they could have acted otherwise and eaten/exercised differently. It may be true that they could have, just as it may be true that the presumption of innocence allows some of the guilty to go free. But people who do not have genes for type 2 diabetes cannot really know what it's like to crave fats and sugars and to be tormented by these cravings. Yes, everyone is tempted, but some are tempted so much more intensely and continually than others! Until we have evidence that prediabetics could have acted otherwise, we should not blame them as individuals or in public policy.

That is compatible with educating young people and acting as if they can transcend their genetic dispositions. We want to think the best of people and to give them hope, but at the same time, we don't want to condemn them when they turn out to be less than ideal.

Finally, the history of eugenics shows that we almost always make huge mistakes in public policy about genetics, especially in oversimplifying complex issues. Responsibility may exist on a gradient, corresponding to a gradient of free will, such that some people have more than others. Two people with the same genes, placed at birth in different families (like Twain's *The Prince and the Pauper*) might as adults have differing degrees of free will and responsibility for their health or disease. On this perspective, poor people from dysfunctional families with no medical insurance, with genes predisposing them to diabetes or cancer, and little education will have less free will than well-educated young adults from loving, well-off families with good medical coverage who are blessed to have inherited good genes.

FURTHER READING AND RESOURCES

Catherine Hayes, "Genetic Testing for Huntington's—A Family Issue," New England Journal of Medicine, 327, no. 20, 1993.

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CHAPTER 17

Preventing the Global Spread of AIDS

This chapter emphasizes prevention of AIDS as a worldwide problem and as a challenge for bioethics. In a sense, such prevention is the ultimate classic case because already in human history, someone has become infected or died of HIV over 65 million times. Millions more new people become infected each year, raising the question of how we can slow this scourge.

The heart of the chapter discusses four approaches to stopping AIDS. As it explains, part of our problem stems from conflicts between these approaches, where each accuses the others of being part of the problem.

The chapter also discusses past epidemics, misunderstandings of AIDS, the transmission, clinical course, and treatment of AIDS, the scandal over HIV-infection of the blood supply, Kimberly Bergalis' case, homosexuality, contact tracing, mandatory screening, and preventive programs that exchange needles.

BACKGROUND: EPIDEMICS, PLAGUES, AND AIDS

Throughout human history, epidemics have always terrified humans. The deadly bacterial disease known as *the black death* or simply, the *plague*, had its great outbreak in 1348 in Europe.

It had two forms: bubonic plague, the most common and classic, is characterized by inflamed swellings of the lymphatic glands in the groin and armpits, and is transmitted by fleas. Rats and other small mammals carried fleas to humans, and the bites of fleas transmitted plague to humans.

The bacillus *Yersinia pestis* causes bubonic plague. Untreated bubonic plague killed 50 percent of its victims. Today, antibiotics treat its earliest stages.

A virulent complication of untreated bubonic plague, *pneumonic plague*, involves the lungs. Easily transmitted when one person coughs on another, the microbe kills almost universally. Because of it, many physicians of the 14th century decided their calling lay elsewhere.

In the same century, astrologers claimed that plague resulted from the conjunction of Saturn, Mars, and Jupiter; others claimed it resulted from sulfurous

fumes released by earthquakes. Clergy taught that God had sent it to punish humans for great sins.

Historian Barbara Tuchman tells us that during medieval epidemics, "Organized groups of 200 to 300 . . . marched from city to city, stripped to the waist, scourging themselves with leather whips tipped with iron spikes until they bled. While they cried aloud to Christ and the Virgin for pity, . . . the watching townspeople sobbed in sympathy." In so marching, they spread infected fleas.

The fearful ignorance of the times required *scapegoats* (in the Bible, goats were sacrificed to atone for bad things and to ward off worse things). So people accused Orthodox Jews, with their distinctive dress, of poisoning wells and spreading plague. When atonement processions reached cities, they often attacked the Jewish quarter, trapped Jews inside, and set the area on fire. When plague followed, Jews were blamed, not the procession.

Leprosy, cholera, and syphilis also terrified people. Leprosy, or Hansen's disease, creates lesions on the skin and kills slowly over years. Twentieth century medicine learned that people only get infected through exposure over many months through the skin or mucosa. Before then, society banished lepers and forced them to live in isolated places in lepers' colonies, and if they walked out, to ring cowbells to warn people off.

Great epidemics of cholera from infected water also created fear and loathing of its victims. During the epidemic of 1813, Americans blamed those who fell ill, especially wanton prostitutes, drunk Irish, lazy blacks, and the dirty poor who lived along creeks used for both drinking water and defecation. Ministers praised God for cholera for "cleansing the filth from society."

In 1854, physician John Snow realized that cholera only broke out in the district that received water from the Broad Street pump in London; he discovered that infected water spread cholera and that clean water could prevent it. Nevertheless, Americans preferred to believe that sin and being Irish caused cholera, so many more died in the third great cholera epidemic of 1862.

Not until acceptance of the germ theory of disease after 1900 did public health prevent epidemics of cholera. In other words, it took a half century for a medical insight to be translated into public policy to save millions of lives.

Victims of syphilis were also blamed for their disease. As discussed earlier, moralists blamed vice for the disease whereas scientists blamed spirochetes. (Ch. 10 on the Tuskegee Study discusses syphilis.)

A Brief History of AIDS

The first proven case of HIV came from a blood sample collected in 1959 from a man in Kinshasa, Democratic Republic of Congo. Genetic analysis of his blood suggests that HIV-1 may have stemmed from a virus that existed in the early 1940s or even the late 1930s.

Researcher Beatrice Hahn and her team at UAB proved in 1999 by DNA sequencing that the virus spread to humans from wild chimpanzees in southern Cameroon; HIV infected the blood of hunters there through catching, killing, and cutting up these chimps for bushmeat.²

Around 1978, gay men in the United States, Sweden, and Haiti begin to show signs of what would later be called AIDS. Between 1979 and 1981, Kaposi's sarcoma, and *Pneumocystis carinii* pneumonia (PCP) unexpectedly showed up in gay males in Los Angeles and New York.

