UIC Law Review

Volume 27 | Issue 2 Article 1

Winter 1995

HIV-AIDS in the 1990s AIDS Law Symposium: Legal, Ethical, and Policy Issues: Introduction, 27 J. Marshall L. Rev. 239 (1994)

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INTRODUCTION

HIV-AIDS IN THE 1990s

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. . . Arthur Ashe, Kimberly Bergalis, Ryan White . . .

In the decade since the accidental discovery of AIDS, the HIV-AIDS epidemic has affected nearly all aspects of life, including virtually every legal subject. HIV-AIDS has already killed millions worldwide, and will kill many millions more. The costs of the epidemic — both direct and indirect — in diversion of resources, in lost productivity, in pain and suffering of those living and dying with the disease and of their families and friends are beyond comprehension. And, no cure, not even a vaccine, is on the horizon.

. . . Rock Hudson, Larry Kramer, Rudolph Nureyev . . .

As the old saying goes, "History tends to repeat itself." Undoubtedly this is because, with the passage of one or more generations to dull memories, society has not passed on its experiences effectively enough to avoid recreating the mistakes of the past. Societal responsiveness to disease, including mental illness, is no exception. Indeed, it is especially illustrative of the point. Consider, as examples, the unenlightened and counterproductive reactions in this century to individuals afflicted with leprosy, with tuberculosis, and with mental disorders. Consider as well how, during this century, our society has dealt with — or simply ignored — those with physical disabilities. And, abuses of our physically and mentally challenged citizens continue in many ways.

. . . Cookie Mueller, Bradford Perino, Darlene Winfrey . . .

The AIDS episode is another tragic rerun of history. So many people and institutions reacted so badly to the news of AIDS. Why did reason, or at least compassion, not overcome prejudice? People with AIDS, suspected of having AIDS, and sometimes even suspected of being at heightened risk for AIDS were fired from their jobs, denied access to public school classrooms, deprived of custody and visitation with their children, refused services of a variety of

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kinds, derided and defamed throughout society, and otherwise discriminated against. Violent physical attacks on people with AIDS including school children, gays, prisoners, and others were not uncommon. The Ray family home was intentionally burned to drive them out of their Florida community and to prevent the AIDS-infected Ray children from attending elementary school there.

. . . Nilda Espinosa, Rosemary McCarthy, Elizabeth Ramos . . .

Unfortunately, the frequent analogy between people with AIDS and modern-day lepers was fitting. Since the first cases of AIDS identified in the 1980s were overwhelmingly among gay men, people of color, and intravenous drug users, AIDS got off to a very bad start. The bigotry of many people, and even of some religious leaders, found new opportunities in AIDS issues to fight unpopular groups. Additionally, when the alarming objective medical characteristics of AIDS (that it is incurable, fatal, and transmissible) were thrown into the mix, more people were swept up in the hostility toward AIDS and toward those it infected.

. . . Teresa Havens, Caretha Russell, Ron Sable . . .

In some quarters, AIDS was said to be God's retribution on sinners. In 1993, the mighty Reverend Billy Graham made big headlines from one of his sermons, when he suggested that AIDS might be God's curse on people who engaged in sex outside of marriage. The headlines were much smaller when he recanted days later. The damage was done. What could Ryan White possibly have done at his tender age to have warranted the gruesome dying process through which he suffered? Could any god be that punitive?

. . . Mary Hare, Hector Vargas, Christine Woodhem . . .

For those whose agenda already included unwarranted discrimination and infringement of civil liberties, AIDS has served as important ammunition. It has provided a further excuse for some to promote their views of morality for everyone else and particularly for unpopular groups. Thus, one reason Georgia prosecutors announced for supporting and enforcing the state sodomy statute was to help prevent the spread of AIDS. By a five to four vote, the United States Supreme Court upheld that sodomy law and placed its credibility behind this neanderthal mentality (although, curiously, after his retirement one of the five justices changed his mind about the correctness of their decision).

. . . Nancy Accetta, William Robie, Edith Wyrick . . .

