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AIDS: THE RESPONSIBILITY TO CARE

D. Anthony Forrester*

"Our privileges can be no greater than our obligations. The protection of our rights can endure no longer than the performance of our responsibilities."1

SINCE the first cases of acquired immunodeficiency syndrome (AIDS) were reported among members of the gay community in the United States in 1981, the human immunodeficiency virus (HIV) that causes AIDS and AIDS-related conditions (ARC) has precipitated a pandemic unprecedented in modern history. It is currently estimated that about 175,000 Americans will be persons with AIDS or ARC (PWAs) by 1991 and approximately 1.5 million people in the United States are already infected with HIV.2 Over 130 countries throughout the world have reported cases of AIDS,3 and it is anticipated that in the next five years there will be as many as one million new cases of AIDS worldwide.4 Thus, AIDS is a vastly complex, global phenomenon with extraordinary social, cultural, economic and political dimensions and impact.

The worldwide fear and hysteria AIDS has engendered is unprecedented in contemporary society. The profound scope of the AIDS pandemic forces all segments of society to reexamine their values and to address many troublesome legal and ethical issues. Health care and legal professionals are not exempt. Many of these issues are born of the unique epidemiological features of this disease and the pervasive social stigma attached to those afflicted with it. From the perspective of health care providers and

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legal professionals, this stigma may be viewed as much a part of the pathology of AIDS as the virus itself.

Exploring factors contributing to the stigmatization of PWAs may be helpful in formulating an understanding of the challenges health and legal professionals must address during this pandemic. A brief etiological exploration of the stigmatization of PWAs will be followed by a discussion of the legal responsibilities and the perhaps more complex ethical challenges AIDS poses for the next decade.

I. Stigmatization of PWAs

"[T]he anatomy of any myth is the anatomy of the men who believed in it and suffered by it."\(^5\)

It may be considered an accident of history that AIDS was discovered in the gay community of the United States. It could just as easily have been discovered in a number of other countries. Had it been discovered in Africa, for example, it might have been known as a heterosexual disease which, because it is sexually transmitted, also affects gay men. Thus the regrettable, universal and false impression that AIDS is a "gay" disease might not have come about.\(^6\) Unfortunately, the history of this disease cannot be rewritten, and the social and cultural meanings of AIDS continue to contribute to widespread stigmatization of PWAs, frequently resulting in AIDS discrimination.

Undoubtedly, one of the most serious threats PWAs face is the powerful social stigma associated with having AIDS. Thus far, AIDS has had its greatest impact on groups perceived by many as socially "deviant." These groups include gay and bisexual men and intravenous (IV) drug abusers.\(^7\) The indigent and black and Hispanic racial minorities are also disproportionately affected.\(^8\) This stigma has very real and crippling results: PWAs and individuals who have tested positive for the HIV antibody often lose their jobs and insurance benefits. Some have been denied educa-

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6. See International Epidemiology, supra note 4, at 84-85.
7. Quarterly Report to the Domestic Policy Council on the Prevalence and Rate of Spread of HIV and AIDS in the United States, 37 Morbidity & Mortality Weekly Rep. 223, 224 (1988) (68% of cases reported in 1987 were among homosexual and bisexual men and 19% were among IV drug abusers).
tional opportunities and medical care.9

During the social crisis of an epidemic, further stigmatization of already disenfranchised groups serves to project fears of contagion, immorality and mortality outside the normative social group. This, of course, occurs at great expense to the non-normative groups by compounding their stigmatization. Not only are AIDS victims branded as belonging to socially “deviant” groups, they are forced to suffer the consequences of being stigmatized individuals with a stigmatized life-threatening disease.10

As a result of the stigma associated with AIDS, PWAs frequently encounter unfair discrimination.11 Like other forms of discrimination, AIDS discrimination is “the unfair treatment of individuals based upon irrational fears and prejudices about groups.”12 The resulting “us” versus “them” mentality is potentially very costly to society as a whole. Because stigmatized groups, whether HIV-infected or not, fear discrimination, they may naturally be less willing to participate voluntarily in society’s efforts to control the spread of AIDS.13

AIDS engenders much fear and apprehension. For many people, including some health care providers, “AIDS carries with it all the connotations of sin” and images of an illicit disease associated with illicit behavior.14 Two important aspects of “AIDS fear” are the fear of disease and of social disorder.15

Far more complex than the obvious and possibly realistic fear

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11. Not only are PWAs discriminated against in housing, education and employment, but they often experience unfair treatment discrimination. Treatment discrimination occurs when health care providers must make decisions about who is to receive a scarce medical resource, whether it be a nurse’s time or a donor’s kidney. Necessarily, the decision to give to one patient means another must go without. This form of discrimination, however, can be either fair or unfair. Treatment discrimination based on the urgency of a patient’s need or some other objective medical fact is “fair discrimination.” Treatment discrimination based on fear, prejudice or the patient’s personal attributes is “unfair discrimination.” AIDs stigma often results in unfair discrimination against PWAs in treatment decisions.


13. See id. at 1116. “Fear of stigmatized groups . . . intensifies the epidemic through its divisiveness at a time when social cooperation is essential.” Id.


