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### HIV/AIDS: A Postmodern Epidemic and Its Depiction

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# HIV/AIDS: A Postmodern Epidemic and Its Depiction (March 2016): Home

By Sharon Leslie

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## Introduction

The acquired immunodeficiency syndrome (AIDS) epidemic began thirty years ago. According to the World Health Organization (WHO), since then an estimated 39 million people worldwide have died from AIDS-related complications, and approximately 35 million people are currently living with HIV (human immunodeficiency virus), the virus that causes AIDS. In many highly developed countries—the United States certainly among them—HIV infection and AIDS are considered manageable chronic conditions, treatable with a regimen of maintenance medications. An older generation of Americans is familiar with the disease and its history, but today's typical undergraduate student, having been born after the disease became controllable in the United States, may have limited awareness of it. Although the history of HIV/AIDS is relatively short, its story is complex (and still evolving), and its political, social, and cultural dimensions seem almost without limits. Any study of HIV/AIDS is of necessity interdisciplinary, with science and public health, politics and human rights, economics, the arts, intellectual property law, and GLBT and gender studies all connected in a vast network.

This essay surveys materials useful in an undergraduate setting. Many of the resources are scholarly, but others are more personal and even fall under the heading of popular. Because of the worldwide impact of AIDS, there is a huge amount of literature published. Though literature for specific populations in the United States—for example, African Americans—has dwindled as the disease has become more commonplace in the medical mainstream, the growth of the HIV/AIDS literature has been steady, especially the literature about developing countries. This essay touches on some, but certainly not all, of the noteworthy literature on various aspects of HIV/AIDS. Inevitably, some titles that others would find critical will not be included, so readers are encouraged to seek out other resources.

The essay is divided into several parts: the first, "A Brief Overview," provides the broad picture, and others that follow look at resources on particular aspects of HIV/AIDS. Some titles discussed in a given section would be equally comfortable in another. The works cited comprises sections devoted to print, film, and online resources (journals included).

## A Brief Overview

A retrovirus that infects immune system cells, HIV is spread by contact with bodily fluids through unprotected sexual contact, mother-to-child transmission during birth or breastfeeding, sharing contaminated drug needles, or receiving contaminated blood products. The Centers for Disease Control (CDC) estimates the number of new diagnoses of HIV infection in 2013 in the United States was 47,352.<sup>[1]</sup> There are two main strains of HIV, HIV-1 and HIV-2, but this essay will use the terms HIV or HIV/AIDS. There is no cure for HIV infection, but there is treatment.

Antiretroviral therapy (ART) drugs help keep the amount of HIV at low levels in the body, stopping weakening of the immune system. Using a combination of three or more ARTs is called highly active antiretroviral therapy (HAART), aka the "drug cocktail." More than twenty drugs are now approved by the US Food and Drug Administration (FDA) to

treat HIV/AIDS. Ongoing clinical trials are testing dozens of new investigational drugs needed due to drug resistance or side effects from treatment (e.g., increased risk of diabetes and heart problems). New infections can be curbed by behavioral changes such as use of condoms, abstinence, and limiting the number of sexual partners. Male circumcision and needle exchange programs are also effective in reducing infections. Initial attempts at creating a vaccine have failed, but numerous vaccine trials are under way. New classes of drugs are being researched, and other types of prevention, for example, microbial gels, are being studied.