On June 5, 1981, the Centers for Disease Control (CDC) announced the discovery of a mysterious "gay-related infectious disease" (GRID) that had killed 3 gay men; only a month later, 108 cases of GRID were reported and 46 gay men were dead.

Three months after the first report of GRID in the summer of 1981, CDC announced that babies of drug-dependent women in New York City also had the disease; GRID was changed to acquired immune deficiency syndrome or AIDS.

In 1982, when physicians in New York and California had already seen hundreds of cases of AIDS, they did not know its incubation or causative agent. CDC guessed that incubation could be many years and that many thousands of people could be infected. No one then diagnosed with AIDS had ever lived more than two years, so the disease frightened everyone.

In 1983, Luc Montagnier and the Institut Pasteur in France discovered that a virus, the *human immunodeficiency virus*, HIV, caused AIDS. Today his virus is called HIV-1. In 1986, scientists discovered a second form in West Africa, HIV-2, where it may have been infecting residents for decades. HIV-2 seems to develop more slowly and to be milder than HIV-1 but to be more easily transmitted heterosexually (the United States has reported few cases of HIV-2).³

As early as 1982, the CDC warned that donated blood could carry the agent causing AIDS. Blood then could have been screened for hepatitis, thereby indirectly screening for HIV, but officials deemed this too expensive and unfortunately did not do it.

In 1984, the FDA approved the ELISA test for antibodies to HIV. Now blood donated or otherwise obtained could be tested for HIV. However, authorities running blood banks did not immediately test blood using the ELISA test. Why?

First, at the time, each opposing group politicized every fact about HIV and AIDS. A little historical background shows how this occurred. This background may predict what would occur if SARS or a lethal bird flu became epidemic.

AIDS and Ideology

By the end of 1981, CDC epidemiologists realized that gay men were being killed by a new kind of infectious disease of unknown nature and transmission. CDC postulated that sex among gay men might be spreading the disease, especially sex with anonymous partners in bathhouses in cities such as New York and San Francisco.

These bathhouses constituted what epidemiologists call an *amplification system* for the spread of a disease. Because some of the men had many anonymous sexual partners, some of whom, in turn, traveled to other places for sex with numbers of partners, the virus could spread quickly. Another such system was cheap travel by jet around the world. Indeed, CDC identified a gay airline steward as Patient Zero, the first person to bring HIV from Africa to the United States and to introduce it to gay bathhouses.⁴

Sharing needles and syringes to inject drugs constitutes another amplification system. Blood withdrawn from a user's vein mixes both with a drug in the syringe and with viral particles from previous users.

Another amplification system is a community's blood supply. Because plasma is pooled from many sources and because clotting factor for hemophiliacs is similarly pooled, one infected donation can infect many recipients.

The CDC called upon federal and state governments to fund studies to see if a new lethal disease had appeared in the blood system, but none did anything. At the time, medical experts believed that all lethal infectious diseases had been discovered, so no one expected a new one to emerge.

Also in 1981, gay men and lesbians had won some freedom from historical prejudice against them: resistance against oppressive police round-ups began in June 1969 at a bar called the Stonewall Inn in Greenwich Village in New York City. The resistance to harassment shown by gay men in the *Stonewall Riots* fostered a new pride in being gay and encouraged gay men to come out of the closet (of shame and secrecy in which they had been hiding their sexual identity).

Also in North America and Europe during the 1970s, a new sexual freedom ruled among heterosexuals, fueled by birth control, permissive attitudes towards nonmarital sex, Woodstock, mind-altering drugs, and social rebellion against authority. So gay men and lesbians rode the crest of a larger fire of sexual change burning through the forest of traditional society. In medicine, psychiatrists removed homosexuality from their list of psychiatric illnesses.

But many people still feared and ridiculed gay men. Reverend Jerry Falwell, who founded Moral Majority, a religious political organization, blamed gays for AIDS. In 1982, the Secretary of Moral Majority, Greg Dixon, wrote, "If homosexuals are not stopped, they will in time infect the entire nation, and America will be destroyed—as entire civilizations have fallen in the past." This attitude persists, as seen in 2001 when the World Trade Center was destroyed: ministers Falwell and Pat Robertson blamed gays and atheists for the event, saying it was God's punishment on America, echoing earlier clergy who had scapegoated Jews for plague and the Irish for cholera.

The head of the Southern Baptist Convention said that God had created AIDS to "indicate His displeasure with the homosexual lifestyle." Monsignor Edward Clark of St. John's University in Queens, New York, claimed that, "If gay men would stop promiscuous sodomy, the AIDS virus would disappear from America." Politician and media commentator Patrick Buchanan decried, "The poor homosexuals—they have declared war on nature and now nature is exacting an awful retribution."

Reverend Falwell advocated shutting down bathhouses where gay men engaged in anonymous sex. Owners of such bathhouses countered with ads in gay newspapers extolling freedom and lambasting Falwell as a bigot. When gay activist Larry Kramer argued that shutting down bathhouses would save gay men's lives, gay men ridiculed him as a bigot.

Between 1983 and 1987, conservative politicians and clergy sparred verbally about AIDS with liberals and gay people. French philosopher Michel Foucault asserted that HIV did not cause AIDS and that HIV was not spread sexually. Foucault himself patronized bathhouses in the 1970s and died of AIDS in 1984,

becoming perhaps the only philosopher in history to have his views empirically refuted by the manner of his own death.

In the *New York Review of Books*, contributing editor Jonathan Lieberson, a graduate student in philosophy at Columbia University, wrote several influential articles about AIDS in the mid-1980s. In one long article in 1986, he claimed that irrationality about AIDS was running wild, that only 10 percent of HIV-infected people would ever get AIDS, and that contact tracing should never be used to track down sex partners of HIV-infected men, even to save lives, because the newly won freedom of gay men and their sex lives was too important to sacrifice.¹⁰ Around 1989, Lieberson himself died of AIDS (this periodical never apologized for these inaccurate pieces).

Transmission of HIV

Despite many rumors to the contrary, HIV is transmitted in only three ways: through blood, through semen, or to babies during birth or breast-feeding.

