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## Understanding the Psychological Impact of AIDS: The Other Epidemic

Marshall Forstein

*Harvard University*

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# Understanding the Psychological Impact of AIDS:

## The Other Epidemic

*Marshall Forstein, M.D.*

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*HIV has created two epidemics, one of disease, the other the consequence of the psychological response to that disease. Thus far, behavioral change is the only effective means of interrupting the transmission of HIV. The underlying psychological dimensions of the societal and individual responses to AIDS are discussed, with suggestions for how both rational thinking and irrational fears and anxiety contribute to the development of public policy. Examples are given of how short-term solutions to reduce anxiety may actually create long-term problems, potentially increasing the risk of transmission of HIV. Specific psychological mechanisms that contribute to the epidemic of fear are explained. Understanding the fears and incorporating them into a coherent plan for addressing behavioral change are essential if the epidemic is to be contained. Public figures have a responsibility to resist short-term solutions in response to public anxiety.*

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**H**istorical reflection upon the impact of AIDS will eventually document the development of two epidemics, one involving the biophysiological and medical response to a viral illness, the other a psychosocial phenomenon affecting every social, religious, educational, financial, political, and cultural institution within American society and throughout the world. Ultimately, the way in which we as individuals, societies, and nations respond to the psychological effects of this viral, sexually transmitted, blood-borne disease will be as significant as the way in which we respond to the virus itself, with respect to the extent of the epidemic's impact on society.

This article will explore the psychological dimension of the epidemic of fear and anxiety which compounds the disease itself. AIDS has undeniably elucidated many of the problems, deficits, and failures of our society which have been inadequately addressed for some time, such as unequal access to health care, substance abuse, sexually transmitted disease, homophobia, and unequal protection of civil rights. If we are to sufficiently contain the epidemic and minimize the devastation to individuals and social institutions, choices will be required of us individually and collectively which will be made at the

*Dr. Marshall Forstein is codirector of the Outpatient Psychiatry Department at the Cambridge Hospital in Cambridge, Massachusetts, and is an instructor in psychiatry at the Harvard Medical School. He is a member of the American Psychiatric Association's Committee on AIDS and is secretary of the board of directors of the AIDS Action Committee of Massachusetts, in Boston.*

intersection of public health policies, societal values, scientific technology, and an economic reality that includes increasing world needs and decreasing resources. While it is unlikely that all of society's problems will be solved as a means of stopping the epidemic, addressing those problems is essential if appropriate interventions are to be realized. Complicating the societal issues are the complex psychological factors of human sexual behavior, substance abuse and addiction, and varying capacities of individuals to manage fear and anxiety.

AIDS requires, for example, that we take the most difficult, most emotionally charged concerns of our civilization and within the extremes of existing values, morals, social structures, and economics cut through to the essential tasks involved in halting a sexually transmitted disease. Of all the infectious agents in the biosphere for which we do not have a vaccine, HIV is among those we best know how to avoid getting or transmitting. The epidemiology and routes of transmission are clear, although for various reasons there is a curious denial of those data, allowing people to believe what they want to about the disease. Because the virus is transmitted almost always by willful, consensual behavior, the containment of the epidemic is dependent on people knowing what behaviors and risk factors facilitate the transmission from one person to another. This requires education as to the facts, and strategies for helping people integrate psychologically the behavioral changes that will protect them from transmitting or receiving the virus.

So the essential question is, Given what we know, why aren't we doing what we know we can do to stop the transmission of this virus? What is getting in the way of our taking the appropriate steps, of committing our resources to putting an end to the transmission of this virus? Despite the amount of information we have regarding the mode of transmission and the behaviors that put one at risk, many people believe that scientists are wrong, that doctors cannot guarantee complete safety from all risk, and that taking actions to protect oneself, even if they are irrational and in violation of others' basic rights, is warranted.

In the novel *The Plague*, Albert Camus poetically lays out the essential conflict, and resolution, of the task before us through the observations of Dr. Rieux, who begins to fathom the deepest psychological implications of the task of containing the plague:

Only the sea, murmurous behind the dingy checkerboard of houses, told of the unrest, the precariousness, of all things in this world. And, gazing in the direction of the bay, Dr. Rieux called to mind the plague — fires of which Lucretius tells, which the Athenians kindled on the seashore. The dead were brought there after nightfall, but there was not room enough, and the living fought one another with torches for a space where to lay those who had been dear to them; for they had rather engage in bloody conflicts than abandon their dead to the waves. A picture rose before him of the red glow of the pyres mirrored on a wine-dark, slumbrous sea, battling torches whirling sparks across the darkness, and thick fetid smoke rising toward the watchful sky. Yes, it was not beyond the bounds of possibility. . . .

