



## HIV/AIDS and Bioethics: Historical Perspective, Personal Retrospective

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**Abstract.** Problems posed by HIV/AIDS differ from those of past epidemics by virtue of unique properties of the causative agent, dramatic societal changes of the late 20th century, and the transition of medical practice from a professional ethic to a technology-dependent business ethic. HIV/AIDS struck during the coming-of-age of molecular biology and also of bioethics, and the epidemic stimulated the growth of both disciplines. The number of articles published about AIDS and ethics (as identified by a MEDLINE search) peaked in 1990, just before the peak incidence of AIDS in the United States. The character of ethical dialogue has now shifted from familiar moral quandaries such as civil liberty versus public welfare to concerns about vaccine trials and public policy toward the developing world. Physicians and other health care workers who were involved from the onset endured something of an emotional roller coaster. Their compassion-based work ethic was to a large extent replaced by a competence-based work ethic after the introduction in 1996 of highly active antiretroviral therapy. The abundant recent literature on “professionalism” in medicine makes scant mention of AIDS/HIV. The disruptive effect of AIDS/HIV on society would have been substantially greater had relevant technology such as the ability to isolate retroviruses and potent therapy against tuberculosis not been in place. This sobering consideration, along with such recent events as the use of bioterrorism against civilian populations, suggests new relevance for Potter’s definition of “bioethics” as a science of survival in which the biology of ecosystems must be taken into account.

**Key words:** AIDS, bioethics, definitions of ethics, human immunodeficiency virus, virtue ethics

**Abbreviations:** AIDS – Acquired immunodeficiency syndrome; AZT – Azidothymidine (also, zidovudine, ZDV); HAART – Highly active antiretroviral therapy; HCW – Health care worker; HIV – Human immunodeficiency virus

The term “epidemic” is often used loosely. An *epidemic* (“upon the people,” from the Latin roots) arises from an external source, threaten to disrupt society, peaks, and then either disappears or transforms to *endemic* (“among the people,” from the Latin roots) status. Epidemics (and pandemics) challenge society in ways that differ radically from endemic (and hyperendemic) diseases. Rosenberg (1992) suggests that epidemics can be considered as

plays with 4 acts, as follows: (1) progressive revelation; (2) managing randomness; (3) negotiating a public response; and (4) subsidence and retrospection. The acute disruptive effects wrought by the human immunodeficiency virus (HIV, the cause of the acquired immune deficiency syndrome, or AIDS) have largely subsided in western countries, and it is therefore appropriate that we reflect on what the epidemic meant and how it was managed. My credentials for commenting on the multifaceted ethical dimensions of HIV/AIDS are, in proposed ascending order of credibility, as a novice bioethicist, an amateur medical historian, an infectious disease specialist, and an ordinary person searching for a deeper meaning. I will address the uniqueness of HIV/AIDS and its evolving relationship to bioethics, the insights that HIV affords into a virtue-based medical ethics (especially with regard to the tension between the relative roles of competence and compassion in medical practice), and the possible implications of HIV/AIDS for the scope of bioethics as a discipline.

### **HIV/AIDS and its Evolving Relationship to Bioethics**

Salient ethical issues of the great epidemics of past eras such as plague, cholera, and yellow fever included assignment of blame or moral responsibility to one or more groups of people, discrimination against the less fortunate, and the requirement that caregivers choose between courage and cowardice. These issues were and to some extent remain applicable to HIV. However, the problems posed by HIV differ radically from those of past epidemics for at least three reasons:

1. The natural history of HIV disease differs from all previously known pathogens in that it combines a long incubation period with near-uniform mortality. Infecting the CD4+ or “helper” lymphocyte, gradually but relentlessly weakening the immune system, mutating frequently, and imparting no visible external stigmata on its symptomatic but infectious carriers, HIV is a novel pathogen with the potential for enormous damage to *Homo sapiens sapiens* as a species.
2. HIV/AIDS coincided with dramatic societal changes of the late 20th Century. Changes that promoted its spread included jet travel, population expansions, encroachment on tropical forests, wide endorsement of non-monogamous sex, and wide illicit use of addicting drugs by injection. Changes that promoted its containment included the new molecular biology, computer-based medical informatics, social activism, and the nascent bioethics movement.
3. HIV struck during a time of dramatic changes in the structure of medical practice. These included transition from a professional ethic to a business

