# Social Consequences of the Acquired Immunodeficiency Syndrome

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**Awareness of the pertinent psychosocial dimensions of the acquired immunodeficiency syndrome (AIDS) provides researchers and clinicians with an understanding of factors impinging on their relationships with persons at risk for this disease. These observations are made from the standpoint of the American Association of Physicians for Human Rights, a national organization of gay physicians that serves as an advocate in improving health care for gay men and lesbians. Fear and uncertainty in patient care and prognosis as well as loss of confidentiality are among the stresses on gay men with AIDS. Injudicious "expert" pronouncements and sensational stories in the media heighten the fear of persons at risk for the disease as well as the fear and prejudice of the general community. Members of all communities, both heterosexual and gay, scientific and lay, should work together to eliminate social ignorance about AIDS.**

As several observers have noted, the psychosocial aspects of the acquired immunodeficiency syndrome (AIDS) comprise a realm that is yet to be fully investigated (1, 2). The purpose of this article is to increase awareness of the means in which societal attitudes and scientific pronouncements influence each other and affect persons with AIDS. As an internist caring for these patients with a fatal illness, I have been confronted with many attitudes and responses from patients' friends, lovers, and family members as well as from fellow health care workers and members of the community at large. Fear generated by the uncertainties of this disease is a common emotional response for all groups. Fear of loss of confidentiality and exposure of sexual orientation is unique to gay men.

Although recognizing the diversity of groups at risk for AIDS, this discussion addresses in particular the situation of gay men who have thus far composed 75% of persons diagnosed. The Haitians, intravenous drug users, and recipients of blood and blood products who have contracted AIDS certainly have much in common with gay men with the disease. All groups have experienced the terrors of the disease and the fear and prejudice of society. However, as president of the American Association of Physicians for Human Rights, an organization committed to the advocacy of better health care for gay and lesbian persons, I am most sensitive to, and familiar with, the issues confronting the gay community. Indeed, from the earliest days of this epidemic the members of our organization, in their role as advocates for better health care for gay persons, have found themselves at this interface with the patient, science, and society.

▶ From the American Association of Physicians for Human Rights; Philadelphia, Pennsylvania.

## Stresses on Gay Men

Consider first the fears and uncertainty of the gay man diagnosed with AIDS. Told by his physician that he has a fatal illness for which scientists have no cure, he is left to decide when and how to put his affairs in order. For some men, the major decision will be with whom and when to share the news of their diagnosis. Coping with the fear and uncertainty of the illness might seem a sufficient burden in itself. The time, however, has finally come when disclosure of sexual orientation is no longer an option, and the reactions of family and friends must be confronted. Society is aware of the AIDS risk groups, and the diagnosis itself implicates one's sexuality. If family and friends were unaware previously, secrecy is now an impossible luxury. Confidentiality has a hollow ring when one is hospitalized or frequently visiting a physician.

Add then to these grim cloaks of certain death and possible rejection by family yet another mantle, that of guilt. AIDS is well known to be sexually transmitted. In a society that scarcely accepts sexuality, even heterosexuality, the guilt associated with homosexuality and AIDS is crippling. When confronted with persons with severe anxiety about AIDS, I often inquire how they would feel if given that diagnosis. A frequent response is "embarrassed." Fear and guilt combine to produce inordinate levels of anxiety in both those with and those who believe they have AIDS, often preventing them from effectively coping with their illness.

Guilt further magnifies the sense of isolation and estrangement many gay men have experienced throughout much of their lives. Society overtly and subtly ostracizes gay people. Though a gay man may be placed in isolation on a hospital ward to protect others from infection, the message of rejection and isolation is a continuation of the separation he may have felt lifelong. It is the ultimate paradox that a gay man is obliged to place his life in the hands of a society that has taught him to doubt the value of his very existence. He may, in fact, continue to accept this devaluation of his life and feel he is unworthy to receive care (3). There is little difficulty in empathizing with the uncertainty and isolation he must feel.

Society, in turn, suffers anxiety and confusion as it experiences AIDS through the often histrionic and hyperbolic language of the media. Headlines such as Gay Plague, Lethal Scourge, Mysterious Epidemic effectively capture the fears, if not the imagination, of the public. These leads often are accompanied by descriptions of the "innocent victims": the children, the hemophiliacs, and the recipients of transfusions—the blameless being infected by the guilty. Each story emphasizes the endless uncertainties of the disease. For some readers, the only



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certainty is the prejudice that this disease is a curse, a punishment visited on the many but caused by the sins of a few.

These sensational stories, with tones of sin and retribution, underestimate, to the detriment of the public, the progress that has been achieved. Although many questions remain unanswered, much knowledge has been gained (4). Meticulous and perceptive epidemiologic studies have shown the extent and mode of transmission of the AIDS virus. Persistent and imaginative laboratory work in several countries has isolated the virus. The syndrome is no longer the obscure mystery it was previously.

Yet segments of society remain uninformed and their fear and prejudice foment anger. Landlords evict tenants suspected of carrying the illness; hospital unions seek to exclude persons with AIDS from medical care; and morticians refuse to handle the bodies of those who die of the disease. Even the lepers of the past were provided some shelter and support. Those who thought that current technologic sophistication would protect us from the superstitions of our predecessors have seen headlines linking voodoo and AIDS.

