The Ethics of Caring for Patients With HIV or AIDS

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Health care professionals encounter many ethical issues in the care of persons who are HIV positive or who have been diagnosed as having AIDS. Such issues include the allocation of scarce resources for research and health care; the use of various methods of disease control, including mandatory testing, forced isolation, informing of sexual partners, and education; and the determination of the responsibility to treat infected patients.

These issues are presented as a stimulus to readers to examine their own attitudes regarding HIV and AIDS. The usefulness and limitations of occupational therapy’s professional code in resolving ethical dilemmas are discussed, followed by the description of a process that can be used to analyze and solve these dilemmas.

The instant headline status of AIDS and HIV infection in both the professional and the public press reflects the universal fears and concerns regarding the containment and control of this deadly disease. The U.S. Public Health Service currently estimates that between 1 million and 1.5 million people in the United States are infected with HIV, and the Centers for Disease Control has projected that the annual incidence of AIDS will increase to 60,000 by 1990 and to 365,000 by 1992 (Heyward & Curran, 1988). The present article discusses some of the ethical dilemmas that health care professionals must face when making decisions about the identification and treatment of persons with HIV infection or AIDS. Some concerns specific to occupational therapy are also addressed.

Milliken and Greenblatt (1987) stated, “The ethical issues surrounding the acquired immunodeficiency syndrome (AIDS) epidemic have been prominent since the initial description of AIDS in homosexuals during 1981. . . . As in times of previous epidemics, conflicts between individual rights and societal imperatives come to the forefront as public health authorities grapple with methods of epidemic control” (p. 443).

The determination of an ethical course in the care and treatment of persons with AIDS and in the control and prevention of the disease requires that the health care professional make decisions on several parameters. Some of the questions that must be answered are as follows:

1. How should resources be allocated to care for AIDS patients? What amount of funding should be designated for HIV and AIDS research?
2. What are the best methods of disease control?
3. Does the patient have the right to decide who should be informed?
4. Does the health care professional have an obligation to inform persons who test positive for HIV and to report these persons as carriers of the disease?
5. Do health care professionals have the duty to treat persons with AIDS? Do health care professionals have the right to refuse to treat such patients?

Some of the more pressing ethical dilemmas for health care professionals arise in the treatment of persons with AIDS or HIV. The tough decisions that must be made regarding the treatment of persons who have contagious, life-threatening diseases, however, are not new. The care of persons with plague, typhus, malaria, polio, leprosy, and tuberculosis has caused concern and fear. During a plague in Florence in 1348, Boccaccio wrote of his frustrations in finding no
cure for the disease (Winwar, 1955). He particularly bemoaned the fate of physicians who in caring for their patients contracted the disease and perished. The modern-day epidemic of AIDS, however, carries more of a stigma because of its association with homosexuality and drug abuse.

Allocation of Resources

How should we use available personnel and materials? What kind and quantity of medical resources should we expend? The treatment of persons in the final stages of the disease raises questions about when, how, and if to resuscitate, the use of certain surgical procedures, and the “initiation or withdrawal of assisted ventilation or artificial nutrition” (Milliken & Greenblatt, 1987, p. 447). Such decisions are common in the treatment of terminally ill patients, but they are made more difficult in cases of AIDS due to the relatively young age of the patients. Moreover, the expense involved in the use of universal precautions has contributed to the skyrocketing cost of health care provision and health care insurance.

Another critical financial concern is the amount of money needed to support research efforts to find a cure and effective methods of prevention for the disease. James D. Watkins, chair of the Presidential Commission on the Human HIV Epidemic, during a media briefing about the commission’s report, estimated that more than $3 billion would be needed annually to support an adequate national research effort (“Pessimistic Outlook,” 1988). Some people vigorously oppose the allocation of such large sums of taxpayers’ money to find a cure for a disease that affects a relatively small percentage of the population (Kilpatrick, 1988).