Without treatment, HIV causes a progressive weakening of the immune system, resulting in the body's inability to ward off normal infections. Without anti-retroviral drugs, the average time between HIV-infection and full-blown AIDS in 2005 was 9.5 years, and 9.2 months between AIDS and death.

Cells called T4 lymphocytes (or simply T4 cells) indicate the health of the immune system: the lower the number of cells, the worse it is doing. When the count of T4 cells drops below 200, a person with AIDS usually gets *opportunistic infections* such as Kaposi's sarcoma, PCP, a fungal infection called oral thrush, or cervical cancer.

Testing Blood, Again

In the midst of the above controversies, authorities in 1984 weighed whether to test America's blood for hepatitis as an indirect test for HIV. Those *against* testing won.

Encouraged by people such as Foucault and the *New York Review of Books*, some vocal gay men argued that their donations of blood should not be "quarantined" and that HIV had not really been proven to cause AIDS. Blood banks worried that, if they screened blood, they might lose income (although they do not technically charge for blood, they make money classifying, transferring, and storing blood).

In May 1984, Stanford University started screening blood for HIV. Two months later, defending a national decision *not* to screen, Health and Human Services Secretary Margaret Heckler said, "I want to assure the American people that the blood supply is 100 percent safe"¹¹

Joseph Bove, MD, who chaired the FDA's committee overseeing the safety of the nation's blood, said the "overreacting press" was causing hysteria about blood. When the CDC counted 73 cases of deaths from AIDS caused by transfusion in March, 1984, Bove dismissed this danger: "More people are killed by bee stings." Six months later, 269 people had died of AIDS from tainted blood.

In so assuring Americans, Bove and Heckler either lied, were incompetent, or both. In March 1985, most American blood banks began using the ELISA test to

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screen blood, a full year after they should have. Because of this lag, thousands of Americans and most hemophiliacs became infected with HIV. One of them was Rvan White, a hemophiliac who died at age 18 in 1990.

Chapter 17 Preventing the Global Spread of AIDS

In 1985, a woman who was a prostitute and intravenous drug-user tested positive for HIV. Now that Ryan White and she had the disease, it seemed to be no longer just a gay disease. Now it had infiltrated heterosexuals and the blood supply.

Until 1986, people had hoped that most HIV-infected people would not die. Then that changed dramatically when researchers predicted that, without treatment, almost all the HIV-infected would get AIDS and die.

The same year, a few gutsy people founded ACT-UP to help people with AIDS. Its demonstrations forced the FDA to shorten by two years its process for approving new drugs and in 1987, AZT (zidovudine) became the first anti-HIV

A decade later in 1996, scientists discovered protease inhibitors. These drugs block the protease enzyme, needed to create new, mature particles of HIV. These drugs allowed people with AIDS to live somewhat normal lives.

At the start of AIDS, 25 percent of women born of infected mothers became infected. AZT blocks such vertical transmission to less than 1 percent.

Protease inhibitors plus AZT can cost \$10,000 a year and cause severe complications. Because they require an obsessive attention to daily regimens, few people taking them work regular jobs. In short, they do not cure AIDS, but provide a way to survive it.

Kimberly Bergalis's Case

In December 1987, David Acer, a dentist in Jensen Beach, Fla., extracted two molars from 21 year-old Kimberly Bergalis, a junior at the University of Florida in Gainesville. After graduating in 1990, Kimberly tested positive for HIV.

A young white male in his early 30s, Dr. Acer admitted to having had sexual relations over the previous decade with 100 to 150 men. In September 1987, he developed Kaposi's sarcoma. In July 1989, he sold his practice, sold his tools and destroyed his records. In September 1990, he died of AIDS.

When his former patients tested themselves for HIV, six others tested positive. By using DNA sequencing, CDC proved that Dr. Acer was the source of infection in all his infected patients.

All the patients felt betrayed by the health professions. Kimberly Bergalis died publicly and painfully. In 1991, with little hair and weighing only 70 pounds, she testified before Congress, urging it to pass a law making it a felony for HIV-positive health professionals to interact with patients without revealing their HIV status. The law never passed and Kimberly died in December 1991 at age 25.

Exactly how or why Dr. Acer infected his patients remains a mystery. Some people believe that he deliberately infected heterosexuals so that Americans would no longer see AIDS as a disease of gay men. What he did will never be known for sure.

In some ways it is better if Dr. Acer deliberately infected Kimberly. Why is that? Because if he did, then she did not get infected through unsafe dental/medical practices, and hence, no reason exists to test dentists/physicians for HIV. Retrospective analysis of cases of HIV+ dentists, surgeons, and internists reveal virtually no cases of accidental infection of patients. In general, probability of infection varies with amount of blood injected, how deeply the injection goes, and how much virus the blood contains. Also, the same procedures (double-gloving, masking, and not reusing needles) that protect patients from infection also protect physicians and dentists from patients.

THREE ETHICAL ISSUES IN STOPPING THE SPREAD OF AIDS

Homosexuality

Some people believe that teaching gay men how to practice safe sex condones sex between men. Although similar objections can be made to teaching safe sex, many people feel that sex between men should not be tolerated. Homosexuality has existed for thousands of years. In ancient Greece, bisexuality among men was popular, and leading Greek men such as Socrates preferred male lovers. Gay figures include Roman emperor Hadrian, King Frederick the Great of Prussia, playwright Tennessee Williams, and novelist Gore Vidal. According to the late Yale historian John Boswell, Christianity tolerated homosexuality more before the 12th century than in later centuries.14

Although a minority of people see homosexuality as a choice, virtually all medical researchers believe that sexual orientation is biologically determined. In 1991, cancer researcher Simon LeVay published a paper in Science asserting that a specific region of the X chromosome in 40 pairs of gay men was associated with their sexual preference for men. The media dubbed this "the gay gene." Some people believe that if a person has one copy of this gene, he or she may or may not become gay, depending on the person's experiences. But if the person gets two copies of the gene, it is inevitable that the person will be gay.

The lived experience of gay men and lesbians testifies to the truth of this biological view. Virtually every gay man and lesbian reports as children and teenagers fighting against his or her inner sexual attraction and trying to fit the norm of heterosexuality in advertising and culture. Because teenagers want to fit in, most gay and lesbian teenagers resist being attracted to members of the same sex and date heterosexually. Their sexual orientation appears to be a resisted discovery rather than a choice.