### Uncertainty in Medical Treatment

Now enter the physician-scientist, no more or less the carrier of society's prejudices than other professionals, armed with an array of instruments and skills never before wielded in such a concentrated fashion against a single disease. The syndrome ignites a sense of awe and wonderment among physicians and researchers alike that is impressive. The possibilities for insights gained from this lethal experiment of nature are enticing. The challenge has indeed been accepted; the pressure to achieve has been applied. Because AIDS is our number one health priority, promises are made that tests for the virus will be available in months and vaccines will be developed soon. Rhetoric replaces planning and scientific rivalry supplants the priority of relieving human suffering.

Yet uncertainty is an all too familiar feeling to the scientist as well as the person with AIDS or the member of society watching on. Jay Katz (5) has written:

> It is a fact of life that human beings find it difficult to maintain a consistent, self-conscious appreciation of the extent to which uncertainty accompanies them on their daily rounds and to integrate that uncertainty with whatever certainties inform their conduct. Physicians are not exempt from this human proclivity.

He argues that although aware of uncertainty, the physician—and one could add the researcher as well—largely denies ambiguity when actions or comments are called for. Renee Fox (6) has written in depth about the effects of uncertainty on medical students and physicians. She has described three forms of uncertainty.

> The first results from incomplete or imperfect mastery of available knowledge. . . .The second depends upon limitations in current medical knowledge. . . .A third . . . derives from the difficulty in distinguishing between personal ignorance or ineptitude and the limitations of present medical knowledge.

The acquired immunodeficiency syndrome lends itself to particular uncertainty then, in view of the limited amount of data available and the limitations on the diffusion of this information to health care workers and persons in the lay community. The limited knowledge of the social life of the gay community further impairs the practitioner's ability to comprehend and address the social ramifications of the disease.

In such an atmosphere of uncertainty, great value is placed on the "expert," the one who presumably knows the answer to the riddle if anyone does. With AIDS-related issues, as in other areas of medicine and society, the media have capitalized on these "sources" of information and have given wide dissemination to their views. Paul Atkinson (7) suggests the danger in this, however.

> We must be careful not to mistake the nature of the "expert" as an ideal type: it should not be treated as an empirical description of how persons designated "scientists" or "experts" actually behave on all occasions. There can be no question that any individual "expert" acts in a quizzical, reflexive manner for all purposes and for all of the time. While he or she *can* do so, one is not constrained so to do. For most practical purposes, then, the "expert" has his or her own "natural attitude."

In short, all of an expert's opinions and statements are not based on special expertise, but may well derive from that "natural attitude" independent of the expert knowledge. Unfortunately, experts in one area may know little about other areas.

The term *pre-AIDS* and the finding of the human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV) in saliva are examples of bits of knowledge inappropriately extrapolated to suggest that persons with persistent adenopathy will all develop AIDS and that AIDS is spread through saliva. Despite the limitations of knowledge in both these areas, the preponderance of data supports the opposite conclusion in both cases. Nonetheless, expert pronouncements such as these have created further fear among persons at risk for AIDS and persons in the general community.

Again at this interface among scientists, persons with AIDS, and society in general, we see "the pervasive and fateful human need to remain in control over one's internal and external world by seemingly understanding them, even at the expense of falsifying the data (5)." Though few will falsify data, many will speak beyond the limits of their expertise.

### Confidentiality

The anxiety and uncertainty associated with AIDS are potent stimuli for research. As the largest group at risk, gay men are the subjects of countless research studies and surveillance activities. The gay community is acutely aware of the pressing need to study and explore the disease, but maintenance of confidentiality of data collected in research is also a priority of persons labeled by society as "sexual deviants."

Thus, fear of disclosure of name and identifying data has been a pervasive concern of the members of the various risk groups, but this fear has been poorly and only grudgingly understood by many politicians, researchers,

and public health officials. This sort of tunnel vision is exemplified in a quotation from an article on AIDS and public policy (8):

> Although there is little precedence to suggest abuse of confidential data, the issue is sensitive here because of the societal view on homosexuality. In the case of AIDS, the oversensitized issue of sexual identity threatens to be so compelling that it hamstrings investigations whose outcome might well save thousands of lives. Ironically, this is one instance where the homosexual community itself may cause the establishment to inappropriately respond to their needs.

Although identifying the applicable cost:benefit analysis, Dr. Panem is at a loss to explain the preoccupation of the gay community with confidentiality in light of the greater need for research.

A brief reflection on previously mentioned concerns of gay men will render an explanation for this paradox. Again recall the sense of isolation and estrangement that many gay men feel in relation to society at large. I have listened recently to a New York radio announcer "entertain" his vast audience by threatening the studio go-fer with the most degrading of all assignments, being sent to fetch a gay magazine. Of more substance, however, are the numerous articles about the Texas-based Physicians Against AIDS, whose sham public health program strives to reinstate sodomy laws. By outlawing homosexuality, they allegedly seek to eliminate the repository for the disease. Such efforts are superfluous in the 24 states in which sodomy laws are still in force.

The medical literature is replete with articles exemplifying the extent to which gay men and their sexuality are misunderstood. For example, an editorial in the *Southern Medical Journal* in February 1984 (9) expounds the obvious solution to the AIDS problems as the necessary conversion of homosexuals to heterosexuality. Dr. Fletcher writes:

> Certain cause-and-effect data are convincing—so convincing that health care providers, in this age of unbridled enthusiasm for preventive medicine, would do well to seek reversal treatment for the homosexual patients just as vigorously as they would for alcoholics or heavy cigarette smokers, for what may not be treated might well be avoided.