Disease Control

Some of the more apparent methods to control the spread of AIDS are (a) universal mandatory testing for HIV, (b) forced isolation of all persons with AIDS and perhaps of all HIV carriers, (c) the practice of tracing and contacting sexual partners and those with whom the infected person has shared needles, and (d) education. Each of these methods, however, has inherent problems.

Universal mandatory testing. Methods by which to screen large numbers of people already exist. Besides the problem of false-positive and false-negative results, however, is the question of how test results would be used. Mass screening programs have serious personal and societal implications. Although mass screening would allow HIV carriers to receive early counseling and drug therapy, such counseling does not ensure the cessation of promiscuous behavior. Additionally, if positive test results are reported to a public agency (e.g., public health department), the infected person may be ostracized by his or her family and friends.

Forced isolation. Persons with HIV or AIDS may face forced isolation from society, just as persons with tuberculosis did approximately two decades ago. In Cuba, persons with AIDS are forcibly detained (Betancourt, 1988). Although these persons, under the jurisdiction of the Ministry of the Interior, are asked to voluntarily report to an isolation facility, if they do not comply they are taken there by force. This response to the AIDS epidemic raises concerns about the individual’s rights.

One might believe that forced confinement is possible only in countries considered less democratic than the United States. But even in this country, some legal and health professionals have been debating the legitimacy of confining to psychiatric institutions those HIV-positive persons who engage in promiscuous sexual activity (Appelbaum, 1988). Appelbaum noted the distinction between quarantine and civil commitment laws. Some states permit the quarantine of persons with transmittable infectious diseases. Quarantine facilities are unavailable in certain areas, however, and because the laws have fallen into disuse, they are not easily invoked. Conversely, civil commitment laws are used regularly to detain persons considered dangerous to the general public. Although Appelbaum discussed the inappropriateness of the use of civil commitment to confine persons with HIV or AIDS, he believed that there would be continuing pressure from public officials to use the mental health system for this purpose unless other means of detention are created (Appelbaum, 1988).

Informing others. In June 1988, the American Medical Association (AMA) issued a policy report outlining the steps that a physician should follow in informing third parties that a patient is infected with HIV. The report stated that the physician should first encourage the patient to inform third parties who may be at risk. If this fails, the physician should notify public health authorities. Finally, if the authorities do not act, the physician should directly inform and counsel those persons who are endangered (“AMA Takes Stand,” 1988).

The AMA has also urged states to establish systems by which they can trace and contact sexual partners of HIV-positive persons, much like the methods used to contact the sexual partners of persons with venereal disease. This policy has drawn sharp criticism from gay activists, who believe it to be an oversimplified solution to a complex problem. Jeff Levi, executive director of the National Gay and Lesbian Task Force, maintains that the problem requires a flexible approach rather than one standard procedure for the notification of partners (“AMA Takes Stand,” 1988).
Education. The least invasive disease control strategy is education. Examples of such efforts are former Surgeon General Koop's mailing of an educational pamphlet to all U.S. citizens and the showing of short informational clips on national television. Although these materials are developed in the interest of increasing public understanding and awareness, I have found that some persons consider these materials to be a serious invasion of their privacy and an affront to their values. Nonetheless, the perceived threat of AIDS is so great that the otherwise conservative Reagan administration provided funding for the preparation and wide distribution of these materials.

Professionals' Duty To Treat AIDS Patients

Fear and ignorance. Because a cure or a preventive vaccine does not exist, some health care professionals question their duty to treat persons with AIDS. They express their fear both actively and passively by refusing to provide certain types of care or by providing only that care that does not necessitate close physical contact with the patient. Some of this fear evolves from a lack of knowledge or mistrust of the information provided. Although research has shown that HIV infection can only be transmitted perinatally, through infected blood or blood products, or through unprotected sexual activity, doubt still exists among health care professionals. For example, in a 1987 study of nurses and physicians conducted at New York's Beth Israel Medical Center, 64% of the respondents were unsure or did not believe that they had been given accurate information about the risk of contracting HIV (“Ignorance About AIDS,” 1988).