But these extravagant forebodings dwindled in the light of reason. True, the word "plague" had been uttered; true, at this very moment one or two victims were being seized and laid low by the disease. Still, that could stop, or be stopped. It was only a matter of lucidly recognizing what had to be recognized; of dispelling extraneous shadows and doing what needed to be done. Then the plague would come to an end, because it was unthinkable, or, rather, because one thought of it on misleading lines. If, as was most likely, it died out, all would be well. If not, one would know it anyhow for what it was and what steps should be taken for coping with and finally overcoming it.

The doctor opened the window, and at once the noises of the town grew louder. The brief, intermittent sibilance of a machine-saw came from a nearby workshop. Rieux



pulled himself together. There lay certitude; there, in the daily round. All the rest hung on mere threads and trivial contingencies; you couldn't waste your time on it. The thing was to do your job as it should be done.<sup>1</sup>

The job to be done is to contain the spread of the virus. This means finding a cure or adequate treatment for those infected, a vaccine for those not yet infected, and/or a method for behaviorally containing the spread of the virus. These attempts to curtail the devastation of this virus in society call upon the most sophisticated technological and biomedical techniques, and upon complex ways of changing individuals' drug usage and sexual behavior. What lies at the heart of the psychological difficulties facing individuals and social institutions is that currently the containment of the spread of HIV infection is almost exclusively dependent on changing at-risk behaviors. The fear that the AIDS virus is out of control parallels long-standing fears in our society that sexual and addictive behaviors are also out of control.

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### **Psychological Responses: The Limbic/Cortical Partnership**

An essential characteristic of the human mind helps to explain the psychological dimensions of the epidemic of fear and anxiety. The most ancient part of the human brain, evolved over millions of years, continues to share structure and function with the brains of lesser animals, such as reptiles. These structures collectively constitute the limbic system, the repository of human emotions such as fear and anxiety, and visceral drives such as hunger, thirst, and sexual desire. This might be called our reptilian legacy. What distinguishes humans from other species is a much more recent, evolutionarily speaking, part of the brain called the neocortex. The human cortex allows for the development of language, of logical and deductive reasoning, of rational thought. Further, it allows human beings, perhaps alone among all species, to contemplate their own existence, to know and perceive the passage of time, and to foretell their own mortality.

As a species, we are still on a journey to make the most of this exquisite partnership of limbic and cortical capacities. Neither capacity alone is capable of sustaining human life, but either one alone is capable of destroying it. Emotional, irrational responses that are based on fear can prevent us from making reasoned, albeit difficult, choices needed to contain crises that threaten us. Purely rational responses that ignore emotional impact may seem logical yet be impossible to implement. Each challenge to our species, such as the AIDS epidemic, requires further maturation of the delicate balance between cortical and limbic systems; paying attention to the limbic system allows us to understand and experience our fears, while attention to the cortical system allows us to manage those fears in a way that leads to effective control and appropriate changes.

Given this schematic representation of the human psyche, three potential modes for approaching the presence of HIV in our society can be described. One mode is confined to limbic arousal and response, such as the fight-or-flight reflex. This is the need to do something immediately to quiet the anxiety and fear of AIDS. Decisions that are based exclusively on limbic arousal lead to the perception that the fear is allayed, while not addressing the immediate and long-term effects of such responses. The second mode involves a strictly cortical response. It assumes that the whole of human behavior and motivation, and the AIDS virus itself, can be managed with a totally rational approach. Relying only on logic, cause-and-effect argument, and quantification of the problems

associated with the HIV epidemic obviates the need to acknowledge and treat the fear and anxiety.

The essential problem with an exclusively rational approach is that it precludes the concern for the psychological consequences of any decisions. Denying that even rational decisions engender emotional responses simplifies the situation greatly, but does not provide for the emotional consequences.

The third mode, which is in fact the only really viable one, derives from understanding and utilizing both the limbic arousal and the cortical capacities to formulate an integrated response to any human dilemma or crisis. This requires respect for the complexity of human behavior and emotional conflict which must inform intellectual decisions. It allows us to know the fears for what they are, and enables us to contain them when reason suggests they may be out of control and harmful to the long-term prospects of societal survival.