15. Schulman, supra note 12, at 1115.
of contagion, fear of AIDS as a disease is compounded by a number of factors. First, human sexuality and, more specifically, homosexuality and bisexuality, are issues about which many members of society are uncomfortable and ill-informed. A second factor is society's ambivalence regarding mental illness. As treatment modalities improve and life expectancy lengthens for PWAs, it is likely that we will see greatly increased numbers of HIV-demented people. This will exact increased physical and fiscal demands on existing and future mental health care systems as well as other social resources. The invariably fatal prognosis is a third factor which contributes to the fear of AIDS as a disease. The fear of death is primal and pervasive, even among health care providers. In fact, health practitioners' personal

16. Id. at 1117. Human immunodeficiency virus (HIV) penetrates nervous cells resulting in damage to the brain and nervous system in approximately 60% of AIDS patients. Felix, Mueller & Schmid, AIDS in the Long-Term Care Setting, 7 St. Louis Pub. L. Rev. 115, 117 (1988). The neurological damage results in cognitive changes which progress quickly from mild confusion to inability to speak or function independently. Barnes, AIDS-Related Brain Damage Unexplained, 252 Science 1091, 1091 (1986). Motor problems such as poor coordination accompany the cognitive changes. Id. For a detailed discussion of AIDS dementia, see id.

17. One economist estimates the lifetime costs for an AIDS patient's medical care, encompassing hospital, physician, drug (including AZT) and home-care nursing costs, at $57,000 in 1988 and $61,000 in 1991. Hellinger, Forecasting the Personal Medical Care Costs of AIDS from 1988 Through 1991, 103 Pub. Health Rep. 309, 309 (1988). Three different 1986 studies estimated the lifetime cost per AIDS patient at $150,000, $94,000 and $70,000 respectively. Id. at 312. These estimates included hospital costs and $2,000-$4,000 for non-inpatient costs. Id. at 311-12. Some commentators suggest that many AIDS patients remain in hospitals longer than necessary because home health care and community-based services are not widely available. Felix, Mueller & Schmid, supra note 16, at 115-16. Therefore, if more care were available on an outpatient basis or in long-term care facilities rather than hospitals, the average cost per AIDS patient would be much less. Id. at 116. In fact, it has been noted that the "average length of [hospital] stay has dropped from 18 to 11 days because of increased treatment in outpatient settings." Hellinger, supra, at 313. Hellinger attributes the vast disparity between the high 1986 estimated cost of $150,000 and the 1988 estimate of $57,000 to efficiency in treatment and less dependency on hospital services. Id.

One should rely on these cost estimates with caution as many factors which contribute to the costs may change in the future. Such factors include: (1) a change in the predominant specific AIDS manifestation (e.g., Kaposi's sarcoma which is less costly to treat than Pneumocystis carinii pneumonia); (2) a shift in the geographic distribution of AIDS cases; (3) future scientific advances; and (4) even less dependency on hospital services. Id. at 314.


19. Even though the probability of dying from being struck by a bolt of lightning exceeds the probability of dying from AIDS contracted on the job, the fear of AIDS is very real and may overcome an individual's sense of professional responsibility. Albert, A Right to Treatment for AIDS Patients?, 92 Dick. L. Rev. 743, 745 (1988).
fears regarding mortality may be particularly exacerbated by a fatal disease affecting large numbers of young, previously healthy people—in other words, people very much like themselves.

The fear of social disorder, relative to the AIDS pandemic, stems from the attrition of PWAs from the work force, thus removing their economic contributions from society. This is further compounded by their acutely increased needs for public support for medical care, food and housing.\footnote{20. See Schulman, supra note 12, at 1117. The fear of social disorder is a fear of chaos which may result from the increased demands and decreased economic contributions of PWAs. Id.}

Historically, society has dealt with the fear of social disorder by focusing social panic onto such stigmatized groups.\footnote{21. Id. at 1118.} This has resulted in counterproductive scapegoating and isolation. For example, in an effort to control the spread of sexually transmitted diseases (STDs), 30,000 prostitutes were isolated during World War I.\footnote{22. Brandt, AIDS: From Social History to Social Policy, 14 Law Med. & Health Care 231, 233 (1986).} In spite of the infringement on the civil liberties of these people, the incidence of STDs increased dramatically during this period.\footnote{23. Id. Similarly, as a result of fear during World War II, the United States Supreme Court upheld the exclusion of certain Japanese-Americans from their homes.\footnote{24. See Korematsu v. United States, 323 U.S. 214, 219-20 (1944). The social fear which resulted in the 1942 detention of Japanese-Americans has been compared to the fear in the current AIDS crisis. See Barnes, AIDS and Mr. Korematsu: Minorities at Times of Crisis, 7 St. Louis U. Pub. L. Rev. 35 (1988). Barnes concludes that the painful and lasting social divisions which have resulted from the treatment of Japanese-Americans should teach that “widespread HIV testing without antidiscrimination laws [and] quarantining HIV-exposed people . . . will only exacerbate the crisis.” Id. at 43. See also Schulman, supra note 12, at 1118 (shameful impulse of scapegoating was demonstrated in treatment of Japanese-Americans in World War II).} Similarly, as a result of fear during World War II, the United States Supreme Court upheld the exclusion of certain Japanese-Americans from their homes.\footnote{25. See Durham, The Ethical Dimensions of AIDS, in The Person with AIDS: Nursing Perspectives 229, 232 (J. Durham & F. Cohen eds. 1987).} Fortunately, two recent legislative proposals that would have resulted in the scapegoating and isolation of PWAs were not successful. A prime example of the social panic engendered by AIDS fear is a 1986 referendum supported by Lyndon LaRouche that would have declared AIDS an infectious, contagious and easily communicable disease.\footnote{26. Durham, The Ethical Dimensions of AIDS, in The Person with AIDS: Nursing Perspectives 229, 232 (J. Durham & F. Cohen eds. 1987).} California voters defeated this legislation, legislation that would have mandated a quarantine of HIV-infected persons in camps and would have resulted in the loss of
employment of all infected food handlers and teachers. In 1988, California voters soundly defeated the Dannemeyer "Reporting Exposure to AIDS Initiative" (Proposition 102), a law that would have, among other things, eliminated all anonymous HIV screening in California and would have allowed employers and insurers to require HIV testing of applicants as a condition of employment and insurance coverage. Such extreme measures are irrational and counterproductive: few who believed that they had been exposed to HIV through high risk behavior would voluntarily submit themselves to testing. In effect, such measures would simply serve to drive AIDS underground and would surely thwart public health efforts such as screening, counseling and education to prevent the further spread of this deadly disease.