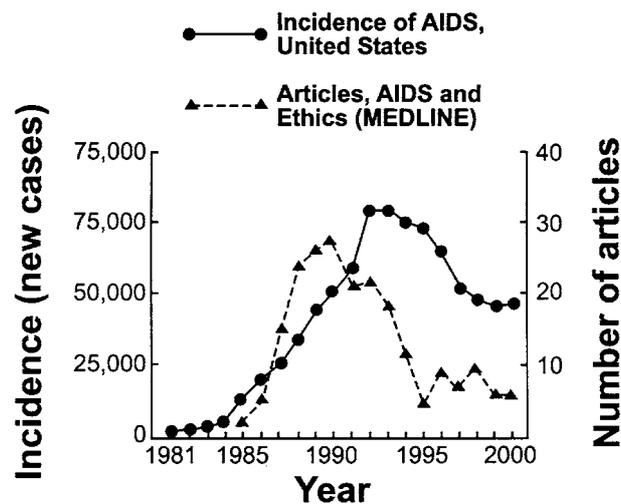


Figure 1. Relationship of the incidence (new cases) of AIDS in the United States to the number of articles dealing with AIDS and ethics, as identified by a MEDLINE search. The case definition of AIDS was liberalized (that is, made more inclusive) in 1993.

ethic; increasing reliance on technology to the detriment of hands-on care; and advances in surgery and intensive care that increased the likelihood of blood and body fluid exposures among medical personnel.

The changing structure of medical practice would affect the way physicians, with their diminished autonomy, would cope with such ethical principles as beneficence and justice.

During the late 1980s, wags quipped that HIV comprised 3 epidemics: one of disease, one of fear, and one of meetings. Wide-ranging dialogue spawned what might be called a mini-epidemic of peer-reviewed articles dealing with AIDS and HIV that peaked in 1990, just before the disease itself peaked in the United States (Figure 1). Few areas of bioethics and general ethics were left untouched. The inevitable issues of moral responsibility, blame, and prejudice that characterized the great epidemics of previous centuries (Ludmerer, 1989) were resolved to a remarkable extent, at least in Western countries. Ethics as a discipline, including bioethics, was enormously enriched by its having to deal with HIV/AIDS (Pinching et al., 2000; Unschuld, 2000).

Analysis of the medical literature on AIDS and ethics reveals qualitative as well as quantitative changes over time. Early debate focused on familiar categories of ethical discourse such as civil liberties versus the public welfare, confidentiality, and discrimination (Kelly, 1987; Rubenstein, 1987; Manuel et al., 1990; Bayer, 1992). Introduction of a blood test in 1985 triggered debate on the ethics of screening including informed consent. Recognition of

patient-to-health care worker (HCW) transmission stirred debates concerning self-interest versus the duty to treat, especially in the surgical literature, although most transmissions to HCWs affected non-physicians (for example, nurses, phlebotomists, and apheresis technicians). Availability of antiretroviral drugs called into question the ethics of placebo-controlled trials (Porter et al., 1992). In retrospect, early termination of the first trial of zidovudine (AZT) because of ethical considerations was probably unwise, as the benefit of AZT monotherapy proved to be short-lived. By the mid-1990s, many of the early dilemmas had been largely resolved either by consensus or by case and/or statutory law. Patients lived longer, and new technologies shifted the emphasis to include advance directives and end-of-life care (Curtis and Marquis, 1997). Today's dialogue centers around the ethics of clinical research, including vaccine trials, and the ethics of public policy pertaining to the rampant spread of HIV in the developing world (Abdool Karim, 2000; Cohen, 1998; Farmer, 2001; McLellan, 2001; Pinching et al., 2000; Shapiro and Meslin, 2001).