Many people harbor the false belief that state or federal laws protect sexual orientation. Only if Congress, a state, a city, or a county passed such a law would it be illegal to evict or fire someone because of homosexuality. Currently, except for San Francisco and two cities in Colorado, it is legal to do so almost everywhere.

Indeed, in Bowers v. Hardwick, the U. S. Supreme Court in 1988 allowed Georgia to keep a law making forms of anal and oral intercourse illegal between members of the same sex. Ironically, a footnote to the decision did not allow the state to criminalize the same behavior among heterosexuals. Obviously, this decision violates Mill's harm principle and cries out for an explanation of why such sexual behavior between members of the same sex is a crime, but not a crime when between members of different sexes.

Five years later in 2003, the U.S. Supreme Court admitted in *Lawrence* v. *Texas* that it had made a mistake, that the issue was not (as the *Bowers* court said) whether the Constitution conferred upon "homosexuals a right to engage in sodomy," but whether the Constitution conferred a liberty interest to all Americans broad enough to allow consenting sex among adults.¹⁵

As we will see below, worldviews collide over homosexuality and stopping AIDS. Is conceptualizing homosexuality as an evil lifestyle *homophobia*? Part of the problem of stopping AIDS? Or is tolerance of homosexuality, drugs, and other "immorality" a root cause of the spread of AIDS?

Needle Exchange Programs

Needle exchange programs (NEPs) prevent the spread of HIV by giving drug users a clean needle and syringe each time they inject drugs, eliminating the need to share a possibly contaminated syringe. One study in New Haven, Connecticut achieved a 33 percent reduction in HIV transmission by giving out clean needles to at-risk persons. A 1992 study by the CDC of 23 NEPs seemed to show no increase in drug usage by giving out clean needles.

But do such NEPs encourage nonusers to try hard drugs? If using such drugs had no risk of disease, might not more people use them?

Public health officials worry about *the exposure rate*. What that means is, in most populations, a small percentage of people will always become addicted after exposure to an addictive drug, be that alcohol or heroin. If the same, say, 2 percent of people always become addicted, it matters a lot whether the population exposed is 20 thousand or 20 million.

Prohibition kept alcohol's exposure rate low. Similarly, keeping cocaine and heroin illegal keeps their exposure rate low.

HIV Exceptionalism

In the first decade of AIDS, authorities in public health bowed to pressure from AIDS activists and did not pursue contact tracing the way they had with other sexually transmissible diseases. Because of prejudice against gay men, they feared that tracing those exposed to HIV might lead to some people losing their medical insurance or jobs. Besides, until AZT arrived in 1986, authorities could offer no treatment, so the benefits of identification were scant. So authorities made an exception for contact tracing for HIV.

Today, with AZT and protease inhibitors, early notification can save lives by helping the infected get prompt treatment.

Now if a HIV+ person knowingly practices unsafe sex, he can be charged in many states with a crime. In 1997 in New York, Nushawn Williams knew he was HIV+ and infected 28 teenage girls; he went to jail for doing so. In this case, contact tracing prevented even more girls from becoming infected.

HIV exceptionalism is now generally regarded in public health as a mistake. It succumbed to pressure from gay activists, and may have cost some of them their lives.

In 2006, the CDC recommended routine testing of all patients by doctors for HIV. Of course this created controversy. Conservative religious groups retorted that no reason existed to test people in traditional marriages.

STOPPING THE WORLDWIDE SPREAD OF HIV: FIVE VIEWS

In the first edition of this book in 1990, it seemed shocking that by 1987, 60,000 Americans had died of AIDS, more people than had died in the Vietnam War, and researchers guessed that in 1990, 10 million people might be infected worldwide. In 1992, Larry Kramer wrote:

When I first became aware of this disease, there were only 43 cases in the United States; now there are 12 million people infected with AIDS around the world; within the next eight years, this figure could rise to 40 million. From 43 [people] to 40 million should be enough not only to cause some level of panic, but also to make everyone ask: how is this plague spreading so quickly? Indeed, 1 million new people worldwide were infected with the AIDS virus last year alone. 16

Fourteen years after Larry Kramer wrote this, and after a quarter century of AIDS, we have little more wisdom on how to stop AIDS. Meanwhile, the number of victims of AIDS in the world now ceases to shock people and even numbs them.

By 2001, AIDS had killed nearly a half a million Americans, but in America, HIV-infection had become a chronic infection that people could live with. American patients then could even morally think about getting married or becoming parents. But in the developing world where most people lived, AIDS seemed unstoppable.

In the summer of 2001, when the virus had killed 20 million people and infected another 40 million, Secretary-General Kofi Annan of the United Nations called for a special, new, concerted effort to arrest the disease. Rock stars such as Bono pressured America to give more aid, which it did.

Five years later in the summer of 2006, Kofi Annan offered a depressing assessment: despite great progress in human events, the spread of AIDS was "the single greatest reversal in the history of human development."

Why was he so gloomy? Answer: exactly 25 years after Americans first heard of AIDS, the disease had killed 25 million people on the planet. The small bit of progress was that "only" 40 million people worldwide were then infected, the same number as five years before (although five million of the previous 40 million had since died). The 2001 conference had aimed at universal access to treatment, costing \$20 billion a year, but only \$10 billion had actually been donated each year. 17

Year	HIV+ People	Number Killed ¹⁸
1981	600	200
1990	10,000,000	1,000,000
1999	30,000,000	10,000,000
2006	40,000,000	25,000,000

The most urgent issue now in medicine concerns stopping the spread of AIDS. Bad answers affect more people's lives than any other issue, as HIV could infect perhaps a billion people over the next half-century. Said differently, more lives could be saved by stopping the spread of AIDS than by all medicine's surgery, drugs, and high-tech interventions.

From this perspective, global bioethics clamors for attention. Even domestic questions about resources at the end of life seem related: how can Americans spend so much at the end of life when so many millions of the world die of preventable diseases?