Those interested in basic information about HIV/AIDS written in layperson language can go to the US National Library of Medicine's website *MedlinePlus*, which offers fact sheets on all stages of infection and for specific populations. Textbooks (many of which are regularly updated) can be valuable introductory resources outside the classroom. For example, Hung Fan, Ross Conner, and Luis Villarreal's *AIDS: Science and Society* (now in its seventh edition) offers a comprehensive introduction; reviews biological, psychological, behavioral, and societal aspects of HIV/AIDS; and provides a companion website with summaries and Q&A review questions. Another introductory textbook is Benjamin Weeks and Teri Shors's *AIDS: The Biological Basis*, which offers a comprehensive overview in layperson terminology and test questions at the end of each chapter. *Encyclopedia of AIDS: A Social, Political, Cultural, and Scientific Record of the HIV Epidemic*, edited by Raymond Smith, is in need of updating, but it contains reliable information on many subjects from experts in the field. For greater depth of clinical information, *Sande's HIV/AIDS Medicine: Medical Management of AIDS*, an annual edited by Paul Volberding et al., covers all clinical aspects of HIV/AIDS infection. Jay Levy's *HIV and the Pathogenesis of AIDS* (now in its third edition) is also a reliable clinical text. Journals focused on HIV/AIDS are numerous. Among those addressing current treatment and research are *AIDS: Official Journal of the International AIDS Society* and *JAIDS: Journal of Acquired Immune Deficiency Syndromes*, both available online.

New drugs would not be possible without clinical testing. Among the resources on clinical trials is Sana Loue and Earl Pike's valuable *Case Studies in Ethics and HIV Research*. The authors use case studies to examine the ethical complexities of dealing with an ill population desperate for a cure, and they address such topics as informed consent, human-subject research committees, confidentiality, and research in vulnerable populations. Those interested in current clinical trials will find detailed information at *AIDSinfo*, an online resource from the US Department of Health and Human Services, and *ClinicalTrials.gov*, the primary source for clinical trials in the United States. For international trials, the World Health Organization's *International Clinical Trials Registry Platform* is a comprehensive resource.

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[1] Centers for Disease Control and Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, *HIV/AIDS Statistics Overview*, <http://www.cdc.gov/hiv/statistics/overview/index.html>.

## The Epidemic: A Time Line

### A Time Line

A basic knowledge of the history of epidemics is helpful in understanding the transmission and epidemiology of HIV/AIDS. William McNeill's *Plagues and Peoples* offers a historical and sociological overview of epidemics. McNeill details, in a relatively cheerful tone, how biological evolution, the recent ease of travel and human migration, and

human interventions alter natural balances/processes and lead to disease transmission. In *The Coming Plague: Newly Emerging Diseases in a World out of Balance*, Laurie Garrett provides a vast, comprehensive picture of the course of epidemics over the centuries. Like McNeill, she notes that the increase in human population and ease of travel together serve as a perfect springboard for the spread of viruses. *The Patient as Victim and Vector: Ethics and Infectious Disease*, by Margaret Battin and others, examines disease control policies of the past (e.g., containment, isolation) and how to plan ahead for new epidemics.

In the 1970s, North America found itself relatively epidemic and plague free. Smallpox, measles, polio, and cholera had been eradicated thanks to vaccination programs and advanced sanitation procedures, and these diseases were believed to be limited to less developed countries. Things changed in 1981. In June, the CDC reported five cases of *Pneumocystis pneumonia* (PCP), which affects primarily immunocompromised individuals, in homosexual men in Los Angeles. By the end of 1981, the CDC had received some seventy reports of PCP infections in Los Angeles and New York City. The infection was initially called “GRID,” or “gay-related immune deficiency.” The CDC soon identified the outbreak as a new infectious disease and established the term “acquired immune deficiency syndrome”—“AIDS.” The cause was still unknown. The epidemic advanced rapidly.

The historical impact of HIV/AIDS is bound up with the public’s attitude toward the populations first affected. The American Psychiatric Association, until 1973, classified homosexuality as a psychological disorder, curable with psychotherapy. The gay rights movement had started only a few years prior with the 1969 “Stonewall riots.” Because AIDS first appeared in gay men and injection drug users, it was stigmatized by many and seen as “divine retribution” by others. Though eventually science confirmed that exchange of HIV-infected bodily fluids, not homosexuality or immorality, was the cause of AIDS, the government’s cautious response in researching and finding drugs for treatment infuriated the gay population, which already felt marginalized.