Two psychologically important capacities have an impact on human sexual and addictive behavior, and on those social structures which are intended to protect people from the unpredictability of the world. These are the capacity to contain ambiguity and uncertainty, and the capacity to act on the basis of the relative risks or benefits of any particular activity.

The necessary balance between the cortical and limbic structures depends on the capacity to understand and contain ambiguity and uncertainty. This capacity develops as a complex psychological response to a world in which a person perceives, feels, and believes in the tenuousness and mystery of life while at the same time believing that he or she has some ability to affect, perhaps even to manage, the vicissitudes of life. In an existential way, the capacity to contain ambiguity and uncertainty correlates with the capacity to contain anxiety about the very nature of human existence. Fear and anxiety increase the desire for answers and action, even if the long-term effects of such are undesirable. Short-term solutions to ameliorate anxiety are often more acceptable than tolerating that anxiety and delaying the gratifying, more long-term solution. When the fear and anxiety become overwhelming, irrational choices and decisions may be employed to attempt to decrease the painful feelings. The desire to reduce pain, physical or emotional, is a basic drive, and the basis of much human behavior. At times, addictive behavior, whether with drugs or sex, may be the only available level of adaptation which can even momentarily alleviate the psychic pain.

The psychological capacity to manage fear and anxiety results from a very complex evolution of personal character, experience in the world, native intelligence (cognitive ability), and basic beliefs and tenets about the human condition. Within any society confronting something as frightening as the AIDS epidemic, there is inevitably a great range of ability to conceptualize, contain, and manage the emotional impact of the reality. Like the individual brain, the societal mind must understand its components, validate and acknowledge the emotional issues, but not allow fear to preclude reasoned choices that take into account the human response to any particular decision.

The ability to make decisions on the basis of a perception of the relative risk of certain activities compared to that of others is evoked in the extreme when feelings of uncertainty, fear, and vulnerability collide. Mothers, for example, who don't think twice about sending a child to school on a bus will take the child out of school for fear of infection because a child with AIDS is attending, although the risk of the child dying in a bus accident is greater by a thousand-fold. The unwillingness of some, even after the epidemiological data are presented, to change that attitude and behavior (of withdrawing their child from



school) may be a representation of the irrational distortion of the relative risks involved. In a way, AIDS allows parents to do something to protect their children. But the attempt to protect their children from the dangers of living in this world gets particularly exacerbated with respect to AIDS precisely because parents are so terrified of the very activities that are associated with the transmission of the virus: sexual activity and drug use. Now, more than ever, it is impossible to deny that those very activities which challenge the control parents have over their children are associated with death itself.

The lack of faith and belief in their own parenting capacities leads to the refusal to acknowledge the nearly zero risk of their child getting infected by attending school with a child with HIV positivity or with AIDS. Parents irrationally try to control the situation in the present, when the fears are those which extend into their future sense of how much control they will have over their children, perhaps even over their own lives.

Politicians and policymakers, for example, may try to quiet the popular anxiety, and their own, by formulating immediately acceptable policies, even though the long-term effects of such policies may be counterproductive. For scientists, especially physicians, having an immediately available test result, for example, may decrease uncertainty in the short term without necessarily achieving the long-term goals.

Examining in detail the history and use of HIV antibody testing will highlight these essential psychological issues as they pertain to the policy and educational decision making whose stated goal is to stop the transmission of HIV.

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### **HIV Antibody Testing: The Psychological Dimensions**

The development of the antibody test began with the expressed desire to make the blood supply safe from contaminated blood donors. As a laboratory test, the HIV ELISA is exquisitely sensitive, capturing in its net almost all of the contaminated blood donated. "Almost all" will always be the best that any test can do when it comes to screening blood for anything. In the case of HIV, donors who are infected but have not yet produced antibodies will not be captured by the present tests. Even an antigen test, which will presumably not have the same window of incubation before antibodies are identifiable, will suffer from the statistical latitude of error that is inevitable in any laboratory test situation. Thus, at the very best, blood recipients can expect an extremely safe blood supply, but not a perfectly safe one. This means that we must all accept a certain level of risk and make informed judgments about the use of blood transfusions. In a positive way, AIDS has probably done more to reduce the inappropriate use of blood products than all of the medical education doctors get about the risks and benefits of transfusions.

The public, however, finds it difficult to tolerate any level of risk when it comes to the blood supply. At the basis of this is perhaps more than the question of quantifiable relative risk. The individual's subjective perception of that risk may be fundamental. The same people who clamor for a perfectly safe blood supply, and who become outraged when science cannot deliver it, are likely to take significantly greater risks with their lives every day, such as driving a car, flying, and so on. In comparison, the risk of dying from AIDS as a result of a blood transfusion after March 1985, when antibody screening of blood began, is less than one in one hundred thousand. A white male who lives in an urban area in the United States has a one in one hundred and thirty chance of being killed by a gun. For a black male, that chance increases to one in five.