Not unexpectedly, the institution of marriage has not escaped the sweep of the AIDS-morality debate. There have been many proposals for mandatory premarital HIV-testing, and Illinois and Louisiana enacted and applied such laws for short periods. Several premarital HIV-testing proposals are currently pending in various states, although medical care experts roundly view mandatory HIV-

testing statutes as contrary to sound health care goals. Furthermore, some have strongly objected to the idea of allowing same-sex marriages, on the assertion that such relationships would encourage the transmission of HIV. But, the result of same-sex marriages would be just the opposite, for the promotion of monogamous relationships (whether heterosexual or homosexual) would help curb the spread of HIV. The history of the institution of marriage has been blemished by comparable efforts to alienate people and to keep them in their place on a number of prior occasions. For instance, early in American history married women were treated almost as mere chattels belonging to their husbands; slaves were forbidden to marry at all; and people of color were prohibited from marrying whites. Society has not learned enough lessons from history. Sadly, for many people, HIV-AIDS had to strike them or at least strike someone close to them before they displayed concern about the disease and the individuals with it. Self-interest can be a driving force, but in the case of this deadly and incurable virus the positive consequences of self-interest driven concern have simply taken far too long. Why has it taken any thought at all to appreciate that people suffering with HIV-AIDS are just that, people, people entitled to privacy and deserving of dignity?

. . . Ova Adams, Lila Emmrict, Nina Johnson . . .

In the last decade, the understanding of HIV-AIDS has changed dramatically in so many ways — medically, economically, politically, and legally. We now appreciate that it is not just *AIDS* (a rapid killer of those who contract the virus). HIV-AIDS, for most of those infected, constitutes a long-term chronic condition, possibly fifteen to twenty years in duration. As science finds new treatment protocols for the symptoms of HIV-AIDS, the life expectancies of those affected should increase still further. The implications are far-reaching. People living with HIV-AIDS (PLWAs) will often live with it for a very long time, suffering from the physical and psychological effects of the disease, as well as, perhaps, from the unwarranted discrimination associated with it. PLWAs will be infected and infectious for the remainder of their lives. Hence, the diagnosis of HIV is at the same time both a life sentence and a death sentence for the infected individual. It constitutes a sentence of lifelong confinement to a body playing host to a virus that will work to destroy the immune system. It constitutes a sentence of certain premature death from AIDS-related conditions (unless life is shortened by some intervening cause).

. . . Henrietta Adams, Geoffrey Bowers, Mauro Montoya . . .

Some of us wonder about the ethical and moral questions of doctors and scientists keeping human bodies alive by treating only the symptoms of this deadly and incurable virus. Treating symp-

toms most assuredly prolongs the duration of life. But what about its quality? By keeping people alive longer, they fall prey to a wider array of opportunistic infections and ailments which are thereby afforded a chance to invade the body. In the early days of AIDS, most people died more rapid deaths, usually from pneumosistis carinii pneumonia alone. Today, the bodies of many people with HIV-AIDS become hosts to a range of problems (cancers, dementia, herpes, shingles, tuberculosis, and others illnesses).

. . . J.D. Doherty, Daniel Hanson, Katherine Mickel . . .

It is not surprising to find that the profile of the individual most likely to commit suicide parallels closely the profiles of many PLWAs. So many PLWAs undergo a loss of support systems among friends and family; they confront significant changes including changes of residences and the eventual loss of the ability to work; and they suffer heavy financial consequences. PLWAs sometimes endure great physical and emotional pain, including the decline of their physical appearances (which can constitute a most alarming development). In other words, PLWAs suffer a loss of that most reassuring factor — control. The catastrophic loss of control alters ones life dramatically. Life for many PLWAs becomes a sequence of events done *to* them, rather than a series of real choices. Life for them is largely a kind of obstacle course in which their bodies are no longer user friendly.

. . . Traci Hoskins, Charlie Palomino, Daniel Sotomayer . . .

Suicidal ideations are not uncommon among PLWAs. The suicide rate for PLWAs is significantly higher than for the general population. Suicide and assisted suicide provide choices which help preserve some degree of personal autonomy, personal privacy, and personal control. As Jack Kavorkian continues his campaign to familiarize people with assisted suicide in his role as "Doctor Death," both the public and the public's officials should become more comfortable with the concept. Suicide and assisted suicide can be quite rational choices and should be legitimized under such circumstances.