Credit for the identification of HIV as the cause of AIDS goes to virologists Luc Montagnier (of the French Pasteur Institute) and Robert Gallo (at the National Cancer Institute), who in the mid-1980s independently isolated virus genomes they suspected caused AIDS. The men’s discoveries were more or less simultaneous, though Montagnier actually made the breakthrough discovery and shared his samples with Gallo. Both men applied for US patents for their discoveries, and the patent office approved Gallo’s test because his application predated that of Montagnier. This stirred up great controversy. The French government sued the United States, and years of court filings ensued. The suit was dropped when the National Cancer Institute agreed to share credit for the discovery of HIV with Montagnier, add Montagnier’s name to the patent, and share royalties from the sales of the diagnostic test kit.<sup>[1]</sup> The two scientists recount these travails, Gallo in *Virus Hunting: AIDS, Cancer, and the Human Retrovirus: A Story of Scientific Discovery* and Montagnier in *Virus: The Co-Discoverer of HIV Tracks Its Rampage and Charts the Future*. In 2008, Montagnier and two coworkers won the Nobel Prize in medicine for their discovery of HIV; Robert Gallo was not included. In his *The Burdens of Disease: Epidemics and Human Response in Western History*, J. N. Hays discusses the “unseemly wrangle” between Gallo and Montagnier in a chapter titled “Disease and Power.”

Several books try to trace the evolutionary trail of HIV. Edward Hooper’s *The River: A Journey to the Source of HIV and AIDS* hypothesizes that HIV initially came from the Belgian Congo through an experimental oral polio vaccine contaminated with simian immunodeficiency virus. That scenario has since been proven incorrect, although the author claims otherwise. Jacques Pepin offers a different theory in *The Origins of AIDS*, an engaging account of the initial transmission of the virus from chimpanzees to humans by the consumption of “bushmeat.” The chief virtue of

Pepin's treatment, which is supplemented with maps and graphs, is that it offers gleanings of the history of the political structure of many African countries.

In 1985, actor Rock Hudson, having denied for decades that he was homosexual, announced he was HIV-positive; he died three months later. In 1986, President Reagan first mentioned the word "AIDS" in a public speech. Many religious entities saw AIDS as a moral issue and used the church's influence in political circles to assure needle exchange programs were not funded by the government and that sex education classes in public schools taught that abstinence, not condoms, was the best way to prevent disease. Peter Allen's *The Wages of Sin: Sex and Disease, Past and Present* describes the battle of the so-called religious Right as it tried to enforce traditional biblical ways of dealing with sexual behavior and gender roles.

The first antiretroviral drug, azidothymidine (AZT), was approved by the FDA in 1987, with a proposed cost to the patient of \$10,000 per year. A grassroots organization, the AIDS Coalition to Unleash Power (ACT UP), immediately sprang up to protest the high price of treatment and the paucity of research being done to find a cure. Under pressure from ACT UP, the manufacturer of AZT, Burroughs-Wellcome, lowered the price of the drug. Larry Kramer was one of the founders of ACT UP, and in his *Reports from the Holocaust: The Making of an AIDS Activist* he confirms exactly how furious he was at lives lost: the book comprises reprints of Kramer's letters to government officials and essays criticizing New York City Mayor Ed Koch, President Reagan, and particularly the NIH for taking so long to get drugs to market. The documentary feature film *How to Survive a Plague* shows how ACT UP, through determination and public demonstrations, forced the FDA to change the drug approval process by speeding up clinical trials and so getting drugs to market faster. The *ACT UP Oral History Project* preserves the legacy of the organization by providing an online collection of interviews with surviving members, in both video and transcribed PDF formats.

In Benjamin Shepard's *White Nights and Ascending Shadows: An Oral History of the San Francisco AIDS Epidemic*, a collection of interviews, thirty San Franciscans reveal how the epidemic affected the San Francisco population and led to "gay rights [becoming] human rights." Cleve Jones's memoir (written with Jeff Dawson), *Stitching a Revolution: The Making of an Activist*, recounts the path he took to launch the AIDS Memorial Quilt—online at *The AIDS Memorial Quilt*—to recognize those lost to AIDS. The quilt, which Jones termed a "traditional-family-values symbol," became known worldwide. Undeniably, the best-known book on the early days of HIV/AIDS is journalist Randy Shilts's *And the Band Played On: Politics, People, and the AIDS Epidemic*, an enormous tome that recounts the history of the first five years of the epidemic in a novelesque style. Another excellent resource for understanding the contemporaneous reaction to the disease is Carol Pogash's *As Real as It Gets*, which includes interviews with the clinical staff of San Francisco General Hospital, the epicenter for treating the outbreak on the West Coast.