II. Legal Responsibilities of Health Care Professionals to Provide Care for PWAs

"AIDS poses the most profound issues of constitutional law and public health since the Supreme Court approved compulsory immunization in 1905."

PWAs must look to health care institutions, the employees of such institutions and self-employed physicians for medical treatment during the debilitating course of AIDS. The duties which may be imposed on each of these entities to care for the PWA can be quite dissimilar, as they rest on distinct theories.

One commentator has suggested that the common law doctrine of reliance upon a gratuitous undertaking guarantees the PWA the right to emergency treatment in a hospital emergency room. State statutes also may require a hospital to provide

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26. Id.
27. See State Voters Defeat Reporting Initiative, Approve Criminal Suspect Testing Measure, AIDS Pol'y & L., Nov. 16, 1988, at 1. However, the voters passed another measure which would allow judges to order individuals charged with sexual crimes to be involuntarily tested for HIV. Id.
29. Brennan, Ensuring Adequate Health Care for the Sick: The Challenge of the Acquired Immunodeficiency Syndrome as an Occupational Disease, 1988 Duke L.J. 29, 37-38; see also Wilmington Gen. Hosp. v. Manlove, 174 A.2d 135, 140 (Del. 1961) (to find liability, there must be unmistakable emergency and reliance on well-established custom of emergency services). Under this common law doctrine, proving that an unmistakable emergency exists may be an insurmountable hurdle for the PWA to overcome. See Fabian v. Matzko, 236 Pa. Super. 267, 269, 273, 344 A.2d 569, 570, 572 (1975) (telephone call to hospital indicating sudden, severe headache, vomiting and stiffness in back of neck does not amount to unmistakable emergency when patient had seen family physician same day).
emergency services for the PWA. Nevertheless, the right to receive emergency care does not provide a right to total health care, as the PWA will frequently require care in nonemergency situations.

Federal statutory provisions such as the Rehabilitation Act of 1973 and the Hospital Survey and Construction Act may prevent certain hospitals from denying emergency as well as non-emergency care to PWAs. These acts condition the receipt of federal funds upon the absence of discrimination in general. As neither of these acts has been tested in the AIDS context, it is difficult to be certain of their effectiveness in assuring health care for PWAs.

Even if an institutional duty to provide care to PWAs is recognized, there is still a practical problem on an individual level. Specifically, when a health care institution accepts PWAs as patients, can it require its employees to provide care for them? If employees of health care institutions fail to carry out patient as-

30. See Brennan, supra note 29, at 38; see also Thompson v. Sun City Community Hosp., Inc., 141 Ariz. 597, 688 P.2d 605 (1984). In Thompson, the Arizona Supreme Court held that the statutory standard of care embodied public policy which required "licensed hospitals in this state . . . to accept and render emergency care to all patients who present themselves in need of such care." Id. at 602, 688 P.2d at 610.


35. In School Board v. Arline, 480 U.S. 273, 289 (1987), the United States Supreme Court held that "a person suffering from the contagious disease of tuberculosis can be a handicapped person within the meaning of § 504 of the Rehabilitation Act of 1973." One commentator has suggested that the Supreme Court likewise will prohibit discrimination based on AIDS. Albert, supra note 19, at 771.
signments, it is considered insubordination.\textsuperscript{36} Therefore, physicians and nurses may be disciplined for refusing to provide medical and nursing care for PWAs.\textsuperscript{37} However, this general rule would not be upheld if the health care employee genuinely believed that the institution was not following proper infection control guidelines.\textsuperscript{38} Under the Occupational Safety and Health Act (OSHA),\textsuperscript{39} the employee may complain about potentially unsafe working conditions and refuse "in good faith to expose himself to the dangerous condition" without fear of subsequent reprisals.\textsuperscript{40} An employee may maintain a cause of action for retaliatory dismissal when fired for refusing to work under conditions that are deemed unsafe.\textsuperscript{41}

For health care professionals working independently, removed from the setting of health care institutions, there is less institutional pressure to treat an AIDS patient. However, when an independent physician establishes a professional relationship with a PWA, the common law doctrine of abandonment may impose a duty to continue to provide medical care. Under this doctrine, the physician cannot terminate the relationship unless the patient no longer requires treatment for the ailment, or the stabilized patient has been given notice adequate to permit the individ-

\textsuperscript{36} Creighton, \textit{Legal Aspects of AIDS—Part II, Nursing Mgmt.}, Dec. 1986, at 14. For a discussion of the ability of physicians who are not considered employees of health care institutions to refuse to provide medical treatment for PWAs, see Brennan, \textit{supra} note 29, at 35-37.

\textsuperscript{37} Creighton, \textit{supra} note 36, at 14-15.

\textsuperscript{38} \textit{Id.}

\textsuperscript{39} 29 U.S.C. §§ 651-678 (1982 & Supp. IV 1986). One of the enumerated purposes of OSHA is to "provide[c] medical criteria which will assure insofar as practicable that no employee will suffer diminished health, functional capacity, or life expectancy as a result of his work experience." \textit{Id.} § 651(b)(7). See OSHA guidelines, which are not specific to AIDS, in 29 C.F.R. § 1910 (1987). The Department of Labor has published advance notice of proposed rulemaking noting that no OSHA guideline has been issued specific to reducing occupational exposure to AIDS and inviting comment to ensure a full airing of the issues. Advance Notice of Proposed Rulemaking, 52 Fed. Reg. 45,438 (1987).