The medical literature dwells mainly on the ethical issues facing HCWs, the health care system, and society in response to persons infected with HIV. However, ethics pertaining to patients cannot be ignored. Early in the epidemic, lying by patients to HCWs and others was commonplace and perhaps understandable. The HIV epidemic has since promoted discussions of sexual ethics on such issues as truth telling, partner notification, and the duty to warn (Ainslie, 1999; Bayer, 1996). Less has been written about the ethics of compliance with antiretroviral drug therapy, which should become an issue since resistant viral strains are now being identified in patients who have not been previously treated. This discussion will focus on virtue ethics as they apply to HCWs and on the potential scope of bioethics as a discipline relevant to human survival.

### **HIV/AIDS, Virtue Ethics, and the Relative Roles of Compassion and Competence in Medical Practice**

When the nature of HIV/AIDS including its risk to caregivers became apparent, many opinion leaders exhorted physicians and others toward a virtue-based medical practice with its emphasis on compassion. The importance of virtue to medical practice has become somewhat controversial. Several leading bioethicists hold that virtues are actually dangerous; that today's "stranger medicine" should be guided by moral rules, not virtues; and that the replacement of virtue with the rule of self-interest will lead to a necessary revision of medical ethics. Others assert the continued relevance of the cardinal virtues as listed by Plato (wisdom, temperance, justice,

and courage), the theological virtues as listed by St. Paul (faith, hope, and love or charity), and virtues central to professional behavior as listed by Beauchamp and Childress (compassion, discernment, trustworthiness, and integrity) (Beauchamp and Childress, 1994; Bryan, 2000a; Pellegrino and Thomasma, 1993; Kopelman, 1999). Whether the virtues are few or many, as debated by Plato in the *Meno*, and whether virtue can be taught far exceed the scope of this discussion. I will focus instead on the relative importance of compassion and competence in the practice of medicine. There is, of course, a long tradition of both dating back at least to Hippocrates (“Where there is love of man, there is also love of the art”). However, there is now a wide popular perception that physicians are losing their “compassion” as medicine becomes increasingly technology-dependent and business-oriented.

In 1992, out of considerations separate from HIV and influenced by a colleague (Dr. Donald E. Saunders, Jr.), I ranked four “C’s” of medicine in this order of priority: courage, competence, consistency, and compassion. In giving first priority to courage (rather than to wisdom, as Plato and Thomas Aquinas had it), I took Sir Winston Churchill’s lead that courage makes the other virtues possible. Competence, applied consistently, assures that physicians will be excellent in their duties *qua* physicians. I argued that benevolent competence, in a sense, *is* compassion, whereas compassion without competence is fraud (Bryan, 1997). Although gently chided for this position (Madison, 1997), I agree with Pellegrino that competence is second only to integrity among the physician’s ethical precepts and “the one most peculiar to the physician’s function in society” (Pellegrino, 1979). Who, for instance, would not prefer a gruff contemporary physician armed with antibiotics to the physician famously painted by Sir Luke Fildes in *The Doctor* (first exhibited in 1891), presiding helplessly over the death of a child? Looking retrospectively at how HIV affected my own practice of medicine, I believe that the case for competence as the greater requisite for medical practice has now been settled, at least for this disease.