Concerned about HIV/AIDS within its own borders, in 1987 the US government added HIV to its immigration exclusion list, barring those who tested positive for HIV from other countries from traveling, or immigrating, to the United States. In 1988, the government was concerned enough about the epidemic to establish the Office of AIDS Research (part of the National Institutes of Health) and mail to all households in the country a brochure titled "Understanding AIDS: A Message from the Surgeon General," by C. Everett Koop.<sup>[2]</sup> In 1991, basketball player Earvin "Magic" Johnson announced he was HIV-positive, with the result that he was compelled by fearful teammates to retire from basketball. In 1992, Mary Fisher, a white, affluent Republican, infected through heterosexual sex with

her husband, gave a speech about AIDS to the Republican National Convention. The American general public now took notice of the disease.

In 1995, a new treatment regimen—the aforementioned “drug cocktail”—was developed in the laboratory of Dr. David Ho (one of the major contributors to AIDS research). Patients who were previously near death recovered so remarkably that the phenomenon was called the “Lazarus effect.” Within the space of two years, there was a dramatic decline in AIDS-related deaths in the United States. The Kaiser Family Foundation tracks this, and indeed the entire epidemic, at *The Global HIV/AIDS Epidemic: A Timeline*.

Alongside the passionate descriptions of personal tragedy and the search for a cure, one finds literature by an unorthodox community of denialists. The denialism rabbit hole goes deep: some think the KGB and/or the CIA deliberately infected people; some believe pharmaceutical companies, the medical establishment, and government scientists cannot be trusted. The writings by and about deniers over the years deserve attention because of the historical impact they had and continue to have—in part because some of the authors have respected scientific and academic pedigrees. For example, in the mid-1990s Peter Duesberg—an elected member of the prestigious National Academy of Sciences—published *Inventing the AIDS Virus*, an investigation of why he believed AIDS is not caused by a virus but is the result of using immunity-suppressing recreational drugs (amyl nitrate “poppers,” cocaine, and so on); toxic pharmaceutical drugs such as AZT; and immune system damage by antibiotic drugs used to treat STDs. Another prominent denier is Kary Mullis, a Nobel laureate in chemistry, who wrote in his autobiography, *Dancing Naked in the Mind Field*, that he disagreed with evidence showing that HIV causes AIDS. In 2000, South African President Thabo Mbeki, with counsel from known dissenters such as Duesberg, concurred that HIV was not the cause of AIDS—a position that led Mbeki to delay in obtaining ART drugs for his nation. Mbeki’s inaction and his government’s science phobia are exposed in *The Politics of AIDS Denialism: South Africa’s Failure to Respond* by Pieter Fourie and Melissa Meyer. And in *Debunking Delusions*, Nathan Geffen, founder of South Africa’s Treatment Action Campaign, provides a history of that activist organization. In *The AIDS Conspiracy: Science Fights Back*, Nicoli Nattrass writes not about why the denial theories are wrong or irrational but about the background stories that make denialist theory believable to so many. He recounts the history of medical abuses of blacks at Tuskegee University and in Africa by the apartheid regime—historical events that have led many to believe HIV is a man-made virus or bioweapon.