\textsuperscript{40} 29 C.F.R. § 1977.12 (1987). However, in order for an employee to refuse to work, the employee must have no reasonable alternative such as correction of the dangerous condition after having notified the employer. \textit{Id.} § 1977.12(b)(2). In addition, the condition must be such that a reasonable person would conclude that there was insufficient time to "resort to regular statutory enforcement channels." \textit{Id.}

\textsuperscript{41} See Hentzel v. Singer Co., 138 Cal. App. 3d 290, 293, 304, 188 Cal. Rptr. 159, 160, 168 (1982). Hentzel protested alleged unsafe working conditions caused by smoking in the workplace. \textit{Id.} at 293, 188 Cal. Rptr. at 160. The court ruled that under California law, Hentzel had a cause of action whether or not an OSHA standard or order was violated. \textit{Id.} at 300-01, 188 Cal. Rptr. at 165. \textit{See also} Creighton, \textit{supra} note 36, at 14-15 (employee can refuse to work where conditions are proven unsafe).
individual to locate an equally qualified replacement. Therefore, as Brennan observes, when a PWA enters a stable phase, the physician may withdraw from the relationship without liability. Perhaps the greatest obstacle to imposing a legal duty under the doctrine of abandonment is that it only applies after the physician-patient relationship has begun. It does nothing to prevent a physician from declining to establish such a relationship in the first place.

III. Ethical Challenges to Health Care Professionals

"The need for nursing is universal. Inherent in nursing is respect for life, dignity and rights of man. It is unrestricted by considerations of nationality, race, creed, color, age, sex, politics or social status." 

As members of society, health care professionals also participate in the stigmatization of PWAs. A number of research studies have documented negative attitudes of physicians and nurses toward gay men, IV drug abusers and PWAs in general. These attitudes may be based on the practitioners' opinions about such a patient's personal attributes, lifestyle or personal worth.

42. Brennan, supra note 29, at 35. The cause of action underlying the doctrine of abandonment is breach of the implied contract between the physician and patient. Id. at 35-36. In Miller v. Greater Southeast Community Hospital, 508 A.2d 927 (D.C. 1986), the court limited the application of the doctrine of abandonment to situations in which the patient is in need of immediate medical attention. However, if the patient does not need immediate care, providing the patient with a list of alternative physicians will relieve the physician from liability. Id. at 929.

43. Brennan, supra note 29, at 37. "The majority of AIDS patients' clinical courses are quite stable at times." Id.

44. For a discussion of the physician's ethical duty to treat an AIDS patient, see infra notes 57-63 and accompanying text.


Whatever their origins, such attitudes engender social prejudice from which discrimination emerges.

The complex phenomenon of AIDS stigma, in itself, poses major personal and professional challenges to health practitioners who wish to provide PWAs with optimal, sensitive health care. Understanding the social etiology of the AIDS stigma should assist health professionals to: (1) reject and counteract social stereotypes; (2) assess their personal values and risks more accurately; and (3) identify their professional responsibilities in providing health care which demonstrates value for the personal autonomy of PWAs.

A. Personal Safety

The health professions, particularly nursing, have long and distinguished histories replete with examples of care givers who knowingly risked their personal safety to help others. Providing care for PWAs presents at least some degree of risk to the physical well-being of health practitioners. For example, current estimates place the risk of becoming HIV-infected as a result of an accidental needlestick injury at approximately 0.13% to 0.39%.  

Thus, most health care providers are at far greater risk of contracting other serious infectious diseases such as hepatitis-B in the health care setting than AIDS. Although the risk of becoming HIV-infected while providing patient care is minimal, it must be factored into the health practitioner’s estimation of personal risk. Recognizing the conflict between the responsibility to provide care and a practitioner’s concerns for personal safety, professional associations have promulgated numerous official statements in an attempt to guide the practitioner in balancing these competing interests.

For example, in 1986, the Committee on Ethics of the American Nurses’ Association (ANA) published a position paper entitled *Statement Regarding Risk Versus Responsibility in Providing Nursing Care.* This document lists four fundamental criteria for nurses to consider when differentiating between a moral duty and a moral
option to provide care for patients with communicable or infectious diseases. These criteria are as follows:

1. The patient is at significant risk of harm, loss, or damage if the nurse does not assist.
2. The nurse’s intervention or care is directly relevant to preventing harm.
3. The nurse’s care will probably prevent harm, loss, or damage to the patient.
4. The benefit the patient will gain outweighs any harm the nurse might incur and does not present more than minimal risk to the health care provider.50

If all of the above criteria are satisfied, the nurse is morally obligated to provide care.51 If, however, one of these criteria is not met, the nurse may exercise a moral option to provide care or to not provide care.52 The nurse must arrive at an ethically defensible decision by weighing personal risk against the moral responsibility to provide care. For example, it may reasonably be argued that nurses who are immunosuppressed or who are receiving immunosuppressant therapy may choose to exercise their moral option by not providing care for PWAs.53 However, in most instances, the nurse will be morally obligated to provide care for PWAs, given the minimal risk of becoming infected.