These examples belabor the point intentionally. Society persistently communicates its disapproval of sexual variance and seeks to eradicate the same. Is it unexpected that gay men when participating in research, especially government research, would be fearful that research data could be used against them? Alvin Novick (10) has summarized this point of view:

> The fears of persons in at-risk groups and their advocates [are] that the products of surveillance and research on AIDS may be political and social repression, as well as personal exposure and its consequences.

Thus, gay men seek to remain an invisible minority. Loss of confidentiality is a potent threat to the anonymity that gay men see as their principal, if not sole, protection against the discrimination of non-gay society.

Each community has its own priorities and concerns. By sensitively responding to these needs, rather than attempting to refute them, necessary research can be conducted without fear of harm to the subjects. Thoughtful solutions to this dilemma have already been formulated and merit the attention of those engaging in research and surveillance (11). All physicians and researchers should adopt these steps in expanding AIDS-related investigations.

### Conclusion

Fear, uncertainty, and a preoccupation with confidentiality are but a few of the many facets of the scientific and societal responses to AIDS. Many deeply troubling issues, particularly the use of the HTLV-III/LAV antibody test, remain to tax our abilities to balance the needs of the communities at risk for AIDS with the needs of society as a whole (11). Sensitivity to and respect for the needs of all communities ensures us a responsible and valid solution to these problems. We must avoid, however, the simplistic solutions that some propose to protect society. Quarantine (12), imprisonment for alleged contamination of the blood supply, and closure of the bathhouses will only heighten public paranoia and further complicate nascent efforts to understand the communities at risk for this frightening illness.

The uncertainties that frustrate medicine and terrorize the public are best confronted in open discussion, where both the limits of the known and the unknown are exposed without the imposition of "expert" opinion when such opinion is pure speculation. The breadth of biomedical research on AIDS is impressive both for its progress as well as the dearth of psychosocial research. Others have previously identified important directions for further psychosocial research (13).

This is the challenge then that one gay man articulated some months before he died of AIDS (14):

> To those of you not afflicted goes the task of ensuring that our cause is not forgotten by the politicians and civic leaders responsible for allocating funds to carry on the research that feeds our hopes. To you is assigned the work of keeping our plight in the public eye so that . . . those who would declare it to be a problem afflicting only a single segment of our society, cannot accomplish what people of good conscience know is patently wrong. We are not bad people. We are merely gay, and that is no reason to regard us with disdain. Those of us physically unable to carry on this message look to you for champions.

I, as a gay man at risk for AIDS, as a physician caring for persons with AIDS, and as an advocate for persons with AIDS when they are confronted with societal intolerance, urge that we sensitize ourselves to these issues imbedded in the interface of science, society, and AIDS. Let us all champion the elimination of social ignorance about AIDS as we pursue the prevention and cure of this disease. This syndrome is a problem facing all of society, not gay men, Haitians, or drug users alone. Its solution lies in the combined efforts of all members of society working together. Let us then work together.

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## References

1. BRANDT EN JR. The concentric effects of the acquired immune deficiency syndrome [Editorial]. *Public Health Rep.* 1984;**99**:1-2.
2. BATCHELOR WF. AIDS. *Am Psychol.* 1984;**39**:1277-8.
3. VINOGRADOV S, THORNTON JE. If I have AIDS, then let me die now! *Hastings Cent Rep.* 1984;**14**:24-6.
4. BRANDT EN JR. AIDS research: charting new directions. *Public Health Rep.* 1984;**99**:433-5.
5. KATZ J. Why doctors don't disclose uncertainty. *Hastings Cent Rep.* 1984;**14**:35-44.
6. FOX R. Training for uncertainty. IN: MERTON RK, READER G, KENDALL P, eds. *The Student-Physician.* Cambridge; Massachusetts: Harvard University Press; 1957:208-9.
7. ATKINSON P. Training for certainty. *Soc Sci Med.* 1984;**19**:949-56.
8. PANEM S. AIDS, public policy and biomedical research. *Chest.* 1984;**85**:416-22.
9. FLETCHER JL. Homosexuality: kick and kickback [Editorial]. *South Med J.* 1984;**77**:149-50.
10. NOVICK A. At risk for AIDS: confidentiality in research and surveillance. *IRB.* 1984;**6**:10-1.
11. BAYER R, LEVINE C, MURRAY TH. Guidelines for confidentiality in research in AIDS. *IRB.* 1984;**6**:1-7.
12. NOVICK A. Quarantine and AIDS. *Conn Med.* 1985;**49**:81-3.
13. COATES TJ, TEMOSHOK L, MANDEL J. Psychosocial research is essential to understanding and treating AIDS. *Am Psychol.* 1984;**39**:1309-14.
14. FERRARA AJ. My experience with AIDS. *Am Psychol.* 1984;**39**:1285-7.