During the late 1990s, in the wake of the realization that treatment with HAART worked and saved lives, the demand for less expensive drugs in developing countries became an international cause. Western pharmaceutical companies, backed by the US government, refused to allow affordable generic versions of their drugs to be made and sold at lower prices to poverty-stricken countries. Dylan Mohan Gray’s documentary film *Fire in the Blood: Medicine, Monopoly, Malice* records efforts by activists and NGOs to bring essential medications to Africa. (The film also serves as an excellent resource for understanding the intricate issues surrounding politics, patent laws, and intellectual property rights.) Among the many people interviewed in the film are Archbishop Desmond Tutu, President Bill Clinton, and Joseph Stiglitz, Nobel laureate in economics. *The Global Governance of HIV/AIDS: Intellectual Property and Access to Essential Medicines*, edited by Obijiofor Aginam, John Harrington, and Peter Yu, explains the complex international trade and intellectual property protection issues of HIV/AIDS medications. In the late 2000s, newly elected President Barack Obama introduced the White House’s National HIV/AIDS Strategy and ended the HIV travel and immigration ban, thus allowing the International AIDS Conference to return to the United States for the first

time in more than twenty years. In *AIDS at 30: A History*, Victoria Harden, founding director of NIH's Stetten Museum (which is devoted to NIH biomedical history), looks at HIV/AIDS from the perspective of an NIH medical researcher. The book is rich with illustrations of primary source materials from NIH and National Library of Medicine collections. Harden also created a website, *In Their Own Words: NIH Researchers Recall the Early Years of AIDS*, which provides oral histories—in the form of transcripts with NIH scientists—and a good deal more. And in *While the World Sleeps: Writing from the First Twenty Years of the Global AIDS Plague*, editor Chris Bull collects published essays by such authors as Fran Lebowitz and Stephen Jay Gould.

Researching new treatments and funding treatment of those infected are critical, but education and prevention also play a huge role in dealing with HIV/AIDS. But changing behavior is difficult. The gay community's early attempts to stop the epidemic and prevent more infections are depicted in two excellent documentaries. *Sex Positive: A Frontlines Memoir of the Battle over Safer Sex* tells the story of Richard Berkowitz and others who started the safe-sex revolution. Joseph Sonnabend, a physician, suggested that "interrupting disease transmission" would prevent more HIV infections, and that led Berkowitz and activist Michael Callen to create a booklet titled "How to Have Sex in an Epidemic – One Approach," which advocated condom use and other safe-sex methods. Because condom use was unnecessary in the gay community, the message was difficult to convey, especially at the height of the gay sexual liberation movement. This is discussed in the documentary *Sex in an Epidemic*, which provides interviews with the founders of the Gay Men's Health Crisis and chronicles efforts in New York City to promote safe sex. The film includes footage from the first ACT UP protest and interviews with key players.

Other resources on prevention include *Innovations in HIV Prevention Research and Practice through Community Engagement*, edited by Scott Rhodes, which discusses how to reduce exposure and transmission using community-based participatory research. Though intended for public health practitioners, the CDC's online *Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention* highlights successful projects identified through systematic reviews. Rachel Golden et al. provide *Best Evidence Structural Interventions for HIV Prevention*, which offers evidence-based best practices for structural (versus behavioral) interventions. The online magazine *POZ* provides prevention information and treatment advances, offering daily research updates and the benefit of an extensive social networking community. Project Inform's *P.I. Perspective* newsletter, which targets those with HIV/AIDS and hepatitis C and provides "inspiration, information and advocacy for people with HIV/AIDS and hepatitis C," offers monthly digests of recent research.

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[1] Howard L. Singer, "Institut Pasteur v. United States: The AIDS Patent Dispute, the Contract Disputes Act and the International Exchange of Scientific Data," *American Journal of Law & Medicine* 15 (1989): 439.