. . . Carmen Albanese, Deborah Haynes, Bob Yee . . .

HIV-AIDS goes so far as to cheat the living of our memories of those it has taken. There is a tendency for our first and strongest recollection of a deceased family member or friend to be one of our very last times together. Since HIV-AIDS can be so savage in its effects on many people, our memories tend to picture the individual struggling with HIV-AIDS to be withered, suffering, financially strapped, and often hospitalized. HIV-AIDS is more cruel in this regard than most other diseases because it takes young people at the prime of life. Thus, the contrast is great between the image of a formerly youthful vibrant person and the same individual nearing

death due to HIV-AIDS. Those of us who survive and remember must consciously attempt to put the unpleasant memories behind each time we think about a family member or friend lost to HIV-AIDS. Indeed, HIV-AIDS might be the cruelest of diseases as it robs both the dying of their dignity and the living of their memories.

. . . Edward Kalish, Rand Schrader, Susan Zwick . . .

Some people who die from HIV-AIDS related illness are not even permitted to rest in peace. There have been controversies because morticians and funeral homes did not want to handle their bodies or their funeral services (which might be attended by undesirables, like other people with HIV-AIDS). There have been disputes about what HIV-AIDS related information can, should, or must be included in death certificates, in obituaries, and on cemetery headstones. There have been fights with life insurance companies which have refused to pay under policies allegedly entered into fraudulently by people who knew they were dying of HIV-AIDS and who did not disclose that fact. There have been battles over their estates based on alleged incapacity or undue influence brought about in the context of HIV-AIDS.

. . . Michael Borowski, Rita Gadsden, Daisy Keys . . .

The recent recognition of a drug resistant strain of tuberculosis (TB) associated with HIV-AIDS may pose especially serious medical and legal questions. The panic and hysteria about HIV-AIDS has been subject to some degree of containment because, although HIV is transmissible, it is not really "contagious" in the sense that the latter term is generally understood. HIV is not casually transmitted. It is bloodborne, not airborne. However, TB can be a very different phenomenon. When a TB carrier is in an active or infectious stage (which can last for a long time and which can recur), the disease may easily be transmitted through tiny aerosolized droplets from the TB carrier. The quarantine and abuse of individuals with TB in sanatoria around the United States occurred recently enough in our history to stand out as a grim reminder of the terrible human and economic costs of an epidemic of a genuinely contagious nature. If TB associated with HIV-AIDS becomes more prevalent in future years, many of the policies of this past decade will be subject to reconsideration. Furthermore, both HIV-AIDS and the growing TB problem pose significant complications for the current federal focus on health care reform. Only time will answer the question of how the enormous costs of HIV-AIDS and TB will be spread in the economic and political wrangling which will produce health care "reform."

. . . Perry Ellis, Liberace, Paul Stein . . .

The financial realities of HIV-AIDS are, and will continue to be, staggering. It is an expensive illness — for the research, the hospitalizations, and the drugs. As we keep PLWAs alive for longer periods, the cost of their care will rise. Increasingly, taxpayers will be forced to pay the price of this epidemic as its costs are spread among all of us. For example, many HIV-infected infants are born to drug-using parents, in impoverished and dysfunctional families. Those babies are often abandoned to the hospitals where they are born or to the public welfare system. Most assuredly, one or both of their parents will die from the effects of HIV-AIDS (if the children survive that long), so the children may become orphans — invoking the necessity of at least some governmental involvement. As another illustration, some employers and health insurers continue their attempts to avoid paying the medical care costs of those with HIV-AIDS by excluding such coverage from health insurance policies or by capping the level of HIV-AIDS related benefits. The consequence is, that when employees with HIV-AIDS can no longer work and can no longer afford the price of their health care, the public system requires that all of us share the costs — just as all of us will end up sharing the costs of the natural disasters of 1993-94 (hurricanes, Midwest floods, and California fires and earthquakes). Further, legislatures persist in legislating about too many facets of the HIV-AIDS epidemic, and we have even needlessly prosecuted and incarcerated numerous individuals for allegedly exposing others to HIV. Governments have squandered a great deal of funds on educational awareness campaigns about HIV-AIDS that imitate the worthless "just say no to drugs" campaign of Nancy Reagan and others. This all costs money, a lot of money.