# Implications of the Acquired Immunodeficiency Syndrome for Health Policy


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**The acquired immunodeficiency syndrome (AIDS) has spread rapidly through the high-risk population and has created fear and anxiety. The health policy implications of such a disorder are difficult to assess because the disease was totally unknown until a few years ago and because it occurs primarily in homosexual men and intravenous drug users. The latter factor has raised sociopolitical issues not present in other epidemics. Detection and surveillance systems, capabilities for prompt and effective scientific response, central coordination of scientific efforts, public information mechanisms, role definitions, and guidelines for funding are needed. The scientific community must study this epidemic and the total societal response to it with a view towards being better prepared in the future.**


THE ACQUIRED immunodeficiency syndrome (AIDS) is a terrifying disease that hit the United States with the swiftness of a tornado, and without any warning. It has spread rapidly through the high-risk population and, because of its devastating nature, has caused great fear and anxiety in the total population. I will examine the health policy implications of AIDS, limiting the discussion to the United States because that is the situation with which I am most familiar. The scientific community must study this epidemic and society's response to it and learn all that we can. It will be difficult to reach this vital goal in the existing partisan political atmosphere, but, as the scriptures say, this too shall pass, and we will become more concerned with the discovery of truth than the exposure of errors, real or perceived. Serious scholars are undertaking such an effort.

The syndrome was first encountered early in 1981 with the report of several cases from the UCLA Medical Center. The early reports led to some confusion for various reasons, the drug issue in particular. The basic question was where to begin?

In looking at the health policy issues two special features of AIDS must be considered: The first is that medical science had never encountered a disease like AIDS, although immunodeficiency syndromes had been recognized. These syndromes, however, generally affected infants or persons receiving exogenous immunosuppressants for transplants, malignancies, and other problems. There had been occassional reports of an unexplained immunodeficiency; however, it was the cases in adults that had no apparent cause that led to the recognition of a new disease entity. The second feature is that the syndrome was occurring mainly in gay men and intravenous drug users. Because of the population affected, there are many sociopolitical factors that are not present in other outbreaks of disease. To some extent, the AIDS epidemic is unique in the history of the United States and I would suspect in the history of medicine.


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### Detection System

We need an effective and sensitive detection system for AIDS. Our present detection system depends largely on the cooperation of physicians treating patients. This difficulty was compounded because AIDS was unknown and many physicians did not recognize it as an entity, leading to delayed reporting. Indeed, after the syndrome was fully described, review of medical reports showed cases occurring before 1981.

In the United States, the principal mechanism for early detection is at the Centers for Disease Control (CDC). Physicians are encouraged to report unusual cases or outbreaks to the CDC; however, it should be emphasized that this is a voluntary system, dependent on physicians' willingness to cooperate and their ability to detect a new disease or one that is uncommon.

A second method for early detection is the scientific literature. Reports of unusual cases appear regularly in medical journals. There is no real process for continuous monitoring of journals to detect these unusual cases. I am not sure there should be such a mechanism because of the numerous false leads. Fortunately, investigators in the various specialties tend to review case reports and raise questions if they notice similarities.

### Surveillance System

A continuous surveillance system is needed to encourage physicians to report cases of defined illnesses. At the federal level this is a voluntary system, although most


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states mandate reporting. The system depends largely on the physician's ability to recognize the disease in a patient. However, because of the characteristics of the two groups of people in whom AIDS primarily occurs, patients risk societal repercussions if their disease is known. For example, it is illegal to use certain drugs and most intravenous drug users are susceptible to prosecution. In many jurisdictions in this country, various homosexual acts are also illegal. Because of the strong views many people hold about homosexuality, persons with AIDS could lose jobs, housing, and other societal benefits.

I believe in a policy of voluntary reporting when patient identifiers are used. One reason is that there is no good way to detect violations of a mandatory reporting system because it depends so much on recognition and accurate diagnosis of the disease. Second, a mandatory reporting system using identifiers is in conflict with an individual's right to privacy, especially for a disease with the societal implications of AIDS. Although the present surveillance system is very effective at protecting the rights of citizens, it is clear that numerous groups can create political heat to reveal the names of persons reported to have AIDS.

Many concerned, dedicated, and informed public health officials would disagree with this position, feeling that the rights of the many outweigh the rights of the few, especially when we are talking about a disease as deadly as AIDS. This is going to be a continuing debate and one that must be encouraged. However, on the basis of the information I now have, I am content with my position.

#### Response Capability

We need a prompt and competent response capability. The syndrome affects one of the body's principal defense mechanisms, has an extremely high case-fatality rate, and is scientifically quite complex. In the United States, our scientific apparatus depends largely on investigators at universities and research institutes throughout the country. In dealing with AIDS, it has been necessary to mobilize these investigators to respond to this public health emergency, and that takes time. It has been possible, however, to mobilize the intramural scientific apparatus of the U.S. Public Health Service to bring its expertise to this problem.

Our current system has built-in delays, and I seriously doubt that it can be altered greatly. It is clear, however, that there must be a mechanism for emergency procedures to deal with epidemics like AIDS without sacrificing quality. I am not critizing the past and current efforts. I believe the Public Health Service responded effectively, and I commend all of the people who were involved. However, we should reexamine our response capability and improve it if necessary.

It is essential that there be central coordination of the total scientific effort. Central coordination will minimize duplication; permit the most promising leads to be followed promptly and efficiently; and provide a mechanism for sharing information before it becomes public, thereby permitting an assessment of significance. Again, the Public Health Service can effect such central coordination without being so proscriptive as to interfere with the work of brilliant scientists who have insights into the process that others do not have. The danger of developing a rigid plan of attack or of becoming too centrally focused is that the insights of genius are ignored. It is a delicate balance.