[2] U.S. Department of Health and Human Services, *Understanding AIDS: A Message from the Surgeon General*, <http://profiles.nlm.nih.gov/ps/access/QQBDR.pdf>

## The Sociology of AIDS

The HIV/AIDS epidemic has affected some communities more than others. *African Americans and HIV/AIDS: Understanding and Addressing the Epidemic*, edited by Donna Hubbard McCree, Kenneth Terrill Jones, and Ann

O’Leary, discusses the health disparity between the white and black communities and the psychosocial variables and contextual factors that may affect prevention efforts. In 1993, in response to the AIDS epidemic, James Jones updated his well-known *Bad Blood: The Tuskegee Syphilis Experiment* to include a chapter on AIDS, in which he noted that Tuskegee was the “historical lens” through which blacks viewed AIDS. *Endgame: AIDS in Black America*, a PBS *Frontline* documentary, ably shows the reach of AIDS in the disadvantaged minority populations of the rural and urban United States. The documentary *DeepSouth* looks at people in the rural South affected by HIV—for example, a young, gay, HIV-positive black man in Mississippi who looks for support from his “gay family” instead of his “blood family.” The popular literature also includes useful titles on HIV/AIDS in the black community. Among the interesting—if not scholarly—works are J. L. King’s *On the Down Low: A Journey into the Lives of “Straight” Black Men Who Sleep with Men* and Keith Boykin’s *Beyond the Down Low: Sex, Lies, and Denial in Black America*, which describe the denial and shame of bisexual black men who lead secret lives and do not identify themselves as such. In *Structural Intimacies: Sexual Stories in the Black AIDS Epidemic*, Sonja Mackenzie uses interviews to reveal how blacks feel about the racism, stigma, and poverty associated with HIV/AIDS and discusses how operating “on the down low” adds to the shame and stigma of black gay males, thus the racism of the expression. The denialism issue is addressed in *Not in My Family: AIDS in the African-American Community*, an edited collection of essays from black religious and political leaders and public figures recounting their personal stories about HIV/AIDS and the stigma, beliefs, and discrimination in the African American community.

Other sociological studies include Robert Klitzman and Ronald Bayer’s *Mortal Secrets: Truth and Lies in the Age of AIDS*, which looks at people living with AIDS (commonly referred to as PLWAs) and their attitudes about disclosing their HIV status. In *In the Shadow of the Epidemic: Being HIV-Negative in the Age of AIDS*, clinical psychologist Walt Odets assesses psychological issues of those who test HIV-negative. In 2010, the American South accounted for almost half of new AIDS diagnoses.<sup>[1]</sup> In *You’re the First One I’ve Told: The Faces of HIV in the Deep South*, Kathryn Whetten and Brian Pence expand on the first edition of this work—subtitled “New Faces of HIV in the South,” and published more than a decade ago—by adding first-person life histories in which participants in a Duke University research study, “Coping with HIV/AIDS in the Southeast,” reveal their distrust of the health care system and the additional burden HIV infection places on the poor. Edited by Negar Akhavi, *AIDS Sutra: Untold Stories from India*, a collection of essays written by Indian authors known mostly for their literary works (e.g., Salman Rushdie), looks at the effect of HIV/AIDS on India’s people. *The Wisdom of Whores: Bureaucrats, Brothels, and the Business of AIDS*, by journalist-turned-epidemiologist Elizabeth Pisani, provides a lively, candid picture of boots-on-the-ground public health work in Indonesia. In *Religion and AIDS in Africa*, Jenny Trinitapoli and Alexander Weinreb discuss the implications of the United States President’s Emergency Plan for AIDS Relief (PEPFAR), which provides funding for prevention and treatment to many developing countries (e.g., South Africa, Vietnam). PEPFAR includes a congressionally mandated “ABC policy” (Abstinence, Be Faithful, Use Condoms).<sup>[2]</sup> The authors note the sad irony that condom use is prohibited in some of Africa’s main religions and abstinence-based prevention efforts have been found to be ineffective.<sup>[3]</sup>