A recent oral history of the HIV epidemic based on interviews with infectious diseases specialists who were involved from the onset (Bayer and Oppenheimer, 2000) sheds light on this issue and has helped me see my own career much more clearly. Many and perhaps most of the physicians who were in the forefront of the AIDS/HIV epidemic in the United States chose to specialize in infectious diseases because this discipline did not require ongoing commitment to patients with end-stage chronic illness. HIV changed our practices, indeed our lives! Early on, we were bewildered and frustrated by an illness we did not understand, an illness that was killing bright, previously healthy young adults. We had little to offer except concern and compassion. We made house calls, went to funerals, and advocated

for reason and tolerance wherever we went: conferences, town meetings, churches, radio and television studios. We sometimes found it difficult to set appropriate limits, as Abraham Verghese describes in his autobiographical account, *In My Country* (Verghese, 1994). My memories of that era include the emaciated young men dying in their bedrooms of intractable diarrhea, the horrendous ulcers caused by herpes simplex virus, and the gratitude that patients expressed for helping them to a “good death,” or even for a simple hug. The HIV/AIDS epidemic enabled me and countless others to appreciate more fully the role of the physician as it existed in previous eras. The optimism that followed the introduction in 1987 of zidovudine (AZT) proved short-lived as viral strains became resistant, and most of us experienced at least a measure of burnout.

The introduction in 1996 of highly active antiretroviral therapy (HAART) radically altered the prognosis for patients with HIV and the practices of infectious diseases specialists and other “AIDS doctors” (Zuger, 2000). The disease became “medicalized.” Previous concerns and anxieties about helping patients to good deaths were replaced by concerns and anxieties that drugs were being prescribed correctly and optimally. This transition reflects a shift in the dominant value of the work ethic from compassion to competence (Figure 2). Compassion in its purest sense (from the Latin root, “to suffer with” and therefore a much greater commitment than empathy, sympathy, or basic human kindness) was no longer paramount. Caring should always inform competence in order to assure that medicine remains benevolent. However, competence assumes priority over naked “compassion” whenever appropriate technology (such as HAART) becomes available. As medicine inexorably becomes less of an art and more of a science and as well-informed patients place even more emphasis on competence and quality control, the importance of compassion will become increasingly unclear. Medicine’s accelerated trend toward a business ethic designed to deliver a commodity will make the maintenance of compassion an increasingly difficult challenge for physicians and other health care workers.

A MEDLINE search combining “competence” and “compassion” as search terms reveals that most of the recent dialogue has been in the nursing literature rather than the medical literature. Roach (1993) proposed 5 C’s of nursing practice (compassion, competence, confidence, conscience, and commitment), to which Pusari (1998) added 3 more (courage, culture, and communication). Nursing educators have given serious thought to the relative merits of a competence-based and compassion-based ethics. In recent years the medical literature has, however, featured a large number of articles dealing with “professionalism” (Bryan, 2000b; Swick, 2000). Although the definition of medical professionalism is somewhat problematic, most observers believe

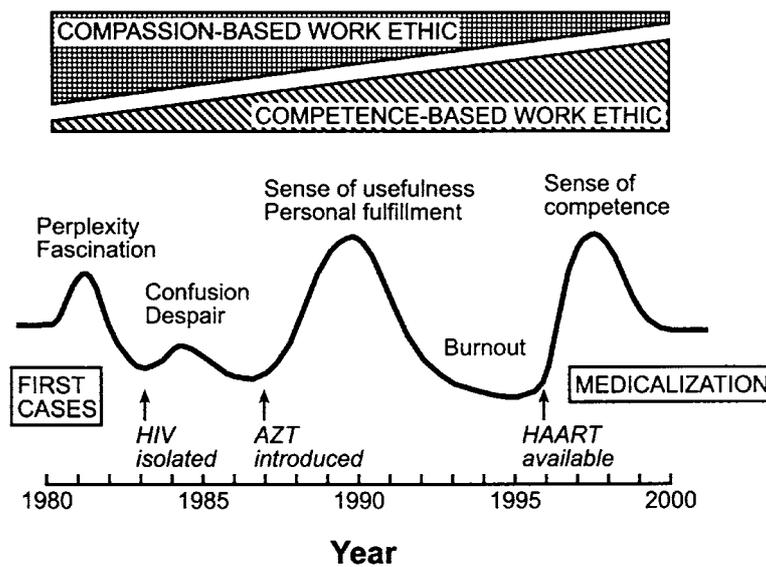


Figure 2. The emotional responses of physicians and other health care workers who were heavily involved with HIV/AIDS from its onset changed over time as new technologies became available. The progression from a compassion-based work ethic to a competence-based work ethic was accelerated by the introduction in 1996 of highly active antiretroviral therapy (HAART). (Based on personal reflection and on the oral histories recorded by Bayer and Oppenheimer [2000]).

that its essence entails putting the patient's best interests ahead of one's own. HIV/AIDS, before the introduction of HAART, posed an ultimate test of professionalism in this sense.