#### Public Information

There must be mechanisms to provide information to the public. This is also a complex problem. One does not want to share scientific information that has not been reviewed by scientific peers or otherwise verified, and such review takes time. Deciding to await scientific review can bring, as it did with AIDS, charges that the scientists are more interested in priority of publications than they are in the health of the public. I believe those charges to be unfounded. Reasonable and rational competition among scientists is desirable. We are a competitive society and I would not change that.

Once results are verified and their implications clearly understood, however, that information should be communicated to the public as soon as possible. Unfortunately, I do not think we were as effective in communicating information as we should have been early in the AIDS epidemic. We did not have a good process for assessing the implications of scientific knowledge and we often had scientists disagreeing in the public press. This disagreement led to confusion and real anxiety and panic, which was eventually corrected. There has to be a central mechanism for presenting information, including that about scientific disagreements, to the public so that they can be informed. It is important to reassure people while not minimizing risks. I do not believe that scare tactics transfer information effectively. The data are clear; people learn more from rational, quiet discourse than they do from cries of alarm and impending disaster.

#### Role of Health Services

One of the most difficult issues to deal with in the AIDS epidemic is the proper role of the U.S. Public Health Service. Because of the sociopolitical implications of AIDS, there has been great pressure for the Public Health Service and individual scientists in it to take positions on societal issues, such as the rights of homosexuals. That is not the role of a scientific organization. Individual scientists can hold whatever views they wish. They should, however, make it clear that those are personal views.

The role of public health service agencies is to control disease processes. Prevention is clearly the most effective control measure we have, and information and educational programs are essential controls that should be exercised freely. Issues that are marginal to that main effort do not fall within the role of public health service agencies and should be avoided. Let me emphasize that this is in no way a policy that should interfere with the rights of individual scientists to express freely their personal views.

### Funding and Patient Care

Finally, there must be a rational approach to funding all of these efforts. Throwing money at a problem rarely speeds up the solution, especially when the problem is as complex as AIDS. Starving the efforts will clearly not lead to a solution either. Thus, there must be a process within the government to set adequate funding levels and to see that the funds are made available. Funding has been the most contentious issue for AIDS, and the debate will continue. The unfortunate aspect of that debate so far is that it has detracted from the major issue of scientific progress.

I have not discussed medical care for patients with AIDS, another complex issue and one that deserves more time and greater competence than I possess. It is clear, however, that adequate care for patients with AIDS must be provided. This issue deserves more consideration than it has received thus far.

### Need for Mechanisms

I have tried to discuss those health policy issues that I feel are key, although others might identify different issues. There is agreement, however, that there must be mechanisms for detection, surveillance, and scientific investigation of this epidemic. With time and careful thought, a process can be constructed that builds on our experiences thus far and that learns from our efforts. We should consider a caution first voiced by Caleb Colton, an English clergyman, who said, "We ought not to be overanxious to encourage innovation. . .for an old system must ever have two advantages of a new one; it is established and it is understood."

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# Ethical Dilemmas in Caring for Patients with the Acquired Immunodeficiency Syndrome

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**Caring for patients with the acquired immunodeficiency syndrome (AIDS) raises ethical dilemmas about when to provide life-sustaining treatments such as mechanical ventilation and cardiopulmonary resuscitation. In addition, many patients become mentally incompetent and unable to participate in decisions. Homosexual men may want their lover or a friend to make decisions for them, but the patient's partner or friend cannot make these decisions unless he is legally designated. Decision-making guidelines may be hard to implement because caring for patients with AIDS is stressful. We describe three cases that illustrate the difficult ethical dilemmas and stresses of caring for these patients.**

ETHICAL DILEMMAS occur frequently in caring for patients with the acquired immunodeficiency syndrome (AIDS). Patients have a mean survival of less than 8 months after hospitalization for opportunistic infection, even with optimal treatment (1). Thus, patients and physicians frequently must decide whether supportive care might be more appropriate than life-sustaining treatments, such as mechanical ventilation and cardiopulmonary resuscitation.

These dilemmas are important for several reasons. First, current ethical and legal guidelines recommend shared decisions by physicians and informed competent patients. For some patients, however, physicians may believe further treatment is futile and that life-sustaining treatments are inappropriate, no matter what the patient wishes. Such unilateral decisions may raise ethical issues.

Second, patients with AIDS frequently become mentally incompetent and unable to participate in decisions. For such patients, current guidelines recommend shared decision-making by physicians and the patient's family. Many homosexual men with AIDS, however, want their lover or a friend, not a family member, to make decisions if they are unable to do so. The patient's partner or a friend cannot make these decisions unless legally designated as a durable power of attorney.

Third, decision-making guidelines may be difficult to implement because caring for patients with AIDS is stressful. Many patients are young, well educated, and in many ways similar to their caregivers. As one resident said, talking about life-sustaining treatments with these patients is like "telling your brother he is going to die."

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An increasing number of physicians will be faced with these dilemmas. More than 8000 new cases of AIDS are expected to occur in 1985 and 40 000 new cases are expected in the next 2 years (1). These dilemmas already arise frequently at hospitals that care for many patients with AIDS, such as San Francisco General Hospital. This hospital has a special ward for these patients and a daily census of 20 to 25 patients with AIDS or AIDS-related diagnoses. The medical service policy is for caregivers to discuss life-sustaining treatments and cardiopulmonary resuscitation with these patients within 72 hours of admission. An order not to resuscitate, if deemed appropriate, must be written by the attending physician and documented in the progress notes.