If moral actions create the greatest good for the greatest number of humans, then moral people will now be fighting AIDS. In the next 10 years and if past trends continue, the 40 million people infected in 2006 could pass HIV on to another 40, 50, or even 60 million people.

Sub-Saharan Africa has the greatest pool of HIV-infection, containing 26 million infected people. South Africa, even with a relatively advanced economy, has 5.5 million infected.

China and India cause concern because of amplification systems there. Parts of China's blood supply is infected, which its officials often deny. Migratory laborers in India acquire HIV from prostitutes and pass it along to their wives and then to newborn children. In 2006, India surpassed South Africa as the country with the largest sheer number of citizens with AIDS, having 5.6 million to South Africa's 5.5 million. Asia altogether in 2006 had over 8 million infections.

Eastern Europe and central Asia (the Ukraine, Kazakhstan, etc.), with large numbers of intravenous drug-users, in 2005 had 1.6 million infected, up from 1 million in 2000.19

Facing the Problem Head-On

Given the vast extent of the problem, how do we stop the spread of HIV around the globe? Part of the answer is a moral one. Do we attack the behavior or the microbe in trying to stop the spread? Do we use nonmoralistic education or moralistic condemnation? Is money spent on education in developing countries helpful? Are cheap anti-AIDS drugs worthwhile when the numbers infected keep doubling and when many lack clean water? Would it be more efficient to triage countries with masses of infected people and then concentrate resources where they might save the most lives? These are the questions for the rest of this chapter,

The following section sketches four views of how to stop AIDS from spreading further. This section also features some exchanges between proponents of the different views.

Educational Prevention

Ultimately, humanity's only hope of preventing HIV is nonmoralistic education. Self-interested humans can learn. Learn what? To protect themselves against HIV by negotiating safe sex, using clean needles, avoiding infected blood, and taking drugs to prevent infection of newborns.

Prevention outranks cure, especially as AIDS has no cure. Not only is "an ounce of prevention worth a pound of cure," but prevention costs much less.

Cynics deride education to prevent infection, but education has worked. The number of new infections in the developed world declined rapidly in the 1990s and 2000s. Blood became safe, people routinely used condoms, and mothers stopped HIV from infecting their babies.

In the late 1980s, Thailand modeled how to arrest HIV. With a national campaign for 100 percent use of condoms, it advertised on television, hired outreach workers, ran testimonials by its royal family, and educated its sex workers, drugusers, and citizens in preventing HIV-infection. It allowed free access to testing and counseling, and protected the infected against discrimination. It gave out free AZT and championed production of generic anti-AIDS drugs for the poor. Over the next decade, new infections dropped 80 percent, preventing 200,000 HIVinfections.²⁰

Similar efforts worked in Uganda. Led by President Yoweri Museveni, Uganda ran testimonials on radio and television by famous Ugandans diagnosed with HIV. Infection rates during the 1990s among Uganda's youth dropped dramatically. At the same time, the rate of HIV-infection there dropped by half in rural areas and by two-thirds among urban, pregnant women.

Perhaps the most surprising success in educational prevention is Brazil. Like Cuba, Brazil has a large commercial sex industry for both its citizens and tourists, so in 1990 its large cities had high rates of HIV-infection. In 1996, the Brazilian government funded universal access to the latest and best anti-AIDS drugs, resulting over the next decade in the creation of a national system of out-patient centers, Brazilian manufacture of generic anti-AIDS drugs, and sophisticated labs and record-keeping. As a result, deaths from AIDS in Brazil dropped in half and rates of infection in São Paulo and Rio de Janeiro dropped 54 and 73 percent, respectively.21

Brazil's huge population means this program is a great success. Although both Brazil and South Africa have middle-class economies, Brazil's efforts at educational prevention fared much better than South Africa's. Education and prevention do work, given the will and funding.

Feminism

The key to stopping AIDS is to empower women to prevent themselves from getting infected by HIV. The key to that is to empower women to vote, to earn money, and to reject domestic violence.

A noted physician-fighter against AIDS concluded his 2006 review of this disease over 25 years with these words: "The prime mover of the epidemic is not inadequate antiretroviral medications, poverty, or bad luck, but our inability to accept the gothic dimensions of a disease that is transmitted sexually. Only if we cease to dodge this fact will effective HIV-control programs be established. Until then, it is no exaggeration to say that our polite behavior is killing us."22

The gothic dimensions of AIDS include the fact that nasty behavior by men around the world infects millions of women and children, that soldiers use mass rape as a weapon, that women and children are sold into sexual slavery and that poor, powerless women cannot refuse sex from their more powerful, infected husbands. The only name for this behavior is evil.

Chapter 17 Preventing the Global Spread of AIDS

This evil is the kind caused by human decisions. AIDS is not a punishment from God, but a way that sin manifests itself. Consider the case of 13-year old Rhaki in Rajasthan, India:

From a poor, rural family, Rhaki had an arranged marriage at age 13 to a 23 yearold man who worked in the distant city of Mumbai for 11 months of the year. Once a year, her husband returned for a month, during which time he had sex with her. While he lived in Mumbai, he had sex with prostitutes and became HIV+. At age 19, she learned that she and her 2-year old son were HIV+.

Despite the fact that she remained faithful to her husband and used no drugs, she was blamed for bringing shame into her family. She feared she would be ejected from the family and forced to become a prostitute in a distant city.²³

In Namibia, one study found that 95 percent of a thousand women were forced in their first sexual encounter.²⁴ A third of women in Sierra Leone reported the same. In sub-Saharan Africa with two-thirds of the world's HIV infections in 2006, 60 percent of those infected are women.²⁵ Of those newly infected and aged 15 to 24, a whopping 77 percent are women.

Dark reasons exist for this pattern. African men perceive that sex with a young girl is unlikely to infect them with HIV and some believe that sex with a virgin will cure HIV. These practices ensure that many teenage females will become infected.

In South Africa, India, and around the world, an amplification system exists that involves truck drivers, mobile soldiers, and commuting workers. India's new diamond-shaped interstate allows millions of truck drivers to transport commodities from rural areas to cities and ports. Along the way, drivers patronize prostitutes, become infected, and then infect their wives at home, resulting soon in infected babies.