The duty of physicians and other HCWs to assume personal risk on behalf of HIV-infected persons was debated vigorously during the early years of the epidemic (Jonsen, 1985; Pellegrino, 1987; Zuger and Miles, 1987; Pellegrino, 1989; American College of Obstetricians and Gynecologists, 1990; Tegtmeier, 1990). The American Medical Association and other bodies opined that physicians are ethically obligated to administer care within their realms of competence (Council on Ethical and Judicial Affairs, 1998). Tegtmeier (1990) argued that the grounds for imposing an ethical duty are too weak to support and proposed as an alternative an AIDS-specific legal duty. But does society have the right to insist that certain individuals be exposed to unusual or repetitive risks, especially if such risks were unknown when they embarked on their careers? Legions of HCWs – surgeons, intensive care unit nurses, dialysis and apheresis technicians, to name a few – repeatedly exposed themselves to the possibility that one slip of an instrument could infect them with the deadly virus. These HCWs exemplified courage as defined by Walton

(1986): the use of both moral reasoning (facilitated by altruism) and practical reasoning (facilitated by persistence) to overcome obstacles in pursuit of a socially desirable goal.

Postexposure prophylaxis against HIV infection is now available and, while imperfect, offers a large measure of reassurance to HCWs throughout the world. Debate over the ethical duty to care for the HIV-infected has disappeared almost entirely from the medical literature. Moreover, HIV/AIDS has been almost entirely ignored in the recent surging medical literature on “professionalism.” Thus, a MEDLINE search of articles published between mid-1998 and October 2000 reveals 11,664 papers dealing with “AIDS” and 353 papers dealing with “professionalism” but only one paper dealing with both – an article about AIDS-phobia in second year medical students (Kopacz et al, 1999). One explanation for this paucity of discussion about AIDS and professionalism would be that the major points were thoroughly aired during the late 1980s. However, the major papers published during the late 1980s about both “AIDS” and “professionalism” did not appear in journals commonly read by physicians (Loewy, 1986; Fox et al., 1989; Moreno, 1988). The more likely explanation for the paucity of articles dealing with both “AIDS” and “professionalism,” I suggest, is the medicalization of the disease.

### **HIV/AIDS and the Potential Scope of Bioethics as a Discipline**

In the early years of the HIV/AIDS epidemic, some persons complained vocally that not enough was being done, that the responses of government, industry, and the scientific establishments were phlegmatic or indifferent. Quite to the contrary, the rapidity with which progress was made against HIV/AIDS is without precedent in the history of medicine. In 1988, the noted scientist and biology watcher Lewis Thomas exclaimed: “In a long lifetime of looking at biomedical research, I have never seen anything to touch the progress that has already been made in laboratories working on the AIDS virus” (Thomas, 1988). Within 2 years, the causative virus was identified; within 4 years, a blood test was available; within 6 years, drug treatment was being widely used. Were Thomas alive today, he would marvel at our ability to stage the disease with a single phlebotomy (using the CD4+ lymphocyte count and the “viral load” test, which determines the number of copies of viral RNA per mL of blood) better than one can stage just about any other life-threatening illness. He would marvel at our ability to detect resistant virus strains by use of genomic sequencing. He would marvel at our ability to understand the immune system. How was it possible to make such rapid progress against this disease?