An additional consideration impacting a health care practitioner’s choice is the environment and conditions under which the practitioner is expected to work. For instance, health care providers may ethically exercise their moral option not to provide care when the employing agency is not in compliance with currently accepted guidelines to prevent transmission of HIV in the health care environment.54 Clearly, an employer has an obligation to comply with such guidelines as the Centers for Disease Control’s (CDC) Recommendations for Prevention of HIV Transmission in Health-Care Settings. 55 Employers are thus obligated to provide

51. Id.
52. Id.
53. Id. See also Bremner & Brown, Learning to Care for Clients with AIDS—The Practicum Controversy, 7 Nursing & Health Care 251, 252 (1986) ("[Nursing] students with active infections, those who are themselves immunosuppressed, and those who are pregnant should not be assigned as primary providers for AIDS clients.").
54. See supra notes 36-41 and accompanying text.
resources necessary for proper infection control including appropriate equipment, education, enforcement and evaluation on an ongoing basis.\textsuperscript{56} However, there are no "cookbook" solutions when the employer significantly fails to comply with such guidelines. Ultimately, health care professionals are responsible for their own ethical decisions, even when others act irresponsibly.

Like those in the nursing community, many physicians and medical students have expressed concern about the possible transmission of HIV in the health care setting, particularly in clinical settings such as the operating room or cardiac catheterization laboratory where invasive procedures are performed. The Association of American Medical Colleges (AAMC), taking special note of these fears and concerns, has determined: "Medical students, residents, and faculty members have a fundamental responsibility to provide care to all patients assigned to them, regardless of diagnosis."\textsuperscript{57} According to the AAMC, to best address these fears and concerns, as well as to satisfy this responsibility, it is necessary to provide: (1) an accurate portrayal of the personal risks involved in medical practice to prospective medical students; (2) timely information regarding the risk of HIV transmission in clinical settings; (3) training in protective measures and monitoring of compliance with prescribed infection control guidelines; (4) facilities, equipment and personnel appropriate to avoid unnecessary risk; and (5) counseling and continuing education for recalcitrant medical practitioners.\textsuperscript{58}

The Council on Ethical and Judicial Affairs (CEJA) of the American Medical Association (AMA) squarely addressed the conflict between personal safety and the responsibility to provide care when it issued a report entitled \textit{Ethical Issues Involved in the Growing AIDS Crisis}. In this report, the CEJA mandated:

\begin{itemize}
\item[57.] Professional Responsibility in Treating AIDS Patients, 68 J. MED. EDUC. 587, 589 (1988).
\item[58.] \textit{Id.} at 590.
\end{itemize}
A physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is [HIV] sero-positive. The tradition of the American Medical Association, since its organization in 1847, is that: "when an epidemic prevails, a physician must continue his labors without regard to the risk of his own health." 59

Thus, physicians, like nurses, are enjoined by their professional association to assume at least some degree of personal risk to insure that PWAs receive health care. 60 The CEJA report also denounced discrimination by health care providers: "A person who is afflicted with AIDS needs competent, compassionate treatment. Neither those who have the disease nor those who have been infected with the virus should be subjected to discrimination based on fear or prejudice, least of all by members of the health care community." 61

As one commentator has noted, an apparent conflict exists between the CEJA statement mandating treatment of HIV sero-positive patients and the sixth provision of the AMA Principles of Medical Ethics, which provides: "A physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical services." 62 The CEJA has attempted to resolve this conflict by interpreting the principle narrowly. The CEJA recognizes the autonomy of physicians to make such decisions; however, this autonomy is not absolute. The principle is construed to give physicians the freedom to decide how, where and with whom to conduct their practices, but such freedom must not be used as a front to hide illegal or invidious discrimination. 63

Finally, dentists, too, are concerned about AIDS and the potential transmission of HIV in the practice setting. To guide its members, in 1987, the American Dental Association (ADA)

59. COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AMERICAN MEDICAL ASSOCIATION, ETHICAL ISSUES INVOLVED IN THE GROWING AIDS CRISIS (1988) [hereinafter CEJA, ETHICAL ISSUES].
60. Fowler, Acquired Immunodeficiency Syndrome and Refusal to Provide Care, HEART & LUNG, Mar. 1988, at 213, 215.
61. CEJA, ETHICAL ISSUES, supra note 59.
63. Fowler, supra note 60, at 213.
adopted a policy statement on AIDS and HIV infection which states: "The Association believes that HIV-infected individuals should be treated with compassion and dignity. . . . [I]ndividuals with HIV infection should have access to dental treatment."64

The ADA statement, like those of other professional associations, attempts to balance the medical needs of the dental patient against the interests of health practitioners in personal safety and avoiding unreasonable risks of disease.65

Each of the official positions and policy statements reviewed highlights and recognizes the responsibility of health professionals for those with a communicable, fatal disease and the risk involved. While no statement can purport to strike a particular balance for each professional faced with making a choice, such statements should promote rational decisions based on information regarding actual risks and the efficacy of protective measures. Furthermore, as these statements suggest, fear and prejudice are never legitimate grounds for refusing to provide care. Nor is it morally acceptable for health practitioners in particular to display prejudice toward a patient. Rather, health professionals have a moral duty to provide compassionate, competent health care to PWAs, notwithstanding the fact that providing care poses some degree of personal risk.66

B. Personal and Professional Values

Holistic health care for PWAs requires that health care providers gain insight into their own opinions, attitudes and values.67 For example, physicians and nurses typically place a high value on health and health-seeking behaviors in patients. PWAs who continue to abuse IV drugs or to engage in high-risk sexual activity are often perceived as non-health seeking and, therefore, pose a substantial challenge to health practitioners attempting to provide nonjudgmental care. Such conflicting value systems are almost sure to result in ineffective physician-patient and nurse-patient relationships.68 To effectively counter this, health care providers must clarify their values.69 This process fosters personal and professional growth and is accomplished by frank dis-

65. See Fowler, supra note 60, at 214.
66. See id.
67. Farrell, supra note 10, at 75.
68. Id.
69. Id. at 74, 75.

https://digitalcommons.law.villanova.edu/vlr/vol34/iss5/3
cussion of conflicting values and participation in ethics committees and organized educational programs regarding AIDS and PWAs.\textsuperscript{70}

Excellent health care for PWAs is characterized by open interpersonal communication and social support.\textsuperscript{71} Effective care for PWAs, as with \textit{all} patients, requires an accepting, nonjudgmental approach by competent health professionals. Such practitioners are unencumbered by unrealistic fears of contagion or unfair personal prejudices.