South Africa's migratory pattern built up over a century, with millions of men traveling to distant mines to be housed in dormitories. Such patterns dramatically increase nonmarital sex. In Abidjan, the richest city in the Ivory Coast, migrants compose 40 percent of the city's population, and Abidjan has the highest incidence of HIV in West Africa.²⁶

Despite efforts of the United Nations and Christians to stop it, human slavery still exists in parts of northern Africa. In India, Eastern Europe, Mexico, and Korea, young women are tricked, kidnapped, and sold into distant brothels, where they become sex workers, living like slaves.

In Bosnia-Herzegovina, as many as 50,000 women were deliberately raped to make them pariahs. In East Timor, the Congo, Rwanda, Azerbaijan, and Uganda, rape became not only a spoil of war but a weapon in it. In Somalia and Darfur, marauders raped thousands of women and expelled them from their homes.

These are terrible human acts. To face a problem, you must name it. This is the human face of evil. To deal with it, you must confront it. This means that moral condemnation must be a weapon against AIDS. We cannot remain neutral against such appalling acts. We cannot merely pursue bland education and sanitized programs in public health.

Slavery of all kinds must end. Mass rape must end. Forced sex must end. Bad male behavior must end.

Tough love in stopping AIDS hasn't been tough enough. In Cuba, NuShawn Williams would have been executed. What if the government of Ethiopia condemned to die a man who infected his wife with HIV? It is time to take morally tough stands, else another 10 to 15 million women and children will die.

Triage

In some parts of the world, bad behavior is entrenched. Doctors cannot bring peace to warring countries: this is not a medical problem but a political one. Similarly, physicians cannot end slavery or famine: these are larger problems than medicine can solve. Moreover, some countries have corrupt governments, corruption going back a hundred years. It is naïve to think that do-gooder missionaries and physicians with love and education can change much there.

We need to triage countries such as South Africa where President Mbeki for a decade publicly resisted the fact that HIV causes AIDS, and where he not only did not lead the fight against spread of HIV but helped to spread it by his poor example.

Pouring money and time into some countries is a waste. The point of triage is to intervene to leverage at-risk life into saved lives. So, we ignore countries that don't need our help (North America, Europe, Thailand, Uganda) and also ignore countries where nothing we do will make much difference (the Sudan, Ethiopia, the Congo). Then we focus on countries in the middle, perhaps India, where politicians could lead and where people could change their behavior.

And as for the sterling examples of Thailand, Brazil, and Cuba, well no wonder! With their huge commercial sex industries, they successfully combated HIV-infections to avoid losing the hard currency flowing into their struggling economies.

Similarly, education and counseling will only go so far if people don't care for their own safety. After 25 years, most adults on the planet know that having unprotected sex, getting a transfusion of blood, or sharing needles can get you infected with HIV. If your own self-interest doesn't protect you now from HIV, more education certainly won't.

Besides, as gripes Jeffrey Fisher, director of Center for HIV Prevention at the University of Connecticut at Storrs, most AIDS education is bland and generic, and hence, of little value in teaching teenagers how to negotiate usage of condoms during sex or how to safely use hard drugs. "We lack the political will to implement these things," he says.27

Among large portions of the world, primal drives for sexual pleasure, fueled by poor judgment under the influence of alcohol and other drugs, lead people to practice unprotected sex. In Russia and China, despair over the conversion to capitalism has fueled widespread use of drugs.

All these forces swamp educational efforts to stop AIDS. Wisdom lies in recognizing that we can't control the private actions of most people. Wisdom lies in keeping a candle lit as the darkness grows.

Survivors will be fastidiously aware of what behaviors can kill them, and teach their children to be similarly aware. Sure, a billion people may die from AIDS, but humanity will go on. Plagues, flu, and floods have wiped out similar percentages of humanity before, but humanity has survived. Sadly, it is merely part of humanity's Darwinian evolution.

Structuralism

Activist groups such as Partners in Health emphasize that the cause of the spread of AIDS is not irresponsible personal behavior, but evil *structures* of society. Education and prevention will never work until these structures change. So toss out Educational Prevention, Feminism, and Triage: Educational Prevention is mere window-dressing, Feminism focuses wrongly on individuals, and Triage just breeds despair.

As some structuralists lament, "Obviously it is simpler to blame the victims for the rapid spread of AIDS in poor countries than to analyze the socioeconomic and political structures that underlie, frame, and often predetermine such personal 'choices'."²⁸

What evil structures? For starters, poverty, colonialism, apartheid and its legacy, racism, class injustice, and imperialism. Anthropologist Philippe Bourgois argues that in poor communities, lack of good jobs emasculates men who want to be good providers, who then turn to self-destructive behaviors out of frustration, using drugs, selling them, addicting women, and using violence to control others. Feminism for Bourgois ignores the "objective, structural desperation of a population without a viable economy."²⁹

Poverty is a major cause of the spread of HIV-infection. In the 1990s, thousands of dirt-poor farmers in China's Hena province sold their plasma each week. They did so because they could not earn a good living by farming but could do so by selling plasma.

Plasma is collected by taking blood from the donor's body, separating the plasma, and returning the rest of the blood to the donor. In this way, donors can give weekly rather than once a month, with whole blood.

Because the province's blood supply became infected with HIV, most of the donors became infected. Whole villages were wiped out. Moreover, because of the secrecy of the Chinese government, we have no idea how many Chinese patients received infected blood, plasma, or clotting factors. Millions of Chinese could be infected and not suspect it.

Too much of the world adopts a "it won't happen here approach." One commentator bemoans, "for the past 25 years, the lessons learned about HIV prevention and control in one country have failed to inform decisions in others. As a result, the world has witnessed a slow-motion domino effect, as the disease overwhelms country after country." Always, leaders deny that AIDS endangers the country (our blood is safe, we don't have prostitutes) and then, when cases of AIDS surface, those who are infected are blamed as deviant or foreign. "This sort of buck passing has delayed the control of AIDS in every country. By the time the scale of the problem is finally appreciated, a mature epidemic is in place, and the cost of lives and money has increased exponentially."