Isolation of HIV was made possible by the discovery in 1969 of the enzyme reverse transcriptase, which enables RNA to direct the synthesis of a DNA copy of itself. This discovery, combined with subsequent discoveries about the nature of lymphocytes and their products, enabled the isolation in 1979 of the first human retrovirus (now known as human T-cell lymphotropic virus type I). Other advances in molecular biology enabled scientists studying HIV to isolate the viral genes, to determine how the virus attached to certain target cells, and to elucidate the viral life cycle. These insights enabled pharmaceutical firms to formulate “designer drugs” aimed at one or another specific target. Nor should we forget recent advances in the diagnosis and treatment of various infectious diseases that afflict the HIV-infected, such as *Pneumocystis carinii* pneumonia and, especially, tuberculosis. As humans, we usually take these and other technologies for granted. However, a sobering question arises: *What if* AIDS/HIV had struck at any time in history prior to the late 20th Century, before certain relevant coping technologies were available to us?

The first major editorial about AIDS in a medical journal appeared in 1981 and was written by David Durack. Durack posed this question: “Why now and not before?” (Durack, 1981). We now know that retroviruses (the class of viruses that includes HIV) have been around throughout vertebrate evolution and are thus older than *Homo sapiens sapiens*. We also know that retroviruses tend to appear and cross from one species to another with little or no warning. Theoretically, HIV could have shown up in human populations at any point in our history. As an infectious diseases specialist, it strikes me as an incredible coincidence that AIDS made its public appearance in 1981, only two years after the isolation of the first human retrovirus. Had AIDS appeared any earlier – say, much before 1960 – we would have been clueless about what was going on (since we had yet to distinguish between B and T lymphocytes), how to identify the cause (since we had yet to learn about reverse transcriptase), how to identify who was infected and who was not (since, lacking knowledge of the cause, we would have been unable to devise a blood test), and – perhaps even most frighteningly – how to halt the rampant spread of tuberculosis (since we did not have potent drug combinations such as isoniazid and rifampin). If HIV/AIDS had to occur at all, I submit that we were incredibly fortunate that it occurred *only* during the late 20th Century when the relevant coping technologies were in place.

Elsewhere, I have argued that the appearance of HIV/AIDS only during the late 20th Century should imbue us, as a species, with a large measure of humility (Bryan, 1990). Many people today share the feeling that “modern ills” including threats to our common survival must somehow be the price we pay for various comforts and conveniences. Well-publicized examples of

such ills include global warming, disruption of the ozone layer, widespread pollution including nuclear contamination, and the extinction each year of untold numbers of plant and animal species. Examples of newly recognized pathogens that reflect our lifestyle include *Legionella pneumophila* (the cause of Legionnaire's disease, which appeared because of modern heating and cooling systems) and bacterial strains resistant to most available antibiotics (resulting from our indiscriminate use of these agents). We have lost the naïve confidence in linear progress that characterized the Progressive Era of a century ago. Many believe that the long term survival of *Homo sapiens sapiens* stands seriously endangered by a cluster of growing menaces such as overpopulation, proliferation of nuclear weapons, and – since September 11, 2001 – the use of bioterrorism against civilian populations. Thinking about the implications of AIDS/HIV for humanity convinces me that bioethics, if defined broadly, has great potential relevance.

The term “bioethics” was coined in 1970 in two different ways. Van Rensselaer Potter, an oncologist, defined bioethics as a “science of survival” in which “ethical values cannot be separated from biological facts” (Potter, 1970; Reich, 1995; Martensen, 2001). Potter argued that humankind “is urgently in need of new wisdom that will provide the ‘knowledge of how to use knowledge’ for man’s survival and for improvement in the quality of life.” He maintained that bioethics, while informed by the social sciences and the humanities including philosophy, “must be built on the science of biology.” Separately that same year, Sargent Shriver, during a discussion in his Bethesda, Maryland living room about potential Kennedy family sponsorship of a new institute, applied the term “bioethics” to a movement to apply moral philosophy to specific medical dilemmas (Reich, 1995; Jonsen, 1998; Martensen, 2001). The sense in which Shriver used the term “bioethics” has spawned an industry replete with institutes, journals, endowed professorships, required courses, and public visibility. Potter’s definition of “bioethics” has gone largely ignored. However, reflection on Durack’s question – *Why now and not before?* – convinces me that we should look back on AIDS/HIV as a serious warning to our species.