The care of these patients raises important questions about determining what medical treatment is futile and who is the most appropriate decision-maker for an incompetent patient. In this article, we describe three cases that illustrate these issues. We discuss choices about life-sustaining treatment, decision-making for incompetent patients, and physician stress and anxiety.

## Current Decision-Making Guidelines

A medical, legal, and ethical consensus has developed that life-sustaining treatment may be limited when further therapy is medically futile or when the competent patient declines care (2-4). Because such decisions require both technical expertise and informed consent, they should be made jointly by the physician and patient.

If the patient is mentally incompetent and thus unable to participate in decisions, joint decision-making by physicians and families is the traditional approach. The family is assumed to represent the patient's preferences and best interests. When possible, the patient's previously expressed wishes should be followed. Such wishes may also be expressed through living wills or the durable power of attorney for health care (5).

### WHEN IS LIFE-SUSTAINING TREATMENT FUTILE?

When a patient with AIDS does not respond to optimal treatment, the question arises, What more ought to be done?

A 34-year-old heterosexual man with a history of intravenous drug use was hospitalized for *Pneumocystis carinii* pneumonia. When life-sustaining treatment was discussed with the patient, he requested on multiple occasions that "everything be done," including intubation and cardiopulmonary resuscitation if necessary.

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When his pneumonia worsened, trimethoprim-sulfamethoxazole therapy was discontinued and pentamidine begun. The patient continued to want "maximal" care, but he became disoriented and unable to talk to his physicians. The attending physician on the ward wrote in the chart 7 days after admission that the patient "was not a candidate for cardiopulmonary resuscitation." He stated, "Because of the underlying nature of the patient's disease and the fact that he has not responded to initial therapy, I believe that intubation and respiration hold little benefit for the patient." The patient had recently moved to San Francisco and said there was "nobody at all" for doctors to contact.

Two days later, the intern's note stated that the patient is "very alert and oriented" and "seems improved on pentamidine." The care plan, including code status, was not reconsidered. The patient died early the next morning, 12 days after admission.

The decision to withhold life-sustaining treatment in this patient is contrary to the principle of shared decision-making between physicians and competent patients. This raises several questions. When is a unilateral decision by physicians to withhold life-sustaining treatment justified despite the patient's stated wishes to the contrary? How should physicians determine that further treatment is futile?

Physicians are not obligated to provide treatments with no chance of success. Thus, if the chance of survival despite intubation and intensive care for a disease is virtually nil, it is misleading and unnecessary to offer mechanical ventilation and cardiopulmonary resuscitation to patients as an option.

In many cases, however, it is difficult to determine whether further treatment is futile. Survival to hospital discharge after intubation for pneumocystis pneumonia may be as high as 14% (6). Reports in the literature do not indicate what factors influence the prognosis of patients who develop respiratory failure from pneumocystosis or what duration of antibiotic therapy is necessary before treatment can be considered a failure. Most physicians would agree that if a patient had not responded to antibiotic treatments after 1 or 2 days, it would be premature to consider the treatment a failure. On the other hand, if pneumocystosis had progressed despite 3 weeks of therapy with both trimethoprim-sulfamethoxazole and pentamidine, many would consider further antibiotic treatment futile. Clinicians must rely on their experience and judgment and on the opinion of expert consultants. For a new disease like AIDS, knowledge is imperfect and rapidly evolving. When there are uncertainties, life-sustaining treatments like mechanical ventilation may be warranted, if this is consistent with the patient's wishes.

Deciding whether further treatment is futile requires value judgments as well as technical expertise. Reasonable and well-intentioned people will reach different conclusions about whether a treatment with a 15%, 5%, or 1% likelihood of success is futile. The patient, primary physician, consultants, housestaff, and nurses may disagree. Explicit discussion with the patient may improve decision-making. Caregivers may feel differently about a 60-year-old woman with transfusion-related AIDS than they do about a young homosexual man with a history of intravenous drug use. These value judgments may bias a decision unless they are discussed explicitly and distinguished carefully from scientific facts.

Clarifying the goals of treatment is also important because a patient's request that "everything be done" is ambiguous and unclear. The patient can be asked directly, "Can you tell me what you mean when you say 'everything'?" Patients may not understand their prognosis, what mechanical ventilation and cardiopulmonary resuscitation are, and the effectiveness of such treatments. Some patients may simply wish not to be abandoned and mean "everything to make me comfortable while I am dying."

Decisions to limit treatment based on medical futility should be distinguished from decisions based on allocating scarce medical resources, such as intensive care beds. Physicians in busy hospitals may need to consider the availability of intensive care unit beds and their marginal benefit to patients with AIDS as compared to patients with other diagnoses. At San Francisco General Hospital, for example, at some times all medical intensive care beds could be filled by patients with AIDS. This would deny intensive care to patients with other diagnoses or force them to be transferred to other hospitals.

Decisions based on the availability of resources are best made not by the intensive care unit attending or resident physician in an individual case, but through advance planning by hospital administrators, chiefs of service, and, if necessary, local governments and regional health care networks. Many urban areas where AIDS is common have a surfeit rather than a shortage of intensive care unit beds. If one hospital has too many patients with AIDS who require intensive care unit beds, then patients might be admitted to other hospitals.