The connection between the spread of AIDS and structuralism may be put conceptually: an unjust structure is an amplification system for HIV. Women are

forced into prostitution to survive, male manual laborers use drugs to get by, poor hygiene and public health lead to diseases creating sores and infections, making HIV easier to transmit. People sell their bodies and their blood to survive.

Feminism Replies

The key to stopping AIDS is to create social structures that empower women. "Uppity women" means "down with AIDS."

Poor women around the world bear the brunt of AIDS. Such women know they are at-risk but often can do little to protect themselves. Bearing the paycheck, and hence, food and clothing and other goods of life, men control these women. We will only stop AIDS when we give these women more say over voting, jobs, and sex.

Vaccines, vaginal gels, and female condoms need technological breakthroughs to be effective, and one day may be so. In the meantime, women must be allowed to say "No" to abusive infection by males and forced sexual slavery. Unless structures are created to do so, AIDS will grow and grow.

Maybe unfashionable, isn't old-fashioned Feminism better than triaging 20 million people and forgetting about them? At least, Feminism directed at people says that someone *cares* about them (versus the *belle indifference* of Triage).

Structuralism is partly correct in that many of the evil structures of the world lead to the abuse, rape, killing, and HIV-infection of women, but we can help women without having a complete revolution in every society. Realistic change may need to be step-by-step rather than cataclysmic.

So basic rights for mothers, daughters, and wives can be implemented in small, faith-based communities, such as where clergy wield power in African villages. Money, food, and supplies, combined with faith and good-will, can model sex-only-within-marriage. Such an approach will also combat slavery, sexual exploitation of women and children, and be compatible with Islam.

Secular public health proposals that emphasize education may be inappropriate for faith-based, poor communities, where many people are illiterate and ignorant of the most basic science facts. Because AIDS is lethal and because a person only has to get infected once to get a lethal disease, such populations cannot wait to be taught to read or to be taught basic science. They need a solution now, and Feminism is the answer.

Finally, we do not know that moral censure has not worked. Without it, who knows how many more millions might have died or have been infected? Fear of moral condemnation motivates many people, and maybe that is not a bad thing.

AIDS kills. AIDS is caused by HIV. It's bad to infect someone with HIV. It's heinous to do so deliberately or with indifference. What other definition of a bad person do we need? Why not be a little moralistic here? After all, we're talking about *ethics*, not sanitation or legality.

Educational Prevention Responds

The champions of Educational Prevention rejects the moralism of Feminism and Structuralism. First, what's wrong with Feminism in public health is that it really

serves the emotions of the moralizer, not the one condemned. Moralizing did nothing to stop gay men from having sex after AIDS was discovered, but fear of death did. Moralizing only made matters worse.

Chapter 17 Preventing the Global Spread of AIDS

The key claim is that Feminism can change behavior. Is that true? One argument that it won't is that a lot of "tough love" has already been directed against using drugs, much less intravenous drugs. Similarly, a lot of moralism has been directed toward not having sex outside marriage, but has it worked?

If we execute men who infect their wives, who will bring home a paycheck to feed the wives? And the children? Execution sounds like a good idea, but if thought through, it's not. Seeing what would happen to them, wives would protect their husbands and not turn them in to authorities.

For workers in public health, Triage is too pessimistic. Why not generalize that attitude and let everyone starve? Or go without penicillin? Why bother about the rest of the planet at all? Why not let the undeveloped world fight it out among themselves and let the rich nations keep them at a distance, away from their shores? Just stay in your hot tub, enjoying the scenery and sipping your wine.

But is this a *moral* point of view? Sipping wine leisurely while humanity dies? What does the Golden Rule enjoin us to do? Triage does not offer the world a moral solution but gives up on finding one.

The essence of medical morality is to fight pragmatically for the good of the many especially using the tools of medicine. If we give up on that assumption, we might as well give up on medicine.

Triage Replies

The champion of Triage replies, "You're right. If there are six billion people now on the planet and if a billion of them die of AIDS, mostly on the other side of the planet and unknown to me, I don't care. The planet already has too many people and it could easily lose a billion. When stories about AIDS appear on the news, I change the channel. In fact, to avoid such stories, I don't even watch the news anymore".

"I may be morally deficient, but I have enough moral honesty to admit that I have no moral feelings of compassion, shame, or outrage about the mass of human deaths from AIDS. It's going to happen: it's a fact; it's accelerated Darwinian evolution; I don't think governments or missionaries can do anything about it; that's just the way it is. Give me my hot tub and another glass of wine."

Structuralists like economist Jeffrey Sachs argue that if Western nations transferred \$150 billion a year to developing nations, by 2025 poverty could be wiped off the planet. The musician Bono has jumped on this approach. But will simply transferring money end poverty? And will ending poverty stop the spread of AIDS?

Economist William Easterly, a senior research economist at the World Bank, in White Man's Burden, criticizes humanitarian planners who impose their own solutions on developing countries, especially the idea that building infrastructure with foreign aid will end poverty.³¹ Too many programs are funded top-down, with no feedback from poor people. Paul Theroux, who loves Africa, agrees.³²

With AIDS, Easterly argues that more life-years could be saved by not diverting money from antimalarial programs and childhood vaccinations and by fighting ordinary scourges such as tuberculosis. A million people still die each year from malaria in Africa.

Second, Easterly urges the West to focus on prevention rather than cure, especially by giving out condoms rather than giving the infected expensive AIDS medicines.

Third, people's kids starve while they get antiretrovirals. HIV takes almost a decade to make people sick. One infected woman said she didn't need the medicines, but a job to feed her family.

Finally, some countries may be hopeless. Twenty years ago, LiveAid concerts raised \$100 million for Ethiopia, but little changed, and today, life in Ethiopia is among the worst on earth.

Educational Prevention Once Again

The champion of Educational Prevention also rejects the cynicism of Triage. Both Triage and Feminism sound like solutions, but they are not. In fact, they serve the interests of those who espouse them, not the interests of the world's vulnerable women and children.

Triage would have us not offer expensive treatment to those infected but concentrate on preventing new infections. In 2006, the standard of care for HIV-infection is HAART, Highly Active Anti-Retroviral Therapy, which costs \$10,000 a person per year in developed countries and which 90 percent of HIV-infected people in the world do not get.