Again, the ANA offers guidance regarding personal risk, social prejudice and moral responsibility: "Nursing is resolute in its perspective that care should be delivered without prejudice, and it makes no allowance for use of the patient's personal attributes, socioeconomic status, or the nature of the health problem as grounds for discrimination."\textsuperscript{72} Nursing's code of professional ethics insists that "[t]he need for health care is universal, transcending all national, ethnic, racial, religious, cultural, political, educational, economic, developmental, personality, role, and sexual differences. Nursing care is delivered without prejudicial behavior."\textsuperscript{73}

At least two conclusions can be drawn from these statements with regard to PWAs. First, although it is true that health care professionals may exercise a moral option and refuse to provide care where there exists an irreducible risk to personal safety which they perceive to be too great, there is no instance in which health practitioners can ethically refuse to provide care based on personal prejudice.\textsuperscript{74} Second, the personal attributes of patients and the social aspects of their illness are to be used only for their benefit in individualizing their care, not to their detriment.\textsuperscript{75}

\textbf{C. Patient Autonomy}

It is generally accepted that it is the right of the patient to make decisions regarding what constitutes appropriate medical treatment.\textsuperscript{76} However, the ethical challenge to respect PWAs' autonomy in making such decisions is complicated by many fac-

\begin{itemize}
  \item \textsuperscript{70} \textit{Id.} at 76.
  \item \textsuperscript{71} \textit{Id.} at 75.
  \item \textsuperscript{72} ANA, \textit{Risk Statement}, \textit{supra} note 49, at 6.
  \item \textsuperscript{73} AMERICAN NURSES' ASSOCIATION, \textit{Code for Nurses with Interpretive Statements} (1985).
  \item \textsuperscript{74} Fowler, \textit{supra} note 60, at 214.
  \item \textsuperscript{75} \textit{Id.}
  \item \textsuperscript{76} Koenig, \textit{supra} note 9, at 289.
\end{itemize}
tors. For example, AIDS raises special considerations regarding autonomy due to the high incidence of either primary HIV-infection of the brain or secondary opportunistic infections resulting in dementia or other mental impairment. PWAs are often too impaired to competently make health care decisions at those critical times when such decisions must be made.

Thus, health care providers have an ethical obligation to assist PWAs in making health care decisions early in the course of the disease. Advance directives, such as a durable power of attorney for health care (DPAHC), should be discussed with patients in a frank and thoughtful way. These documents allow

77. Id.
78. Id. For a discussion of AIDS dementia, see supra note 16 and accompanying text.
79. Koenig, supra note 9, at 289.
80. When a patient is diagnosed with AIDS, the PWA should be introduced to means to ensure that medical treatment is administered in a manner and to the extent the PWA deems appropriate, since it is likely that this is “one of the last things on his mind.” Mock & Tobin, Estate Planning for Clients with AIDS, 7 ST. LOUIS U. PUB. L. REV. 177, 207 (1988).
81. Advance directives refer to any number of legal methods which allow patients to specify their wishes regarding health care, especially life-sustaining treatment, in advance of losing the capacity to do so. Koenig, supra note 9, at 290. In particular, a power of attorney establishes a principal-agent relationship in which the attorney-in-fact—the agent chosen by the PWA—may make certain decisions on behalf of the principal—the PWA. Mock & Tobin, supra note 80, at 201. However, the principal-agent relationship will end when the principal becomes incompetent unless a durable power of attorney has been established. Id. at 202. The document establishing the durable power of attorney must contain words to the effect that the relationship is not “affected by subsequent disability or capacity of the principal.” Id. at 202 n.137 (quoting UNIFORM PROBATE CODE § 5-501 (1982)). See also Roberts, Use of a Durable Power of Attorney in Asset Management, 3 ME. B.J. 32, 33 (1988) (durable power of attorney survives only if written and states that power is not affected by disability of principal). The existence of a durable power of attorney will obviate the need for a court-appointed conservator which is both time consuming and expensive. Valente & Michaels, Power of Attorney: An Update, N.Y.L.J., Oct. 28, 1988, at 3, col. 1.

The AIDS patient may specify that the agent is empowered to direct his medical treatment. Mock & Tobin, supra note 80, at 201. However, not all states permit a durable power of attorney for health care decisions. Valente & Michaels, supra, at 4. Even in those states that do, the statutes vary considerably. For example, Maine’s statute explicitly provides for an agent to direct medical treatment for the principal. ME. REV. STAT. ANN. tit. 18-A, § 5-501 (West Supp. 1988). See Roberts, supra, at 33. The California statute specifically authorizes a durable power of attorney for health care which permits the principal to make health care decisions including “consent, refusal of consent, or withdrawal of consent to health care.” See CAL. CIV. CODE § 2430 (West Supp. 1989). Pennsylvania, while not specifically referring to a durable power of attorney for health care, does permit the attorney-in-fact to “arrange for and consent to medical, therapeutical and surgical procedures for the principal.” See 20 PA. CONS. STAT. ANN. § 5005(h) (Purdon 1988).