. . . Freddie Mercury, Anthony Perkins, Max Robinson . . .

HIV-AIDS is not the political hot potato that AIDS was in the 1980s, when President Reagan was afraid to speak the word in public, and when two Republican administrations attempted to downplay the extent of the problem. Indeed, adoption of HIV-AIDS legislation, ordinances, and regulations seems to have become a favorite pastime of federal, state, and local officials who have now approved thousands of enactments. And, the frenzy of legislation and amendments will continue unabated. Unfortunately, governmental response to the epidemic has been deficient in a number of respects and has been soundly criticized by both the Report of the Presidential Commission on the Human Immunodeficiency Epidemic in 1988 and the final report of the National Commission on AIDS in 1993. One political bright spot has been the enactment of the Americans With Disabilities Act. The 1990s have the potential to be the time in history of greatest support for challenged Ameri-

cans generally, including those with HIV-AIDS and those perceived as having HIV-AIDS.

. . . Michael Bennett, Gaetan Dugas, Halston . . .

Though AIDS began as an objective scientific phenomenon, it quickly became politicized. But a disease ought to remain an objective thing. Yet, more than any other disease condition in history, HIV-AIDS has been heavily encumbered for a host of reasons — its gruesome and fatal consequences, its incurable nature, its tendency to impact unpopular and minority groups, its exorbitant costs, and its elusiveness. The political maneuvering associated with HIV-AIDS is destined to thrive. Already in the 1990s, the premiere International Conference on AIDS scheduled for Boston was abruptly moved to Amsterdam because of an immigration policy permitting the denial of admission of foreigners with HIV-AIDS. As another example, in October of 1992 the entire Names Project Quilt was displayed (for the fifth time) in Washington, D.C., across from the White House. It was the eve of the Presidential election. The presence of the Quilt, representing some 20,000 persons who have died of HIV-AIDS, prompted the attendance of hundreds of thousands of viewers and mourners — and prompted a good deal of criticism of governmental responsiveness to the epidemic. And, for the fifth time, no President or representative of his administration was willing even to venture across the street to officially acknowledge the Quilt. Political gaming about HIV-AIDS continues. The National Commission on AIDS has been dissolved, but a National AIDS Policy Coordinator has been moved into the Executive Office of the President at the White House. What other disease has been symbolized by a group comparable to ACT-UP, by a quilt acres in size representing its deceased victims, or by an ornament (the overlapped red ribbon) so politically correct that it is widely worn by both ordinary people and the elite? How many diseases arrived to the point that they had their own "awareness" postage stamps? The politics about HIV-AIDS has been truly extraordinary.

. . . Amanda Blake, Peter Lacher, Robert Reed . . .

As striking as anything about HIV-AIDS has been the changes of focus on all fronts as we learn more and more about it. Early, it was called GRID (gay related immune disorder); later, it was AIDS (the rapid killer mentioned earlier); then, ARC (AIDS-related complex) was recognized but that did not last; and now the politically proper term is HIV disease or HIV-AIDS (to acknowledge the full course of the disease and to emphasize its chronic nature). We first focused on gay men, Haitians, and drug users. However, that created a blind spot about HIV-infection among other people of color and among other women. Indeed, women, newborns, and adolescents are now three of the groups with the highest rates of new in-

fections with HIV, and correspondingly with the greatest needs for medical, research, legal, and support attention for the future. Today, there are no longer risk groups, there are risk behaviors.

. . . David Acer, Robert Mapplethorpe, Sylvester . . .