When decisions about individual patients must be made, physicians should reassess the condition of all patients in intensive care units to identify those who might be too sick or too well to benefit from such care. Reducing the number of patients admitted primarily for monitoring or considering temporary measures to increase the number of intensive care unit beds, such as admitting patients to the post-anesthesia area, may be appropriate approaches. Some evidence suggests that physicians can adjust to a moderate scarcity of intensive care unit resources by more efficient use of available beds without adverse medical consequences for patients (7).

### WHO SHOULD DECIDE FOR INCOMPETENT PATIENTS?

Patients with AIDS may become incompetent, often because of central nervous system or severe pulmonary disease. Treatment decisions may be especially difficult for such patients. For example, the patient's wishes may not be known, conflicts may develop between the patient and his family, or a surrogate decision-maker may not have been appointed. The following case illustrates the problems of a patient who had severe conflicts with his family and clear wishes about terminal care.

A 32-year-old homosexual man with Kaposi's sarcoma was admitted for candida esophagitis and cachexia. The patient had been abandoned by his parents and raised by a grandmother. She refused to care for him when she learned of his diagnosis.

His siblings refused to visit although they lived nearby. His parents wrote that his illness was God's punishment for being gay.

The patient knew he was dying. He was attended around the clock by his partner. He had discussed with his partner and his clinic physician his desire not to be intubated. At the suggestion of caregivers, he designated his partner as his durable power of attorney for health care. A no-code order was written.

The patient died of *P. carinii* pneumonia and progressive multifocal leukoencephalopathy 12 days after admission. The patient's father had wanted the body flown back to the Midwest for burial, despite the patient's stated desire to be cremated after a local funeral. Because of the durable power of attorney, the body was released to the patient's friend and the patient's wishes were respected.

This case shows the particular advantages of the durable power of attorney for health care for homosexual men with AIDS. Under California law, it gives legal sanction to proxy decisions. The durable power of attorney allows the competent patient to designate someone, presumably a trusted friend or relative, to make decisions about medical care in accord with the patient's previously stated wishes if he should become incapable of making such decisions.

Because the patient designated his partner as his proxy decision-maker, his wishes about terminal care and funeral arrangements were followed. If a proxy had not been designated, then the patient's next of kin would have become the decision-maker under the common law and medical practice, although this might have prevented the patient's wishes from being respected.

Appointment of a durable power of attorney for health care has advantages for many patients with AIDS, especially those who are not close to their families, who have no family, or who have conflicts with family members. This approach is also useful for patients who have strong preferences about medical care, whether these preferences are for maximal or limited care. Appointment of a surrogate decision-maker has advantages for caregivers as well (5). If the incompetent patient has no immediate family, physicians no longer need to pick a substitute decision-maker, initiate legal proceedings, or make the decisions themselves.

The durable power of attorney, however, does not solve all problems of caring for incompetent patients. For example, the law is ambiguous about providing maximal therapy. The California Medical Association has printed forms that patients may complete to execute a durable power of attorney for health care. Patients may check a request for maximal treatment: "I want my life to be prolonged to the greatest extent possible without regard to my condition, the chances I have for recovery or the cost of the procedures." If the first patient described had appointed a proxy decision-maker and selected this statement, the decision would have been more complicated. It would have been inappropriate for physicians unilaterally to limit care. The proxy would have been obliged to insist on intensive care unit care and cardiopulmonary resuscitation. However, if the patient's condition continued to deteriorate, at some point life would have been prolonged to "the greatest extent possible"; the physicians and proxy could then have agreed to limit life-sustaining treatment.

Ideally, the durable power of attorney should stimulate discussions with patients and their proxies and not substitute for such discussions. It should help the physician anticipate problems or questions. If the patient's preferences are ambiguous or unrealistic, then the physician should clarify the meaning with the patient and proxy through education and counseling and then document these discussions in the medical record.

#### Physician Stress and Anxiety

Caring for patients with AIDS may be highly stressful. These critically ill patients may have long hospitalizations and require many procedures. Many patients do poorly despite optimal treatment or develop new opportunistic infections after successful treatment for one infection. Doctors may wonder, is this all worth it?

In addition, physicians may have emotional reactions to these patients. They may fear they will acquire AIDS from them. Some physicians may not be comfortable with homosexual patients. Caregivers may react to these stresses by either identifying closely with the patient or distancing themselves as much as possible (8).

Particular anxiety may occur when caregivers are unfamiliar with patients. The following case illustrates the reaction of staff at a community hospital to their second patient with AIDS.

A 43-year-old homosexual male musician was hospitalized for evaluation of weight loss, diarrhea, and lymphadenopathy. Kaposi's sarcoma was diagnosed.

Several nurses refused to care for the patient. Physicians were anxious about contaminating themselves while examining the patient because of his frequent fecal incontinence. Sigmoidoscopy was done in the operating room after everything was removed from the room except the operating table. Housekeepers would not clean the patient's room or empty the trash. Food workers left meal trays in the hallway. A crisis developed when the patient's toilet became clogged. The employees who fixed the toilet were convinced that they had acquired AIDS. After 2 weeks, the patient transferred to another hospital.

The patient's resident and the hospital psychologist began an educational program. They visited the AIDS ward at the San Francisco General Hospital and produced a 1-hour videotape of interviews. The hospital adopted published infection control guidelines for patients with AIDS. Anxiety about caring for these patients decreased significantly.