The knock-down argument against offering no HAART treatment at all in certain countries is that such a lack takes away the major reason for testing. When Brazil offered HAART free to all its citizens, testing for HIV zoomed and thousands came forth for treatment. Without treatment, how many would have gotten tested?

Triage is not an option. Let's call it what it is: global medical apartheid. The racial system of apartheid should not be replaced with a medical one.

Triage acquiesces to hopelessness, and hopelessness allows countries to spiral downwards in war, rape, famine, and infection. Triage is not a moral solution but giving up on finding one.

In 2001, breakthroughs occurred with the creation of the Global Fund to Fight AIDS, Tuberculosis, and Malaria as well as the Doha Agreement, allowing poor countries to buy or make generic anti-AIDS drugs. Powerful religious groups pushed the Bush administration to do more for victims of AIDS, and billions of U.S. aid poured forth. Seeing that, huge economies might be destroyed, the World Bank poured money into AIDS prevention. A similar threat to world security galvanized developed nations to respond. These efforts prevented millions of new infections and allowed two to three million people to live with HIV-infection, people who in turn support millions of children.

Conclusion

Stopping the spread of AIDS is not easy, and one reason is that dramatically different views exist about how to do it. One view's solution is another view's problem.

Some of the proposed approaches are too drastic. Structuralism says we must change everything to fix AIDS: eliminate poverty, sexism, racism, and corruption. A tall order and unlikely to happen.

Perhaps the only way to stop AIDS may be to experiment and adopt one view on a small scale, perhaps in a province, where the view can be fully implemented, top to bottom in that society. Whether that approach is Feminism, Educational Prevention, or Structuralism, given different religious backgrounds, provincial leaders, and scientific understanding, a particular approach might work better in one region rather than another. What worked in Brazil might not work in Biafra or Somalia.

The problem discussed in this chapter is unprecedented in bioethics or modern medicine. It is unimaginable to contemplate a billion human HIV-infections over the next five decades. The scale of death would dwarf the Black Plague, created hundreds of millions of orphans, bring down economies in developing nations, create despair over continents, and orphan tens of millions of children.

But the number of infected people did jump from a few hundred in 1981 to 10 million in 1990, and from there to 40 million in 2005, so who knows how many might be infected by the next edition of this text—50 million?

Hopefully, far fewer people than that number will be infected, in part because medicine, and bioethics, find a way to stem the rising tide of infections.

FURTHER READING AND RESOURCES

Alexander Irwin, Joyce Millen, and Dorothy Fallows, Global AIDS: Myths and Facts, South End Press, Cambridge, MA, 2003.

Randy Shilts, And the Band Played On, St. Martin's, New York, 1987.

Anton A. Van Niekerk and Loretta M. Kopelman, *Ethics and AIDS in Africa*, Left Coast Press, Walnut Creek, CA, 2006.

CHAPTER 18

Medicine and Inequality

This chapter focuses on inequality in health care in the United States, especially for the 46 million Americans who lack good medical coverage, a number fast approaching 50 million. It also focuses on the history of Medicare, the federally financed and supervised system of health care for Americans over age 65. The chapter discusses arguments for and against expansion of Medicare to give all Americans universal access to health care.

Rosalyn Schwartz

Rosalyn Schwartz, age 47, white, lives in Ridgefield, New Jersey; she has one child, Andy. She lost her medical coverage when she and her husband divorced in 1987.² At that time, the gift-wrap company where she worked with five other employees (making around \$19,000 a year) provided no medical coverage, though it hoped to do so soon.

When Rosalyn tried to buy an individual policy, because she had a *preexisting* condition—an ulcer—several insurance companies informed her that, if they offered her a policy at all, her premiums would be \$4,000 a year and exclude treatment for ulcers.

In 1988, she found a small lump in her breast. Her physician said it might be cancerous and recommended removing it, but hoping that her employer would soon offer coverage, Rosalyn postponed the lumpectomy.

In 1989, Rosalyn felt pain tear through her hip. By then her breast cancer had metastasized and had eaten into her hip, making the bones there as fragile as glass. When she fell to the floor, her hip socket shattered. In the ambulance, she sobbed and could think only of the costs. "Andy, you've just turned 18," she said. "I have no insurance. Tell them [at the hospital] I have no insurance. But don't sign anything or you'll be responsible."

Breast and prostate cancers are cells gone wild, so they must be excised and radiated as soon as possible. If such cancers reach the bone, it's bad.

Hospitalized for 23 days, Rosalyn had surgery three times. The total cost was \$40,000, half paid by charity. Rosalyn owed the rest, which she paid off at \$10 a month to each of 12 physicians and hospitals.

Accounts of the Cases and Issues that Define Medical Ethics

FIFTH EDITION

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CLASSIC CASES IN MEDICAL ETHICS: ACCOUNTS OF THE CASES THAT SHAPED AND DEFINE MEDICAL ETHICS

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Preface

I first started writing this book for my students 20 years ago when I had already been teaching the emerging field of bioethics for 10 years. I wrote this book for them because existing texts failed to convey the excitement of real cases in bioethics. In this fifth edition, I tried to keep the good parts of past editions ("If it's not broke, don't fix it") and to add to, or improve, them.

Every reviewer used some chapters and not others, so it was difficult to cut any chapter. I decided to edit every chapter, sometimes reducing the number of words by a third, while retaining the essence of each. In addition, I added relevant cases and new issues to each chapter.

Like previous editions, this edition was tested on my undergraduates and medical students during 2006. As in the past, my students freely told me of mistakes and biases, improving the book.

If we date the start of modern bioethics to the 1962 God Committee, we're almost at half a century of bioethics. Professors today must both teach about new issues (face transplants) while showing how they build on previous cases (heart and hand transplants). And sometimes one issue ties them together: a desire to be first in surgery.

Personally, I believe that knowing about real cases and how they were resolved is real education in ethics for people who will one day make medical decisions. Like the spreading ripples of a stone in a pond, more and more cases build up spheres of knowledge that are as close as we can teach to what Aristotle called *phronesis* or practical wisdom.

As always, I would like to hear your comments and can be reached at my email address: pence@uab.edu.

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