How are we to understand why some risks are tolerable even if they are statistically so much greater than others? Why does the person who rails against the imperfect blood

supply not become enraged by the lack of gun control? How do we come to expect medicine and doctors to be perfect in the pursuit of saving lives while at the same time accepting the potential perpetration of violence by one human on another? Do anti-gun control enthusiasts, perhaps, manifest the magical belief that guns provide a certainty of safety and control in an essentially uncontrollable world?

Perhaps the underlying fear manifested by the blood transfusion issue has also to do with the fear of being hurt in an accident, and having others — medical personnel — make decisions of life and death in a moment of complete vulnerability. All of us can imagine daily events in which car accidents may precipitate crises. As horrible as that possibility is, the thought of it is manageable with some denial that it will actually occur. When it comes to the issue of dying at the hand of a gunman, the horror is too much to handle, and more complete denial becomes the psychological device for managing the basic fear of losing one's life. In reality, although having a gun may make a person more potentially lethal to others, it does not make one less vulnerable to another gun.

We associate blood transfusions with crises we consider manageable, and therefore don't totally deny — thereby increasing, perhaps unreasonably — our expectations of safety; we associate gun control with crises that aren't manageable, leading us to totally deny the relative risk, or creating the illusion of total safety by having a gun.

Some fears, to be managed at all, require different levels of repression, leading to different types and degrees of emotional expression. The same psychological mechanisms of defense may be operative with the threat of nuclear disaster.

No one would argue about the rationale for continuing to screen blood for HIV antibodies. No one would argue that increasingly better laboratory tests should be pursued to increase the level of safety. Problems arise, however, when the rational use of HIV antibody testing to screen blood becomes the basis of public health policy that establishes programs for screening large populations of people, with the assumption that doing so will necessarily lead to a reduction in the spread of HIV.

As evidence of how short-term solutions may be sought to allay anxiety, one might examine the U.S. immigration policy, which now requires that persons applying for U.S. residence be HIV antibody tested. Ostensibly, this requirement is put forth as a way of preventing the spread of disease and overloading of the U.S. medical establishment, which already feels the strain of the HIV epidemic. Asymptomatic individuals who are HIV-positive are prevented from immigrating, yet people with other sorts of chronic illness, such as diabetes, arthritis, and cardiovascular disease, are not denied entrance even though they are as likely to utilize U.S. medical resources. While in the short run this policy may seem to contribute to protecting the U.S. population, the long-term implications have never been fully addressed.

For example, what if other nations follow the example of the United States in barring immigrants who test positive? One can imagine that nations, then fearing each other, might begin requiring all tourists and people traveling on business to be certified HIV-free. Soon countries might have standing policies based on the paranoid fantasy that anyone could be carrying the virus and on the unstated acknowledgment that people may have consensual sexual relations. The policies would also arise out of the fear that infected individuals would seek the best level of care possible, burdening nations that had the greatest access to medical care.

Should the notion of testing to protect national boundaries become more acceptable, the consequences might be felt within the United States. The Commonwealth of Massachusetts (well known for its medical establishment and already the mecca for persons suffer-



ing from rare or difficult medical problems) might begin to think it should protect its medical system from ruin by refusing to let neighboring states, which have fewer medical resources, refer all their HIV cases to Massachusetts. At first, Massachusetts hospitals might refuse to treat persons from out of state, but as people found ways to circumvent the rules in order to obtain the best possible AIDS care, state borders might begin to be enforced, with persons being required to produce certification that they had recently tested negative before being allowed to cross state lines.

Although such paranoid fantasies may seem “beyond the bounds of possibility,” the statements of public figures suggest otherwise. Some have called for all HIV-positive people to be distinctively marked so that others might avoid contact with them; others have recommended that all people in high-risk groups, essentially all gay men and intravenous drug users, be contained in some sort of protected “camp”; and some fanatical religious leaders have even called for the outright eradication of homosexual people.<sup>2</sup>

Even reasonable people, when confronted with the rising statistics on those infected and on the estimated cost of treating and caring for the ill, begin to contemplate irrational means of trying to control the epidemic — for instance, by attempting to control other people’s lives. Implementing large-scale mandatory testing with this goal in mind may appear to be rational until one looks at the long-term implications and the cost of implementation.