The PWA may retain control of health care decisions until he becomes in-
patients to specify treatment preferences and designate a surrogate to make decisions about medical care if they become incompetent to do so.\(^{82}\) Proxy decision makers are particularly helpful in planning care for many gay men who wish to have their life partner rather than a legally-sanctioned family member make decisions on their behalf. Knowledgeable health practitioners have a responsibility to anticipate the need for advance directives and initiate discussion of such documents with PWAs.\(^{83}\)

Other ethical challenges confront health practitioners when the expectations and treatment preferences of PWAs or their proxy decision makers are inconsistent with those of the health team or exceed medical realities. For example, one study of PWAs indicated that a sample of gay men, the majority of whom were well educated, significantly overestimated their chances of

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\(^{82}\) Koenig, supra note 9, at 290.

\(^{83}\) Id. at 291.
surviving intensive care treatment for *Pneumocystis carinii* pneumonia—fifty-five percent of this sample of 118 men wanted mechanical ventilation and forty-six percent wanted cardiopulmonary resuscitation. Such unrealistic expectations seriously impair the ability of patients to accurately evaluate the risk-benefit ratio in care planning and, thus, their ability to give truly informed consent.

Medical and nursing paternalism is very tempting in such instances. However, even though altruistically motivated, paternalism by definition negates the ethical principle of patient autonomy. Health professionals are ethically obliged to be knowledgeable regarding currently available therapies as well as their potential risks and benefits for PWAs. Furthermore, health practitioners must communicate this information in a way that is sensitive, supportive and truthful to help PWAs make immediate decisions about treatment preferences and foresee the need to document their wishes about life-sustaining intervention or to designate a proxy to carry out their wishes when they become unable to act for themselves.

D. *AIDS Treatment*

As previously noted, the health professions recognize an ethical obligation to provide care for PWAs. To meet this obligation, health science faculty and practitioners have an ethical responsibility to be sufficiently knowledgeable about the disease to: (1) overcome their fears and personal prejudices; (2) prevent transmission of HIV through occupational exposure; and (3) provide competent, safe, quality care. The health professions, therefore, have a responsibility to assist health care practitioners in meeting these objectives.

The next decade should bring a marked increase in efforts to further educate health care professionals and the public about AIDS. These efforts may best be conducted through the various health science academic curricula and professional associations. Just as there is no segment of society unaffected by AIDS, neither is there an area of specialization in the health care professions

85. Koenig, supra note 9, at 290.
86. Id.
87. For a discussion of the positions taken by various professional health associations, see supra notes 49-66 and accompanying text.
which is not directly affected by AIDS. Health professionals have a responsibility to seek educational opportunities regarding AIDS. It is incumbent upon all of the health science academic programs and specialty associations to develop, implement and evaluate AIDS educational programming for health care students, practitioners and consumers of health care services.

E. AIDS Research

Health care researchers have an obligation to consider the importance of AIDS to our national and international health. Furthermore, health care professionals and scientists should identify areas in which they might contribute individual and collaborative research efforts. In order to provide valuable contributions to the growing body of knowledge about AIDS as a disease and the health care of PWAs, interdisciplinary studies should be undertaken.88

As health care professionals become increasingly involved in scientific study regarding AIDS and PWAs, many ethical dilemmas emerge. Research involving highly stigmatized groups at risk of unfair treatment discrimination89 highlights ethical issues involving PWAs' rights to privacy, anonymity and confidentiality. For example, how heavily does the individual's right to privacy weigh in the balance against the potential social good of health research?90 And given the communal nature of in-patient care facilities and our age of computer-stored (and, therefore, easily accessible) patient records, how can research participants be guaranteed anonymity or confidentiality?91 Also, since it is generally agreed that intrusions into privacy in clinical care and research require informed consent from participants, how can the ethical participation of HIV-demented individuals be obtained? Finally, do the incomplete or accidental findings of apparently sound scientific inquiry hold potential threats of harm either to PWAs directly or by misdirecting future public policy regarding AIDS?

The personal and social risks to PWAs who agree to participate in AIDS research are high. Study participants must be fully

88. See Larson, Nursing Research and AIDS, 37 Nursing Res. 60, 60 (1988).
89. For a discussion of treatment discrimination, see supra note 11.
90. Farrell, supra note 10, at 78.
91. Id. Farrell notes that even though this problem is not unique to AIDS, there may be a greater chance of misuse of information due to the public fear of AIDS. Id. A possible solution is not to computerize results of AIDS testing. The results could be manually delivered into the patient's chart and kept in a sealed envelope. Id.
informed about how research data will be collected, used, stored, and who will have access to it.92 Researchers and clinicians must: (1) faithfully adhere to published guidelines for research involving PWAs; (2) minimize intrusions into PWAs’ privacy; (3) assure anonymity whenever possible; (4) take necessary precautions to ensure confidentiality; and (5) carefully consider the potential influence of study findings on the lives of PWAs and the course of public policy.93

IV. Conclusion

All health care professionals must actively participate in an organized response to the profound legal and ethical challenges posed by AIDS in the next decade. An immediate response to the AIDS pandemic should have three main objectives: (1) to prevent HIV infection; (2) to provide care for those already HIV-infected; and (3) to participate in national and international efforts to fight AIDS and its associated stigma.

First, to prevent the spread of HIV infection, health professionals and lawmakers must base their actions on a sound epidemiological understanding of AIDS. From this knowledge, the concept that the proper focus of prevention is not membership in a high-risk group or HIV-antibody status is derived. Information and education are essential, but not enough. Only if health care and legal professionals make themselves available in a supportive social environment will prevention truly have a fair chance of success.