Likewise the legal focus has shifted in virtually every area affected by HIV-AIDS. The public hysteria about AIDS in the early 1980s led to many blatant and unwarranted reactions. Many of these most conspicuous abuses are behind us. We no longer keep children out of school due solely to their HIV-AIDS status, but infected children's conditions and school attendance should be monitored for their own protection and for that of their classmates. Now, the attention in schools is on such issues as whether condoms can be distributed, what will comprise the content of sex-education and AIDS-education classes, and who should be entitled to decide those questions. We no longer deprive HIV-infected parents of custody or visitation with their children solely on account of the HIV-infection of the parents. Instead, in the family law arena, we must decide what to do about all of the children who are being impacted by HIV-AIDS (those orphaned from parents who died of AIDS, those infected as newborns, and those adolescents who contract HIV due to their experimentation with sex or drugs). Certainly, while some of the most obvious abuses have diminished, more subtle discrimination against people with HIV-AIDS and against people perceived to be at increased risk still exists. The fight against those more subtle tactics will need to be a primary focus for the future.

. . . Roy Cohn, Richard Failla, Jason Worth . . .

There is still much for the law to do, for the various systems are not fully assisting and protecting people with HIV-AIDS and those perceived to have HIV-AIDS. In addition to the problem areas noted earlier, HIV-AIDS educational programs have failed to curb the spread of the virus. Legislation has failed to curb the spread of HIV. Nevertheless, legislatures continue to adopt unnecessarily broad laws criminalizing the conduct of PLWAs, thereby even further stigmatizing people already burdened with the excess baggage associated with HIV-AIDS. Many people with HIV-AIDS continue to be ravaged not only by the disease but also by the system which causes them more physical and emotional pain and suffering than they should have to face and which drives them into poverty before they die. We ought to at least promote a system that allows people to die with dignity.

. . . Vincent Chalk, Timothy Lunsford, Glenn Weaver . . .

As soon as we think we have resolved an issue, other features or angles of the same issue emerge to challenge the legal system and to create further doubt. For instance, it was thought that there

was no risk, or almost no risk, of transmission of HIV from health care professional to patient, but then the case came to light of an HIV-infected Florida dentist who somehow transmitted HIV to six of his patients. Federal authorities have estimated that more than 125 patients nationwide may have been accidentally infected with HIV during the course of care by HIV-infected dentists and surgeons. Some surgeons and dental students with HIV have been prohibited from practicing. Class action suits have been filed against some health professionals who did not disclose their HIV-AIDS before treating patients. And, successful "AIDS phobia" suits (for emotional distress caused by the fear of contracting HIV-AIDS) have been launched by plaintiffs (who did not get HIV) in several fields, including suits against medical care professionals.

. . . Sabrina Kripps, Dan Pettinelli, Larry Taulbee . . .

Most health care workers have taken on the war against this disease with courage and compassion. They have chosen to fight HIV-AIDS and not those people afflicted with it. But we cannot be as proud of all health professionals. In some ways, the arrogance of many members of the medical profession has been divulged in the context of the HIV-AIDS epidemic. Many dentists and surgeons believe they should not be obliged to know their HIV-status and should not have to disclose their HIV-infection to the patients on whom they will perform invasive procedures. Many doctors have opposed early voluntary human trials with experimental HIV-AIDS drugs and therapies (accompanied of course, by informed consent). But patients overwhelmingly favor both, and after all it is *their* lives that hang in the balance. Why should uninfected patients be denied the choice of whether to take some degree of risk of contracting HIV? Why should persons who are dying of HIV-AIDS be denied the choice of treatment with experimental drugs and therapies?

. . . David Barr, Ethyl Eichelberger, Keith Haring . . .

Indeed, it has been cynically, though appropriately, observed that HIV-AIDS is a growth industry. In every one of its aspects there has been an expansion of the individuals and organizations involved with HIV-AIDS — researchers, caregivers, businesses, volunteers, governments, and so on. This includes a very real flood of litigation, for thousands of lawsuits involving HIV-AIDS have been filed.

. . . Megan Nicole, Jeffrey Thacker, Sadie Williamson . . .

The legal profession has responded in several positive ways. Attorneys, law professors, and law students began to write about HIV-AIDS legal issues; and volumes and volumes of papers, articles, and books are now available. There is even a law school casebook on the topic and some thirty to forty law schools have

adopted courses or clinics devoted exclusively to the subject of HIV-AIDS. Lawyers came forward to provide pro bono services to PLWAs who needed legal assistance, and a few public interest law firms devoted to HIV-AIDS matters have been established. Continuing legal education programs for the practicing bar and judges have been developed. But, much more needs to be done in every one of these areas in the 1990s. Within the legal profession, many still harbor prejudices about PLWAs. How fitting was the opening in 1994 of the successful and telling movie *Philadelphia*. If ours is truly the noble profession we so often proclaim it to be, we must lead by example — a better example than we have been setting. And we will have many opportunities to lead, for HIV-AIDS will continue to test our Democracy for a long, long time to come.