Let’s assume, for instance, that everyone applying for a job or currently employed or entering school or presenting at a hospital or clinic were to be mandatorily tested for HIV. Perhaps as many as 100 million tests would have to be performed, at a cost of at least \$3 for each ELISA and approximately \$60 to \$100 for each confirmatory test. All those who tested negative would have to be routinely tested on a regular basis, since the test might not catch HIV-positive people who were without antibodies at the time of testing, or persons who became infected between tests. It could well require several hundred million dollars every several months just to do large-scale screening.

Aside from the cost in dollars, moreover, would be the cost to the well-being of persons who were positive but for whom at this time nothing could be done. Additionally, since in large-scale testing of low-incidence populations there would be an equal number of true and false positives, half the people identified as positive, but who in fact were not, would suffer the psychological damage and stigma of being identified as HIV-positive. The cost to society in terms of productivity would be immeasurable.

Most significantly, the intended goal of such large-scale screening, to reduce the spread of HIV, might actually be negatively affected. There is no evidence, scientifically, that knowing one’s HIV serological status in any way correlates with the ability to manage risk-taking behavior. Once the meaning of the test is clear, people react in many ways to obtaining the results of the test, whether positive or negative. Studies<sup>3</sup> done in several cities, such as Chicago and New York, do not support the position of the Centers for Disease Control (CDC), which advocates that people at high risk be HIV tested. The CDC’s position is based on its belief that knowing one’s antibody status leads to appropriate behavioral modification. In fact, the research to date<sup>4</sup> suggests that individuals who find out their antibody status may differ significantly in their responses. Preliminary research has indicated that people who perceived themselves to be at high risk and who had not made appropriate behavior changes were not likely to do so because of the results of the test. Both for those who were positive and those who were negative, the capacity to behave safely was not affected by the test itself. In some cases, it becomes even more difficult to change at-risk behavior after finding out test results, whether positive or negative.



Psychologically, several possible inferences, supported by clinical experience across the United States, can be made from these findings. Individuals who test negative may begin to feel that they are immune, assuming that if they haven't been infected already they must be invulnerable to the virus. Others develop severe forms of survivor's guilt, not unlike what is seen in Holocaust survivors. Many of these individuals have lost intimate friends and sexual partners to AIDS, and begin to wonder why they have been spared. For some, there is actually an increase in unsafe practices, almost in defiance of their luck to date and in support of their denial about their own mortality.

Individuals who test positive may respond in a number of ways upon learning their antibody status. For some, the fact that they are already infected and the perception that they will die from AIDS engenders a nihilistic, self-destructive attitude. Occasionally, the thought of "taking others with you" becomes revenge for the anger and betrayal they feel on account of contracting AIDS. This derives partly from the stimulation of self-hate in the infected individual, in turn often resulting from internalized homophobia for gay and bisexual men, and from self-loathing in intravenous drug users, who may feel morally corrupt and guilty for their addiction. In addition, the very behavior that places an individual at risk, whether it be addictive use of drugs or compulsive sexual activity (or both), becomes the most available means of decreasing the underlying anxiety.

The growing consideration of the impact of testing on an individual's ability to manage at-risk behaviors has led most public health officials not to support the idea of mandatory testing or of contact tracing. But officials who might be able to manage their own anxiety about not being able to control the epidemic immediately face the fear and demands of some who insist that restrictive policies be enacted to protect society.

Camus again warns of the danger from irrational responses to anxiety-provoking and fearful situations:

All I maintain is that on this earth there are pestilences and there are victims, and it's up to us, so far as possible, not to join forces with the pestilences.<sup>5</sup>

Educating people and providing access to information and social and psychological supports in order to curtail activities that may transmit HIV are the only available methods of rationally addressing the epidemic. Even with the most powerful, all-encompassing efforts, it is certain that there will be casualties: that certain people, for whatever reasons, will continue to engage in activities that put themselves and others at risk. The mere fact that something so small as a virus is transmitted by something so powerful and universal as sexuality, and that it can have such devastating effects on the individual and such enormous consequences for the entire society, upsets our basic sense of security.

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### **AIDS and the Social Environment: The Psychological Implications**

The context in which AIDS developed in the United States is inextricably linked to the psychological difficulties both of infected people and of people responding in any number of ways to the epidemic. Although scientific data and epidemiological studies throughout the world have linked the spread of the virus to blood-to-blood transmission and to sexual activity in which the virus is transmitted (independent of sexual orientation), the fear and anxiety propelling irrational responses are clearly related to what drug use and sex symbolize and mean in our culture. That homosexuality initially was causally associated in both the scientific and the lay mind with the spread of HIV only exacerbated the problem.

