. Few, for example, now argue for widespread or universal mandatory testing. It is also now widely believed that contact tracing should preserve, as much as possible, AIDS patients' privacy.

But with a number of other questions broached in these pages, the only thing clear is that the answers are murky. Do parents of a human immunodeficiency virus (HIV)-infected child have a duty to disclose this fact to parents of the child's playmates? Does a physician have an obligation to warn the spouse of an infected patient who wants this fact kept secret? Should rigorous methodological features that govern AIDS research be relaxed to enhance patients' access to nonapproved drugs?

AIDS and Ethics includes a series of original, seminal essays offering a systematic overview of these and other questions from the perspectives of scholars and practitioners trained in strikingly diverse disciplines and professions. Among the fields represented by the authors are law, medicine, philosophy, political science, religious studies, and social work.

In the first chapter, I explore the broad ethical implications of the AIDS crisis and speculate about the relevance of ethical inquiry, language, and concepts. In the end I conclude that, despite its well-known limitations, applied ethics has much to offer those of us who are troubled by and concerned about the normative dimensions of the disease and society's response to it. I also argue that professionals in the field must look beyond abstract and applied ethical theory and widen their lens to examine their personal moral commitment to work with the AIDS population.

The next several chapters explore the ethical features of a broad range of key policy debates related to AIDS. Ronald Bayer provides a valuable analysis of the shifting tension that has emerged between public health and civil liberties advocates. Bayer traces the evolution of this relationship, beginning with the emergence of AIDS in the early 1980s and continuing along its subsequent course. His insightful assessment offers a sobering look at the historical and political factors that influence the unstable balance between public health safeguards and civil liberties protections.

James Childress focuses specifically on the collection of debates concerning mandatory screening and testing of various populations. Following his presentation of a conceptual template for examining these issues, Childress considers and critiques, in turn, arguments that have been advanced concerning testing and screening of hospital patients, marriage license applicants, pregnant women, newborns, individuals in the state's custody, and international travelers.

Childress' analysis is followed by Carol Levine's comprehensive review of issues related to human subjects research. After her brief review of prevailing ethical standards in research, Levine identifies dilemmas posed by the AIDS crisis, focusing especially on the ethical dimensions of research design, access to nonapproved therapies, the duties of subjects and physicians involved in clinical trials, eligibility for participation in clinical research, and vaccine-related research. As Levine concludes, some of these issues have been largely resolved (such as the need for strict confidentiality safeguards) while others continue to be the subject of intense debate (such as the participation of pregnant women in clinical research on new drugs).

The AIDS crisis has also stimulated considerable debate about health insurance — in particular, emerging insurance industry underwriting practices. Gerald Oppenheimer and Robert Padgug offer a forceful argument that insurers' efforts to limit coverage of HIV-infected individuals and persons with AIDS constitutes a crisis of community. Following their historical review of insurers' shift from an inclusionary "community rating" approach to an exclusionary "experience rating" approach, Oppenheimer and Padgug lobby aggressively for universal and uniform health care coverage. For them, the distressing alternative to universal health care is a fragmented, unfair, and inefficient approach to health insurance that, in the final analysis, will not provide adequate protection to AIDS patients and those at risk for the disease.

One of the most enduring debates concerning AIDS pertains to the use of coercion to contain transmission of the disease. In recent years we have seen a variety of calls for the use of quarantine, isolation, mandatory notification of partners, and other social control measures in an effort to prevent the spread of AIDS. In her chapter on AIDS education, Nora Kizer Bell challenges claims that punitive and coercive measures are the most appropriate public response to the crisis. For Bell, rudimentary principles of democracy call for assertive and frank forms of education designed to prevent the spread of AIDS. Although AIDS may tempt us toward a variety of strict social control tactics, Bell argues that our democratic roots should lead us instead toward voluntary efforts to change attitudes and behavior among those with AIDS or at risk for the disease.

Much of the recent controversy concerning AIDS has focused on the adequacy of public funds dedicated to research, prevention, and treatment. For many, funding has been intolerably inadequate and research progress has been painfully slow. This frustration — along with concern about emerging public policy — has led to diverse forms of militancy and civil disobedience directed at public officials, researchers, religious leaders, and pharmaceutical companies. Courtney Campbell takes a hard, critical look at AIDS activism and assesses the moral warrant claimed by AIDS activists. Campbell explores the extent to which AIDS activists have met the burden of persuasion and the moral criteria that inhere in the tradition of civil disobedience.