. . . Michael Callen, Gia, Steven Temmer . . .

The international picture of HIV-AIDS is bleak. While some diseases of the past attained epidemic proportions, sometimes affecting more than one continent, HIV-AIDS has been accurately described as the world's first truly global pandemic. Several countries of Africa have especially been ravaged already by the disease. Other countries on other continents will follow. HIV-AIDS in the 1990s will continue its trend to disproportionally impact underdeveloped areas (like Eastern Europe and Central and South America) and people of color. The newest region showing signs of the terrible scourge of HIV-AIDS and of the terrible cost of ignoring its presence is Asia. By allowing HIV-AIDS to gain a sure foothold behind a wall of denial, Asia (where more than half the world's population resides) will pay even more gravely than it would otherwise have suffered. It has been predicted that in India alone, soon after the turn of the century, there will be more than twice the number of people with HIV-AIDS than there are in the entire world today. Reflecting this geographical movement of concern, the Tenth International Conference on AIDS will be hosted in Asia for the first time ever when it is held in Yokohama, Japan, in 1994. However, that symbolism will not save Asia from the devastating effects of the disease catastrophe about to engulf it.

. . . Pablo Cruz, Christina Ferdine, Rocky Gagne . . .

The international picture of human rights issues associated with the HIV-AIDS pandemic is also bleak. Many countries of the world do not hold human rights concerns in the same high regard as we claim to do in this country. Thus, the prospects for fair and compassionate care or management of persons with HIV-AIDS are often dim from the beginning. Conditions which we would not tolerate prevail in many other places. For instance, there is mandatory HIV-testing; there are significant travel restrictions for those with HIV-AIDS; there is no regard for the confidentiality of HIV-AIDS

information; there is little or no medical assistance for those with HIV-AIDS; and there is involuntary confinement of many people with HIV-AIDS. And importantly, governments provide very little HIV-AIDS information and education, which people could use to protect themselves from contracting HIV. Government after government around the world is consciously allowing its own people to die because other economic and political interests have priority. It is a disease holocaust.

. . . Tina Chow, Brad Davis, Denholm Elliott . . .

HIV-AIDS will be with us for generations to come. Even if a cure or vaccine were discovered today, HIV-AIDS will still be with us for decades. A cure for HIV-AIDS seems almost impossible. Medical science has proved ineffectual in curing most viral conditions — such as hepatitis and influenza. Discovery of a vaccine is more likely, but even a vaccine is not likely to be helpful for the many millions of people throughout the world who already are infected with HIV. A cure or vaccine would take years to test and approve. Then, there would be the enormous task of distributing such cure or vaccine to all the people who need it and want it. Worldwide, that task might never be fully accomplished. After all, many countries do not have the technology or the money to feed and house their people, let alone the capabilities to distribute an HIV-AIDS drug to all of the people. In some parts of the world, armed conflicts would interfere with distribution efforts. It has been perceptively observed that we will not rid ourselves of HIV-AIDS in any country unless we do so everywhere, because HIV-AIDS is as mobile as the people who transmit it to one another.

. . . Narcella Fisher, Fred Lazarus, Ron Mitzel . . .

There is much more ahead of all of us everywhere in the second decade of this battle. More often than once every minute of every day another human being dies of HIV-AIDS associated causes, and more often than once every minute of every day another human being contracts a new infection of HIV. If only the list of names of those who have died of HIV-AIDS and of those who are living with HIV-AIDS could be frozen as it is. But the sad truth is that we have only begun the list. In analogizing between this epidemic and the deaths of millions of Jews in the Holocaust, social scientist Dennis Altman wrote in his book *AIDS in the Mind of America*, "[A] society that tolerates such prejudice is that much less a good and just society."

. . . Tom Duane, Magic Johnson, Randy Shilts . . .