If the first U.S. cases had not been described in sexually active gay men and in intravenous drug users, but in the white, heterosexual sons of congressional leaders, for instance, the emotional response and mobilization of resources would have been substantially different from what they were. The prolonged silence of the U.S. government, its public policies, and the political ramifications of AIDS arose from the fear of addressing the fundamental issues of homosexuality and drug addiction in the United States. The silence of those in responsible leadership positions allowed the worst attitudes and prejudices to intensify. Imagine, for instance, if soon after the epidemic was under way, the president of the United States had held a press conference, perhaps while sitting on the bed of a man with AIDS, and said: "My fellow Americans, I want you to know that your government is fully committed to dedicating whatever resources we have toward finding a cure and a treatment for those afflicted, and to educating us all about the transmission of this virus. I furthermore implore you not to punish or ostracize people who are sick or who are drug-addicted because of your fear of AIDS." Hearing and watching the president model a posture that deplores homophobia, racism, and irrational acts would provide many Americans with some psychological supports for containing their fear.

The ability of a U.S. president to take such a stance would depend on the public being able to deal with basic issues around sexuality (particularly homosexuality) and drug addiction. From the point of view of persons infected early on — drug addicts and gay men — the position of outcast was already extant. After all, how does a society begin to address the medical and psychological needs of homosexually oriented people who are intentionally invisible within the fabric of American life, and whose basic civil rights are not clearly guaranteed by the Constitution? Furthermore, the very sexual activity that is associated with the transmission of the disease is considered criminal behavior in most of the United States.

Underlying the response by the public and its leaders is the long-standing fear that sexuality and pleasure-seeking behavior, if left unchecked, threaten to tear apart the fabric of society. Those social, legal, and religious institutions which are designed to contain the worst impulses of the species become the deterrents to the use of reasonable strategies for containing this particular epidemic.

How does a government that is purportedly based on the constitutionally determined separation of church and state deal with the teachings of particular religions and the changing social morality, and the need to contain a sexually transmitted disease? What will it take for the condom to be seen as an instrument of death prevention rather than birth control?

When will the debate about whether teenagers should or should not be having sex before marriage or adulthood give way to the reality that the sex lives of pre-adults are not within the control either of institutions or of individuals other than those engaging in sex?

Statistically, about 10 percent of all AIDS cases in the United States are in the age group twenty to twenty-four.<sup>6</sup> Given the latency period of perhaps two to seven years, there can be no doubt that teenagers are being infected. While teens become infected and the reservoir of HIV-positive people increases, the debate continues as to whether the government can support with public funds the kinds of printed materials that graphically speak to the issues of safer sex and condom use. If parents are to feel that they are realistically preparing their children to protect themselves, they must confront their own anxiety about discussing sex with their children, perhaps even their own anxiety about sex itself, and about the inevitable necessity of giving up control of their children.

Many of the fears that operate within each person become institutionalized in public



policy. Thus, several psychological issues contribute to the particular way in which AIDS has become an epidemic of fear arising out of personal experience, or as part of a cultural legacy. The fear of people who are different, such as in racism or homophobia, may be an internalized, acceptable aspect of a particular culture, institutionalized in spite of legal or stated social positions. Take, for example, the Catholic church's position on homosexuality. The church asks us to love the person but deplore the sexual activity. It further supports the denial of homosexuals' basic civil rights, under the guise that these rights are already guaranteed by the Constitution, a position that interpretations of the Supreme Court do not support. The conflict within such powerful institutions as the church becomes incorporated psychologically into the fear and anxiety of the individual who sees homosexuality, perhaps even all of sex, instead of the virus, as the cause of AIDS. Homophobia, the irrational dread of being confronted by homosexuality, becomes the basis for what is publicly put forth in the name of protecting the public health.

A comparison of the AIDS virus with a virus that caused an epidemic of lesser proportions, such as Legionnaires' disease, may be instructional. After all, even though Legionnaires' disease was spread through respiratory contact, breathing did not become a disgraceful, shameful activity. There is something quite different about sex than almost any other human activity which psychologically makes our culture respond regressively and often punitively. The association of sex and death, now profoundly etched in our consciousness, and the basic fears of intimacy and sexual expression which have always been part of our society have created special barriers to the development of coherent, reasonable approaches to this disease. In other nations, where sexuality has traditionally been more easily addressed, the response of the governments has been more decisive, swifter, and less tinged with moral consternation. In Great Britain, for example, where consensual homosexuality is not criminalized, the debate about teaching safer sex is not whether to, but how to.