Using different conceptual lenses, Robert Levine and Abigail Zuger then discuss vexing questions concerning health care professionals' duty to treat AIDS patients. From a phenomenological framework, Levine dismantles the physician-patient relationship into its component parts and speculates about why physicians ask the question "Do I have a duty to treat AIDS patients?" Levine's task is not to answer the

question itself but rather to explain why physicians are moved to ask the question in the first place. Levine begins with the first "moment" of encounter between physician and patient and sheds light on the dynamics of the evolving relationship that account for this now-common query.

The answer to the question about the health care professional's duty to treat is left to Abigail Zuger. Following her brief historical insight into the behavior of physicians during a variety of plagues and epidemics, Zuger examines the ethical norms that have emerged within the medical profession and among individual health care practitioners. She concludes her discussion with a number of thought-provoking observations about health care professionals' moral duty to treat and what patients have the right to expect of them.

There is no question that issues of intimacy are prominent in any discussion of AIDS. Personal details abound concerning sexual activity, drug use, and test results. Not surprisingly, there is considerable controversy pertaining to privacy of information and limitations imposed on it. Ferdinand Schoeman offers us a systematic review of a broad range of privacy issues that have emerged within the AIDS context. Schoeman reviews the nature of privacy norms in general and discusses the various privacy issues that need to be addressed concerning AIDS. For Schoeman the most compelling questions pertain to therapists' obligations to disclose confidential information to protect third parties who may be at risk because of the behavior of an HIV-infected patient or client, the responsibility of an HIV-infected individual to warn others of his or her potential to transmit the disease, the right of health insurers to private information about applicants, and the responsibility of the state to trace sexual contacts of HIV-infected individuals.

It is difficult to examine this diverse collection of ethical issues without bumping into a variety of compelling legal conundra. By now there is a myriad of statutes and legal precedents on issues such as mandatory testing, privacy, employment and school-based discrimination, protection of third parties, the duty to treat, the use of quarantine, and civil liability. Donald Hermann reviews the range of legal issues and developments triggered by the AIDS crisis and alerts readers to fundamental tensions between protection of individual interests and the public's health. His discussion provides a useful perspective on the legal dimensions of the most prominent debates about AIDS and ethics.

This project could not have been completed without the able assistance of a number of colleagues. As is their custom, my editors at Columbia University Press, Ann Miller and Louise Waller, provided

consistently constructive suggestions and encouragement. Louise deserves special credit for having the imagination that led to this project in the first place and for helping me map the book's content. I was especially impressed by her genuine commitment to the substantive issues addressed here. I also want to thank the Rhode Island College Council and Faculty Research Committee for their support.

It is hard to know how to express my appreciation to the authors themselves. These are among the brightest, most dedicated, and talented scholars with whom I have had the privilege to work. Their unique ability to mesh intellectual rigor with compelling prose — under an unusually tight deadline — impressed me continually. They were remarkably tolerant of my editorial suggestions and requests for yet another draft. I am confident that these authors' insights will provide an important lodestar (and lightning rod, perhaps) to those who care deeply about the AIDS crisis.

This has been a difficult project to complete. It has been simultaneously exciting to forge new intellectual paths that are so important and depressing to face the unrelentingly morbid facts produced by AIDS. No other research has forced me to examine, in so intense a fashion, my own ethical beliefs. The nature of this subject is such that one must confront his or her most basic values and biases. I have learned a great deal in the process.

In this regard, I offer my most heartfelt thanks to my wife, Deborah, and daughter, Emma, who help me to understand what the term *virtue* means.

Frederic G. Reamer

■ Contributors

RONALD BAYER is associate professor in the School of Public Health, Columbia University. He received his Ph.D. from the University of Chicago. Currently Bayer is a member of the Committee to Monitor the Social Impact of AIDS, National Research Council, and consultant to the World Health Organization, Global Programme on AIDS. Formerly he was associate for policy studies at The Hastings Center. Bayer is the author of *Private Acts, Social Consequences: AIDS and the Politics of Public Health* (Free Press, 1989) and *Homosexuality and American Psychiatry: The Politics of Diagnosis* (Basic Books, 1981), editor of *The Health and Safety of Workers: The Politics of Professional Responsibility* (Oxford University Press, 1988), and coeditor of *In Search of Equity: Health Needs and the Health Care System* (Plenum Press, 1983).

NORA KIZER BELL is professor of philosophy at the University of South Carolina (Columbia), where she is Chair of the Department of Philosophy. She received her Ph.D. from the University of North Carolina. Bell serves as a medical ethicist at the University of South Carolina School of Medicine, adjunct associate professor at the University of South Carolina School of Public Health, adjunct associate professor at the University of South Carolina School of Medicine (Department of Family and Preventive Medicine), and was an Exxon Fellow in Ethics and Medicine at the Baylor College of Medicine. She is the editor of *Who Decides? Conflicts of Rights in Health Care* (Humana Press, 1982) and is the author of a number of journal articles on medical ethics.