At this hospital information and frank discussion allayed misconceptions about the care of patients with AIDS. In other cases, physicians have refused to care for such patients and sent them to referral hospitals, sometimes without consultation or planning (9, 10). Such transfers pose medical and ethical problems. Patients may suffer from delays in care and from social isolation in an unfamiliar community. The perception of patient "dumping" creates ill-will between physicians and stigmatizes the patients who are transferred (11-13).

Physicians at referral hospitals can provide consultations, see a patient on an ambulatory basis when the patient's condition is stabilized, or accept selected patients in transfer after discussion with the referring physician. However, the number of patients with AIDS is so large in some cities that referral hospitals cannot fully assume the

burden of care.

Caregivers who see many patients with AIDS also are stressed. "When I diagnose pneumocystis, I am pronouncing a death sentence," one physician said. Many physicians find it particularly difficult to talk about life-sustaining treatments with a patient who they have just met and who may need immediate intubation.

Stresses vary with the perspective of the caregiver. Houseofficers who care for patients with AIDS are often pessimistic. Many see these patients only at a time of crisis, not when the patients come for clinic visits and are doing well. Some feel that these patients will die no matter what care they are given. Other housestaff question their own skills and competence if their patients do poorly. In contrast, a researcher testing an experimental drug may seem overly optimistic about the potential benefits of the drug if a patient improves. Housestaff may emphasize the risks of the medication, the extra work involved, and their skepticism about success.

Interns and nurses face particular stresses, because they spend the most time with patients. Nurses bathe patients, change linens, and provide toilet care. Interns do procedures such as arterial blood gas measurements, blood cultures, lumbar punctures, and bone marrow biopsies. Interns may feel that residents and attending physicians avoid discussing life-sustaining treatment with these patients and family members. The intern may also feel pressure from colleagues covering patients at night to get a no-code order before sign out. For these reasons, the intern may feel isolated and resentful.

Several steps may relieve these stresses (8, 14, 15). Caregivers of dying patients should address their own anxieties explicitly and should seek emotional support for themselves from colleagues, friends, and family. Attending physicians should help houseofficers discuss the goals of therapy and life-sustaining treatments with patients. Physicians should also emphasize supportive care to reassure everyone that physicians are not "giving up" and that symptoms will be controlled. Other caregivers such as nurses, social workers, psychiatrists, trained volunteer counselors, or chaplains can help facilitate supportive care.

## Conclusions

As the number of patients with AIDS increases, more physicians will be faced with the difficult ethical dilemmas that occur in the care of these patients. Patients who want aggressive therapy, including life-sustaining treatments, should receive it unless the prospect of success is virtually nil. Patients who want supportive care should be reassured that caregivers will provide this care and not abandon them.

Shared decision-making by physicians and informed competent patients is impossible after patients become mentally incompetent. Physicians should clarify the patient's wishes about life-sustaining treatment when the patient is competent and should encourage patients to provide advance directives, such as a durable power of attorney for health care. The durable power of attorney is particularly important for homosexual men who wish to have their partner or friend, rather than a family member, make decisions for them.

The stress of caring for patients with AIDS makes effective decision-making guidelines more difficult to implement. Patient care can be improved by recognizing these stresses and dealing with them explicitly.

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## References

1. Landesman SH, Ginzburg HM, Weiss SH. The AIDS epidemic. *N Engl J Med.* 1985;**312**:521-5.
2. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Deciding to forego life-sustaining treatment: a report on the ethical, medical, and legal issues in treatment decisions. Washington, D.C.: U.S. Government Printing Office; 1983.
3. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics.* New York: Macmillan Publishing Co.; 1982.
4. Lo B, Steinbrook RL. Deciding whether to resuscitate. *Arch Intern Med.* 1983;**143**:1561-3.
5. Steinbrook R, Lo B. Decision making for incompetent patients by designated proxy. *N Engl J Med.* 1984;**310**:1598-601.
6. Murray JF, Felton CP, Garay SM, et al. Pulmonary complications of the acquired immunodeficiency syndrome: report of a National Heart, Lung, and Blood Institute workshop. *N Engl J Med.* 1984;**310**:1682-8.
7. Singer DE, Carr PL, Mulley AG, Thibault GE. Rationing intensive care—physician responses to a resource shortage. *N Engl J Med.* 1983;**309**:1155-60.
8. McCue JD. The effects of stress on physicians and their medical practice. *N Engl J Med.* 1982;**306**:458-63.
9. Sharpe I. Florida hospital says AIDS patient sent here for humanitarian reasons. *San Francisco Sunday Examiner and Chronicle.* 1983 Oct 9: A-4.
10. Blakey S. Another very sick AIDS patient 'dumped' on S.F. *San Francisco Chronicle.* 1984 Aug 9:3.
11. Wrenn K. No insurance, no admission. *N Engl J Med.* 1985;**312**:373-4.
12. Relman AS. Economic considerations in emergency care: what are hospitals for [Editorial]? *N Engl J Med.* 1985;**312**:372-3.
13. Himmelstein DU, Woolhandler S, Harnly M, et al. Patient transfers: medical practice as social triage. *Am J Public Health.* 1984;**74**:494-6.
14. Artiss KL, Levine AS. Doctor-patient relation in severe illness: a seminar for oncology. *N Engl J Med.* 1973;**288**:1210-4.
15. Tolle SW, Girard DE. The physician's role in the events surrounding patient death. *Arch Intern Med.* 1983;**143**:1447-9.

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