As the HIV/AIDS epidemic has aged, its effect on society and culture has been the subject of scrutiny. Sarah Schulman’s *The Gentrification of the Mind: Witness to a Lost Imagination* is part memoir and part analysis of how society has assimilated AIDS. She believes that older gay people will become marginalized and that a new generation studying “queer theory” in college will know next to nothing about the fight against AIDS. In *AIDS and Its Metaphors*, Susan Sontag traces the language used to depict what was, when the book was published, a new



disease and often described metaphorically as an invasion with the victims under assault. In *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*, Paula Treichler asserts that the AIDS epidemic is “cultural and linguistic as well as biological and biomedical” and that the language society uses to describe AIDS permeates the culture. Much like Sontag’s and Treichler’s books, Cindy Patton’s *Inventing AIDS* looks at AIDS through language and cultural analysis. Patton states that HIV infection assists in identifying and classifying people into categories—class, race, sex—that allow for discrimination. In another book, *Fatal Advice: How Safe-Sex Education Went Wrong*, Patton shows how safe sex is portrayed in HIV prevention. Illustrated with ads from the era, the book compares government-funded AIDS education for the general public and ads created by activists for the gay community: the former feature bullet points and clip art of white people, the latter provocative images of minorities and condoms. Another intriguing visual resource is *AIDS Demo Graphics* by Douglas Crimp with Adam Rolston, which shows the posters, ads, street art, leaflets, and stickers developed by ACT UP New York to create AIDS awareness and incite political action. An excellent online resource is *AIDS Education Posters Collection*, developed by Edward Atwater, which charts the “evolution of AIDS rhetoric.” Last, the National Library of Medicine’s *Visual Culture and Public Health Posters* website includes essays and posters and provides an overview of the medical establishment’s attempts to convey HIV/AIDS information.

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[1] Centers for Disease Control and Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, *HIV and AIDS in the United States by Geographic Distribution*, [http://www.cdc.gov/hiv/pdf/statistics\\_geographic\\_distribution.pdf](http://www.cdc.gov/hiv/pdf/statistics_geographic_distribution.pdf)

[2] U.S. Government, *President’s Emergency Plan for AIDS Relief (PEPFAR)*, <http://www.pepfar.gov/reports/guidance/c19545.htm>

[3] K. Underhill, D Operario, and P. Montgomery, “Abstinence-Only Programs for HIV Infection Prevention in High-Income Countries,” *Cochrane Database of Systematic Reviews*, 4 (December 2007).

## Global Health and Human Rights

UNAIDS reported that in 2012 sub-Saharan Africa accounted for almost 70 percent of the people living with HIV worldwide. Although combination antiretroviral therapy was developed a decade ago, many in Africa still do not have access to it, in spite of the United Nations Commission on Human Rights stating that health is a right and people worldwide with AIDS have a right to ART.[1] This is in part because the African continent, which has more than fifty countries and 2,138 living languages, is plagued by societal issues—wars, famine, crime, corruption, and poverty—that exacerbate the difficulty of treating and preventing AIDS. Numerous books detail issues surrounding human rights on the African continent, particularly in South Africa. A useful basic resource is *HIV/AIDS in South Africa*, edited by S. S. Abdool Karim and Q. Abdool Karim, which is written in layperson language and covers gender and sexuality issues, economics, risk factors, and prevention interventions. *Shattered Dreams?: An Oral History of the South African AIDS Epidemic*, by Gerald Oppenheimer and Ronald Bayer, presents interviews with physicians and nurses (black and white, working at both urban and rural healthcare facilities) on the front lines of South Africa’s epidemic during apartheid. They describe how racial inequality affected not only the health care received, but the health care provided. In *28: Stories of AIDS in Africa*, journalist Stephanie Nolen, a four-time winner of the Amnesty

International Media Award for human rights reporting, profiles women and men from sub-Saharan Africa, including an HIV-positive minister, a child, a prostitute, a physician with Doctors Without Borders, and Nelson Mandela, whose son died of AIDS in 2005. The book contains black-and-white photos of each person profiled and maps showing where interviewees lived. *Women, Motherhood and Living with HIV/AIDS: A Cross-Cultural Perspective*, edited by Pranee Liamputtong, focuses primarily on Asia and Africa and deals with the effect of HIV infection on fertility, child-bearing status, and birth. *Women's Global Health and Human Rights*, edited by Padmini Murthy and Clyde Lanford Smith, provides a broad overview; though only two chapters are devoted specifically to HIV/AIDS, the disease is referred to throughout because of its broad reach across society. *AIDS and Accusation: Haiti and the Geography of Blame*, by Paul Farmer (cofounder of Partners in Health), examines how Haitians have been targets of AIDS-related discrimination since the CDC's 1983 recommendation that physicians be aware of the earliest identified high-risk groups, nicknamed the "4Hs"—hemophiliacs, homosexuals, heroin users, and Haitians. *A Decade of HAART: The Development and Global Impact of Highly Active Antiretroviral Therapy*, edited by José Zuniga et al., collects essays on the impact of HAART worldwide, in nations both wealthy and poor.