COURTNEY S. CAMPBELL is assistant professor in the Department of Religious Studies, Oregon State University. He received his Ph.D.

from the University of Virginia. Formerly he was the editor of the *Hastings Center Report* and associate for religious studies, The Hastings Center. Campbell is the author or coauthor of a number of publications on health care ethics, including "The Moral Meaning of Religion for Bioethics," *Boletín de la OPS*; "At the Edges of Life," *This People*; "Plague, Piety, and Policy," *Second Opinion*; "Ethics, Technology, and Resource Allocation in Health Care," *Michigan Hospitals*; "Patients Who Refuse Treatment in Medical Offices," *Archives of Internal Medicine*; and "AZT: The Ethical Debate," *BioLaw*.

JAMES F. CHILDRESS is the Edwin B. Kyle Professor of Religious Studies and professor of medical education at the University of Virginia, where he is also chairman of the Department of Religious Studies and principal of the Monroe Hill Residential College. He received his Ph.D. from Yale University. Childress is a fellow of the American Academy of Arts and Sciences and of The Hastings Center. He is the author of numerous articles and several books on biomedical ethics, including *Principles of Biomedical Ethics* (with Tom L. Beauchamp, 3d ed., Oxford University Press, 1989); *Priorities in Biomedical Ethics* (The Westminster Press, 1981); and *Who Should Decide?* (Oxford University Press, 1982).

DONALD H. J. HERMANN is professor of law and professor of philosophy as well as director of the Health Law Institute at DePaul University College of Law. He received his J.D. from Columbia University and his Ph.D. in philosophy from Northwestern University. Hermann is editor of the *Journal of Health and Hospital Law* and a fellow of the American Academy of Hospital Attorneys. He is coauthor of *Legal Aspects of AIDS* (Callaghan and Co., 1990) and *AIDS Law in a Nutshell* (West, Publishing Co., 1990) and coeditor of *AIDS: Cases and Materials* (John Marshall Publishing Co., 1989). He is also the author of "Torts: Private Lawsuits About AIDS," in *AIDS and the Law*.

CAROL LEVINE is executive director, Citizens Commission on AIDS. She completed her graduate education in public law and government at Columbia University. Formerly Levine was editor of *The Hastings Center Report* and associate for publications, The Hastings Center. She currently serves as managing editor of *IRB: A Review of Human Subjects Research*, and is a member of the Scientific Committee, American Foundation for AIDS Research. Levine is editor of *Taking Sides: Clashing Views on Controversial Bioethical Issues* (3d ed., Dushkin Publishing Group, 1989) and *Cases in Bioethics from the Hastings Center Report* (2d. ed., St. Martin's Press, 1989) and the author or coauthor of numerous articles on the AIDS crisis, including

"Has AIDS Changed the Ethics of Human Subjects Research?" *Law, Medicine, & Health Care*; "The Ethics of Screening for Early Intervention in HIV Disease," *American Journal of Public Health*; and "HIV Antibody Screening: An Ethical Framework for Evaluating Proposed Programs," *Journal of the American Medical Association*.

ROBERT J. LEVINE is professor of medicine and lecturer in pharmacology at Yale University School of Medicine. He received his M.D. from George Washington University School of Medicine. He is a fellow of The Hastings Center and of the American College of Physicians, a member of the American Society for Clinical Investigation, and president of the American Society of Law and Medicine. Levine, former editor of *Clinical Research*, is editor of *IRB: A Review of Human Subjects Research*. He is the author of numerous publications, including *Ethics and Regulation of Clinical Research* (2d ed., Urban and Schwarzenberg, 1986). Levine teaches medical ethics at Yale University.

GERALD M. OPPENHEIMER is associate professor in the Department of Health and Nutrition Sciences, Brooklyn College, City University of New York. He received his Ph.D. from the University of Chicago. Oppenheimer has authored or coauthored a number of publications on AIDS, including "AIDS and Health Insurance: Social and Ethical Issues," *AIDS and Public Policy Journal*; "AIDS: The Risk to Insurers, The Threat to Equity," *Hastings Center Report*; "AIDS in the Workplace," *Business and Health*; "Causes, Cases, and Cohorts: The Role of Epidemiology in the Historical Construction of AIDS, 1980-1989," in *AIDS: Contemporary History*; and "AIDS in the Workplace: The Ethical Ramifications," in *AIDS: Ethics and Public Policy*.