The second objective, to provide care for those already HIV-infected, requires that all PWAs receive humane care of a quality at least equal to that provided for people suffering from other diseases, as well as comprehensive support and services. Implicit in this objective are the responsibilities health care and legal professionals share: (1) to avail themselves of accurate, up-to-date information about the occupational risks, epidemiology and treatment of AIDS; (2) to act consistently with this knowledge both in their personal and professional lives; and (3) to model appropriate behavior in order to educate professional colleagues and the public about AIDS.

The third objective is to encourage the participation of health and legal professionals in national and international efforts

92. Durham, supra note 25, at 249.
93. Id. at 248-49.
to fight AIDS and its associated stigma. As litigation in the courts and debate in legislative bodies proliferate on issues such as the civil liberties of PWAs, health and legal practitioners must actively provide their colleagues and the public with accurate information and leadership: "[H]ealth professionals, [particularly,] have an obligation to engage in the ensuing national [and international] debate about AIDS health policy issues in an informed manner." 94 Health and legal professionals must be a knowledgeable and vocal force in future decision making regarding such issues as international travel, AIDS in prisons, the neuropsychiatric aspects of HIV infection and AIDS in the workplace.

The AIDS pandemic poses some of the most compelling legal and ethical challenges for health care and legal professionals imaginable. Some of these challenges are unique to AIDS; some are common to other serious illnesses as well. The legal and ethical issues raised by AIDS are amplified by the urgency associated with the pandemic and the complex psychological, political and social problems it engenders. For present and future generations of health care providers and legal professionals, the ultimate challenge of AIDS will be to provide sensitive, compassionate care and counsel while balancing individual rights and liberties against the duty to protect the health and safety of the public as a whole.

APPENDIX A

Statement Regarding Risk Versus Responsibility in Providing Nursing Care*

This statement examines the question, "At what point does it cease to be a nurse’s duty to undergo risk for the benefit of the patient?" That question is particularly relevant for nurses caring for patients afflicted with communicable or infectious diseases such as typhoid, tuberculosis, plague, Hansen’s disease, influenza, Hepatitis B, Legionnaires' disease, cytomegalovirus, and acquired immune deficiency syndrome (AIDS). Not only must nursing care be readily available to individuals afflicted with communicable or infectious diseases, but also nurses must be advised on the risks and the responsibilities they face in providing care to

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94. Koenig, supra note 9, at 288-89.

those individuals. Accepting personal risk that exceeds the limits of duty is not morally obligatory; it is a moral option.

According to the Code for Nurses, nurses may morally refuse to participate in care, but only on the grounds of either patient advocacy or moral objection to a specific type of intervention. Nursing is resolute in its perspective that care should be delivered without prejudice, and it makes no allowance for use of the patient’s personal attributes, socioeconomic status, or the nature of the health problem as grounds for discrimination.

The first statement of the Code for Nurses says, “The nurse provides services with respect for human dignity and the uniqueness of the client unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems.” Here, the code is addressing the issue of nondiscrimination in the allocation of nursing resources (a question of justice and fairness).

Historically, nurses have given care to those in need, even at risk to their own health, life, or limb. Indeed, the Suggested Code of 1926 proclaims that “the most precious possession of this profession is the ideal of service, extending even to the sacrifice of life itself...” Nursing history is replete with examples of nurses who have knowingly incurred great risk in order to care for those in need of nursing or to contribute to the advancement of health science. Contemporary nurses, too, knowingly place themselves in jeopardy when giving care on the battlefield, in places of squalor and poor sanitation at home or abroad, in situations of natural or man-made disaster, and in dealing with persons with communicable or infectious diseases.

As the Suggested Code of 1926 recognizes, the ideal of service is, in fact, an ideal. There are limits to the personal risk of harm the nurse can be expected to accept as a moral duty. The profession does not and cannot demand the sacrifice of the nurse’s well-being, physical, emotional, or otherwise, or the nurse’s life for the benefit of the patient.

For assistance in resolving the question of risk versus responsibility, nurses must turn to the field of ethics for guidance. In ethics, the differentiation between benefiting another as a moral duty and benefiting another as a moral option is found in four fundamental criteria. As applied to nursing, they are as follows:

1. The patient is at significant risk of harm, loss, or damage if the nurse does not assist.
2. The nurse’s intervention or care is directly relevant to preventing harm.
3. The nurse’s care will probably prevent harm, loss, or damage to the patient.
4. The benefit the patient will gain outweighs any harm the nurse might incur and does not present more than minimal risk to the health care provider.

Nursing, as nursing, creates a special relationship between nurse and patient, with special duties for the nurse. The nurse is not a “stranger” and thus is not at liberty to walk away from those in need of nursing assistance. The nurse is obliged to care for those in need of nursing when all four of the criteria are met.

For example, in most instances, it would be considered morally obligatory for a nurse to give care to an AIDS patient. If the nurse is immunosuppressed, however, it could reasonably be argued that the nurse is not morally obligated to care for that patient on the grounds that the fourth criterion, the most crucial, has not been met. Apart from the issue of personal risk to the nurse, it must be mentioned that it is incumbent upon the hospital or agency administration to provide adequate safeguards, such as equipment and enforcement of procedures, for the protection of the nursing staff.

Nursing is a caring profession, oriented toward patient advocacy. Because of nursing’s long history of standing ready to assist the ill and the vulnerable in society, society has come to rely on nursing and to expect that it will rise to the health demands of virtually any occasion. In a sense, this reciprocity is crucial to the profession. All must know that care will be given when needed and that it will not be arbitrarily, prejudicially, or capriciously denied.

Yet there are limits to the moral obligation of the individual nurse to benefit patients. Beneficence stands as a moral duty in those situations where the four criteria can be met. When not all of the criteria can be met, the individual nurse must evaluate the situation according to the criteria and choose whether or not to go beyond the requirement of duty.