Similarly, in the United States drug addiction is treated both as a criminal act and as a medical illness. This conflict represents an underlying psychological ambivalence about whether an individual is to blame for his or her addiction or whether, in fact, it is a disease. The arbitrary distinctions between the use and abuse of alcohol and the use and abuse of other substances illustrates the difficulty in addressing AIDS in the drug-addicted population. Rationally, the best way to curb the spread of HIV is to provide sufficient access to treatment for persons who are addicted, and to legalize and control access to substances that individuals choose to use, separating out the use of the substance from the mechanism of transmission of HIV, that is, sharing contaminated needles. To develop such an approach would require changing institutionalized attitudes and myths about people who become drug-addicted.

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### **Public Policy: The Psychological Context and Constraints**

The success of any long-term program in decreasing the transmission of HIV will ultimately depend on the provision of support and impetus for people to change the behaviors that put them at risk. While the society at large debates the morals and merits of homosexuality, the gay male community has taken charge of itself and has redefined its sexual mores, so that acceptable behavior is now safer behavior. It appears to be more difficult for people who are already sexually active to change their sexual habits than it is to help

people just coming out and becoming sexual to incorporate the safer sex behaviors into their lives.

A proactive, “sex positive” message depends on the presence of a visible gay and lesbian community, with resources to provide persons seeking intimacy with alternative ways of obtaining affirmation of their sexual identity. In rural, isolated areas, such support may be lacking, and the very anxiety of being “out” in some areas may in fact impel gay men to seek out unsafe sexual practices as a way of quelling the anxiety about being homosexual. Public policies, therefore, that are intended to stop the spread of AIDS have got to support the basic protection and civil rights of homosexual people in the United States. Forced underground, considered less valuable in the eyes of society, gay men and lesbians internalize the hatred within that they experience and feel from others who are validated in the world. Public policy can protect the rights of human beings without condoning or encouraging any particular behavior. That is the essential principle behind freedom of choice. Likewise, public policies must take into account the long-term effects of “sex negative” messages that are “rationally intended” to stop AIDS but that ignore the emotional and psychological impact on human beings, who need intimacy and sex in their lives to form the kinds of relationships that make society compassionate and caring. What will our nation look like twenty years from now if a generation of children grow up terrified of sex, more homophobic, more racist, and more addictophobic?

Stopping the spread of HIV in the addicted community requires that sufficient resources be allocated to provide treatment for the underlying disease that leads to the transmission of HIV. The debates about clean needle exchange and what type of drug treatment is best point to the ambivalence the medical profession and society have about treating drug addiction as an illness. We feel morally bound to treat people who are ill, and in fact usually offer a range of treatments for any single medical problem. By criminalizing drug addiction, we absolve ourselves of the responsibility of treating behavior that is self-destructive and potentially dangerous to others. Those who make public policy must be educated about the complex meaning of sharing needles within the IV drug subculture, and what economic opportunities, incentives, and social changes will be required in order to preclude the need for such rituals within the IV community.

If the necessary changes in human behavior are to occur which can minimize the spread of this virus, attention must be paid to the important interface of the psychological, medical, and public policy issues. The inherent bias against psychological understanding, perhaps even a fear of psychological thinking, is evident at even the most sophisticated levels of discussion. The International Conference on AIDS,<sup>7</sup> attended by scientists and policy-makers from all over the world, has had virtually no representation from the psychiatric or psychological profession, even though, when asked, everyone admits that changing behavior is the only available, effective means of stopping the transmission. That scientists meeting with the stated purpose of halting the transmission of AIDS could create an international conference at which psychological professionals are conspicuously absent — even from the planning committee — speaks to the difficulty of addressing the complex psychological aspects of HIV infection. Dealing with such important issues as sexual behavior change and addiction treatment has not heretofore been acceptable within the province of medical science. Yet the achievement of substantial progress in reducing the spread of AIDS is dependent on effectively dealing with those anxiety-provoking issues. How is the general public to begin to deal with the fear and anxiety if professionals them-



selves set out to deal with AIDS without adequately addressing the psychological issues? Even after three years of such a conference, and with complaints by members of both the psychiatric and psychological professions, the conference planning committee has chosen to neglect psychological and psychosocial input in favor of what is considered "hard science." The reality is that scientists are no better prepared to deal with the difficult issues of sex, drugs, and death than the lay population.