ROBERT A. PADGUG is director of health policy, Empire Blue Cross and Blue Shield. He received his Ph.D. from Harvard and formerly served on the faculty of Rutgers University. Padgug is the coeditor of *Passion and Power: Sexuality in History* (Temple University Press, 1989) and is the author or coauthor of numerous journal articles on AIDS, including "AIDS, Private Health Insurance, and the Crisis of Community," *Notre Dame Journal of Law, Ethics, and Public Policy*; "More Than the Story of a Virus: Gay History, Gay Communities, and AIDS," *Radical America*; "AIDS and Health Insurance: Social and Ethical Issues," *AIDS and Public Policy Journal*; and "AIDS: The Risk to Insurance, the Threat to Equity," *Hastings Center Report*.

FREDERIC G. REAMER is professor in the School of Social Work, Rhode Island College. He received his Ph.D. from the University of Chicago. Reamer is the author of *Ethical Dilemmas in Social Service*

(2d. ed., Columbia University Press, 1990) and coauthor of *The Teaching of Social Work Ethics* (The Hastings Center, 1982). He is also the author of numerous other publications on professional ethics, including "AIDS, Social Work, and the 'Duty to Protect,'" *Social Work*; "Toward Ethical Practice: The Relevance of Ethical Theory," *Social Thought*; "Social Work: Calling or Career?" *Hastings Center Report*; "The Emergence of Bioethics in Social Work," *Health and Social Work*; "Values and Ethics," *Encyclopedia of Social Work*; and "The Concept of Paternalism in Social Work," *Social Service Review*. Reamer is editor-in-chief of the *Journal of Social Work Education*.

FERDINAND SCHOEMAN is professor of philosophy at the University of South Carolina (Columbia). He received his Ph.D. from Brandeis University. Schoeman is the editor of *Philosophical Dimensions of Privacy: An Anthology* (Cambridge University Press, 1984) and *Responsibility, Character, and the Emotions: New Essays in Moral Psychology* (Cambridge University Press, 1987). Schoeman is the author of a number of additional publications on the subject of privacy, including "Privacy," *Encyclopedia of Ethics*; "Adolescent Confidentiality and Family Privacy," *John Marshall Law Review*; "Privacy: Philosophical Dimensions," *American Philosophical Quarterly*; and "Privacy and Criminal Justice Policies," *Criminal Justice Ethics*.

ABIGAIL ZUGER is assistant professor of medicine at Albert Einstein College of Medicine. She is also attending physician in the AIDS Center and director of the Infectious Diseases Clinic at Montefiore Medical Center. Zuger received her M.D. from Case Western Reserve University. She was also a fellow in the Center for Clinical Medical Ethics at the University of Chicago Medical Center. Zuger's most recent publications include "Physicians, AIDS, and Occupational Risk: Historic Traditions and Ethical Obligations," *Journal of the American Medical Association*; "AIDS on the Wards: A Residency in Medical Ethics," *Hastings Center Report*; and "Heterosexual Transmission of Human Immunodeficiency Syndrome," *AIDS Update*.

*La vertu refuse la facilité pour compagne . . .
elle demande un chemin âpre et épineux.*

Virtue shuns ease as a companion. . . . It demands
a rough and thorny path.

— Michel de Montaigne

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1. AIDS: The Relevance of Ethics

FREDERIC G. REAMER

AT A RECENT conference I sat on a panel of professionals who are knowledgeable about AIDS. This interdisciplinary panel was convened to consider a variety of ethical issues related to the disease. During the discussion this group was presented with a series of case scenarios that raise complex ethical issues related to the AIDS pandemic. Among them was a case involving a young man with AIDS who refused to inform his girlfriend (his regular sexual partner) about his AIDS status. This fellow was unwilling to disclose details about his illness because he feared unpleasant recriminations and humiliation. He also feared that his partner would leave him at a time when he needed her support.

The panel was asked to consider whether the patient's physician should disclose confidential information to ensure that the patient's girlfriend learns of his AIDS diagnosis so that she can protect herself. We were to assume that every effort already had been made to get the patient to share this information on his own.

This case scenario, which is now distressingly familiar to those involved in the AIDS crisis, is characteristic of a wide variety of ethical choices practitioners are facing. It contains a classic clash of duties and rights, in this instance among the patient's ordinary right to privacy and confidentiality, his obligation toward his girlfriend, and the girlfriend's right to protection from harm. We can add into the mix the corollary tension between the physician's duty to respect confidentiality and her duty to protect third parties.

The panel's discussion of this troubling case had several striking features. First, it was clear that ethical norms related to AIDS are shifting, sometimes rapidly. Most of the panelists acknowledged that *at some point* the physician may be obligated to disclose confidential