Potter’s definition of bioethics comes into play when large populations or even an entire species are threatened by new biologic developments. Consider, for example, the current debates about how best to brace for bioterrorism using the smallpox virus. Is it better to vaccinate everyone, knowing that some people will have serious, even fatal, reactions to the vaccine? Or is it better to wait expectantly and then use a containment strategy when the disease appears? The ethics of immunization (Feudtner and Marcuse, 2001) is but one of many areas for dialogue using, as Potter suggests, biologic facts

to address tough questions in which individual liberties sometimes clash with collective survival.

The opinion is still expressed that AIDS/HIV constitutes today's single greatest threat to human populations. This is the case largely because of trends in the developing world and notably in sub-Saharan Africa that prompted the Secretary-General of the United Nations to declare HIV/AIDS a global emergency. In 1999, there were 2.4 million deaths from AIDS in a population of 640 million in sub-Saharan Africa, compared with 10,000 deaths from AIDS in a population of 273 million in the United States (Weiss, 2001). It is argued that HAART should be made widely available to the people of sub-Saharan Africa on humanitarian and ethical grounds (Farmer, 2001). As an infectious diseases specialist, I would submit the following relevant facts: (1) HIV mutates with unusual frequency, causing viral strains to emerge rapidly in patients who are not fully compliant with their regimens; (2) in the United States, only about one-third of patients are fully compliant with their regimens; (3) nearly 80% of HIV-infected persons who are not fully compliant have viral strains resistant to one or more major drugs; and (4) achieving compliance in certain populations in the United States is difficult to achieve despite substantial funding through federal Ryan White legislation. Taking these facts into account and using Potter's definition of bioethics, I conclude as follows:

1. Public policy toward antiretroviral therapy in developing countries and elsewhere should have strong input from persons experienced in the practical aspects of treatment of HIV/AIDS. I would trust the judgement especially of nurse practitioners who work in Ryan White Clinics, who combine dedication and compassion with a deep understanding of the disease and of human nature.
2. Wholesale use of HAART in populations without an adequate infrastructure for education and compliance is inappropriate and irresponsible, since highly resistant viral strains will inevitably emerge. The best-case scenario would be to use directly observed therapy based on twice daily (or even once daily) dosing.
3. Efforts should concentrate on (a) the development of appropriate infrastructures, (b) demonstration projects designed to convince populations and public officials of the feasibility HAART when adequate infrastructures support its use, and (c) accelerated development and deployment of an effective vaccine.

It seems to me imperative that policy decisions be informed by an intimate working knowledge of the relevant biology.

## Summary

In 1897, William Osler observed to the American Medical Association: “Humanity has but three great enemies: fever, famine, and war; of these by far the greatest, by far the most terrible, is fever” (Osler, 1897). During the 20th Century, overpopulation and nuclear weaponry raised the profiles of famine and war as threats to human survival, but, until recently, infectious diseases were thought by many to have been largely conquered. Like other infectious diseases specialists who trained just prior to HIV/AIDS, I found the epidemic to be more fascinating and more disturbing than science fiction. A pathogen that combined the subtlety and lethality of HIV with the easy transmissibility of measles, smallpox, or influenza could indeed threaten the survival of *Homo sapiens sapiens*, forcing extremely difficult ethical and policy decisions. Looking back and looking forward, the time seems opportune to advance the field of bioethics to include global justice (or “macroethics”) replete with moral pluralism toward all of life including unborn generations. Bioethicists have made many positive contributions toward a rational response to HIV/AIDS. The relationship between biology and moral philosophy must remain synergistic, for in all likelihood the work has only just begun.

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