The American Medical Association in 1987 publicly stated that physicians have a duty to treat the sick and that this duty prevails even when the patient has a transmissible and lethal disease such as AIDS (“Medical Association,” 1987) I believe that the same duty holds for all health care workers. In their chapter entitled “Ethical Issues in AIDS,” Murray and Aumann (1987) stated, “The moral force of professional commitment means nothing if it applies only when safe and convenient. . . . Exaggerated fears of a minimal danger of contracting AIDS are no excuse for failing to live up to professional vows” (p. 142).

Prejudice. Some health care professionals have reacted negatively to the sexual preferences or drug abuse of some AIDS patients. These reactions are then used to rationalize their avoidance of persons with AIDS. In a study conducted at Beth Israel Hospital in New York, approximately 11% of the nurses and 4.5% of the physicians considered AIDS to be “God’s punishment” to homosexuals (“Ignorance About AIDS,” 1988).

Implications for Occupational Therapists

We as occupational therapists may proclaim that we know better and that we have no ethical conflicts when working with and for persons who have HIV or AIDS. A recent survey of 119 occupational therapists (Atchison, Beard, & Lester, 1990), however, indicated that 41% of the respondents feared AIDS more than any other disease, 36% feared contracting AIDS during routine care of patients with AIDS, and 36% feared transmitting the virus to their family and friends.

Although occupational therapists are guided by a professional code of ethics (American Occupational Therapy Association [AOTA], 1988), the code does not provide specific methods for the resolution of ethical dilemmas. Rather, it provides guidelines and a general description of behaviors that are considered desirable for all occupational therapists. Principle I, for example, states that the therapist must “protect the confidential nature of information gained from educational, practice, and investigational activities unless sharing such information could be deemed necessary to protect the well-being of a third party” (AOTA, 1988, p. 795). The determination of when and with whom to share information to protect the patient or others is difficult and is one that is particularly complex when the patient has HIV or AIDS.

Hansen, Kamp, & Reitz (1988) provided one strategy of analysis for the resolution of ethical dilemmas. Additionally, Hansen and Kyler-Hutchison (1989) provided the following five-step process by which the therapist can select a defensible solution:

1. Who are the “players” in the dilemma?
2. What other facts/information do you need?
3. What are the actions which might be taken?
4. What are the consequences (ethical, medical, and/or legal) of each action?
5. Choose an action or combination of actions that you would recommend and can defend.

Either method may prove useful to the therapist who is grappling with the dilemmas that arise when caring for the patient with HIV or AIDS.

I believe that occupational therapists face the same ethical dilemmas regarding HIV and AIDS as do other health care professionals. We must consider many factors when determining which solution is the best for the patient, the occupational therapist, and for society. The resolution of these ethical concerns, like many other concerns that health care workers face, is influenced by the personal and professional values of all of the persons involved. We must remember, however, that the cultural, social, and political climates strongly influence the final determination of an appropriate course of action. We are bound by the ethical code of our profession to care for all who require our services. Although the decision to
treat a person infected with HIV or AIDS is a personal one, we must also consider our moral responsibility and professional accountability and must understand that very little personal risk is involved. The refusal to care for a person with HIV or AIDS because of prejudice or fear is clearly an ethical violation. Equally unethical is subtle discrimination, such as a premature discharge or referral or the choice of a less effective treatment method so as to diminish the need for close physical contact. The ethical care of our patients requires the careful and thoughtful consideration of our own values and attitudes and of the values and needs of all concerned.

Currently, our most effective weapon against AIDS is the diminishment of the fears of health professionals and of society at large. We can best accomplish this by providing everyone with accurate information about HIV and AIDS. This requires frequent updates, because research is continually providing us with a new understanding of the disease’s mechanisms and with the most effective precautionary measures (Heyward & Curran, 1988). Our duty as occupational therapists is to be knowledgeable about HIV and AIDS and to share this knowledge with our colleagues and patients. 

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References