The resistance to spending time and energy on the complex psychological dynamics of addiction and sexual behavior is based partly on the way in which that very psychological understanding would force a different approach to public policy and decision making. Human psychology complicates any simple answer to problems that involve changing deeply imbedded values and habits. Not addressing these issues allows for seemingly straightforward answers and simple solutions, such as testing people premaritally for HIV. Addressing these issues points out the inconsistencies and long-term problems associated with simplistic policies.

Public policy that develops to stop the spread of AIDS must be divided into short-term and long-term plans. Short-term plans require crisis-oriented activities, considered, it is hoped, in terms of the potential long-term ramifications. Strategies that decrease anxiety immediately, or that give a false sense of security and discount the psychological ramifications, may in fact contribute to, rather than stop, the spread of AIDS. Long-term plans must evolve on the basis of what is known about human learning, and behavioral patterns and change. Sex and drug education must begin with the very young, allowing children to grow up without much of the anxiety adults now have about even discussing such subjects. Current community values and doctrines must be challenged so that education that allows for informed, reasoned choices becomes the standard throughout the nation. Critical changes must be made in terms of how sexuality, particularly homosexuality, is dealt with socially and legally. Civil-rights legislation must be seen not as condoning any particular lifestyle, but as essential to guarantee freedom of choice, access to medical care, and protection from punitive public policies. The long-term benefits of allowing younger people who are homosexual to grow up in a society that does not treat them as lepers, criminals, or satanic beings must be understood in terms of how sexual behaviors are used to survive and affirm an identity in a hostile world. Allowing homosexually oriented people to develop healthy self-concepts, to be freed of the anxiety that drives many toward unsafe sex, must inform the change in civil-rights protection.

Drug addiction must be seen as an illness, just like alcoholism. Drugs must be decriminalized, even regulated and administered perhaps in much the same way alcohol is. That would mean confronting the economic implications of the drug traffic in this country and providing access to treatment and rehabilitation. The cost to do so is staggering.

To truly respond to the psychological aspects of AIDS will cost this government and society both dollars and existing public policies and laws. The education of the young will need to be re-prioritized, so that children are coherently educated from the beginning to understand and believe in both the risks to life and the possibilities for decreasing those risks. The separation of church and state will have to be complete, permitting the church to disagree but not regulate education or public policy, which will protect the people through reasonable and appropriate programs.

Finally, public officials and scientists must acknowledge the importance of understanding the anxiety we share as human beings about our mortality, and our attempts to mitigate our fears of it. Public policy must derive from a comprehensive view of human life, with its fears and phobias, inconsistencies and incongruities. Society must be seen as a com-

plex organism, neither wholly rational nor wholly irrational. That individuals sometimes do not act the way others might want, or even the way they might want to act themselves, is part of the human condition. A species as complex as ours requires a complex set of public policies and multiple levels of strategies. No single plan or program will be enough. The makers of public policy carry the significant responsibility of not responding reflexively, but rather leading society into a future that acknowledges the psychological aspect of human beings and pays attention to it in the development of all strategies that attempt to control the spread of this virus or any future threat. 🖤

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## Notes

1. Albert Camus, *The Plague* (New York: Vintage Books, 1948), 39.
2. The author has personally heard this view set forth twice by public figures, one a leading member of the Moral Majority, the other a representative of a pro-family, "anti-AIDS" group from New York City who stated the position during a panel discussion on AIDS in which the author participated and which was aired on the *Dave Finnegan Show*, on Boston's WNEV-TV, Channel 7.
3. HIV Negative Test Often Prompts High Risk Behavior, *AIDS Record* 1:3, March 15, 1987.
4. Personal communication from David Ostrow, M.D., Ph.D., University of Michigan.
5. Camus, *The Plague*, 236.
6. *AIDS Weekly Surveillance Report — United States*, AIDS Program, Center for Infectious Diseases, Centers for Disease Control, February 1988.
7. Third International Conference on AIDS, Washington, D.C., June 1987, and Fourth International Conference on AIDS, Stockholm, Sweden, to be held in June 1988.



**“**I’m of the Jewish faith. Both of my parents were in concentration camps and my father made a comment to me when he first found out what was wrong with me: “Now you know how I felt when I was twenty-two years old and I could die at any minute,” and when he said that, that just . . . that did it, I just decided you can live or die with this, and I chose to live with it. He survived the Holocaust and I’ll survive this.”**”**