Reporter Anne-Christine D'Adesky's *Moving Mountains: The Race to Treat Global AIDS* reports on research in Cuba, India, Africa, Russia, Mexico, and Haiti, where she studied the consequences of patents and trade laws that are keeping hundreds of thousands of people from getting treatment because of resource gaps in the basic infrastructures of many of the countries. *Three Decades of HIV/AIDS in Asia*, edited by Jai Narain, details cultural, political, and economic factors of disease transmission and prevention. *AIDS in the Twenty-First Century: Disease and Globalization*, a well-researched introductory textbook by Tony Barnett and Alan Whiteside, covers the history, etiology, pathogenesis, and spread of the disease, along with economics, health policy, government responses, and prevention strategies, all with a global focus. Taking the position that one must respect human rights to treat patients properly, Lawrence Gostin wrote *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations* as a one-stop resource for HIV/AIDS-related litigation and AIDS policy issues. The book deals with "right to know" partner notification, health data security, needle exchange programs, drug pricing, and rights of health care workers.

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[1] World Health Organization, *Fact Sheet No. 31*, <http://www.ohchr.org/Documents/Publications/Factsheet31.pdf>

## Memoirs

The legacy of the artists and creative people who have died from AIDS or suffered the loss of loved ones is huge. Many of the personal narratives and memoirs about the effect of AIDS on people's lives reflect the fatalistic mood of the 1980s. In *Borrowed Time: An AIDS Memoir*, poet Paul Monette candidly recalls his longtime partner's illness and eventual death. In the wake of that work, while he himself was dying of AIDS-related complications, Monette wrote *Love Alone: 18 Elegies for Rog*, a collection of raw and bitter poems. The autobiographical documentary film *Silverlake Life: The View from Here* balances an intimate love story of two gay men (both HIV-positive) with an account of the daily grind of pharmacy visits, physical exhaustion, and despair as the men were in the last stages of the disease. Tom Joslin—the director of the film and one of its two subjects—died during the making of the film, and film student Peter Friedman completed work on it.

*Love Undetectable: Notes on Friendship, Sex, and Survival* comprises expanded, previously published essays by journalist Andrew Sullivan. He offers a potent description of the early days of his HIV infection and describes AIDS as an “integrator” that helped him feel part of a community. In *Close to the Knives: A Memoir of Disintegration*, painter, writer, and multimedia artist David Wojnarowicz writes with intensity about his years of drug use and street hustling in New York City. He blames his anticipated death (he died a year after the book was published) and the deaths of many others on politicians and doctors who did not move fast enough to stop the disease. In *Heaven’s Coast: A Memoir*, Mark Doty, who went on to earn the 2008 National Book Award for poetry, describes the “slow erasure” of his partner of more than ten years. His grief and rage, and the physical effect of his deep emotions, are reflected in his exceptional prose. Jamaica Kincaid’s memoir, *My Brother*, relates her journey home to Antigua to help care for her brother who was dying of AIDS. *Witness to AIDS*, by Edwin Cameron, a white, HIV-positive South African High Court judge, is both a personal memoir and a story of the moral obligation to challenge and fight the apartheid government. Abraham Verghese’s *My Own Country: A Doctor’s Story of a Town and Its People in the Age of AIDS* recounts the author’s experience treating a Tennessee hospital’s first cases of AIDS.

AIDS memoirs have also taken the form of graphic novels. In his *7 Miles a Second*, David Wojnarowicz uses his intimate, angry narrative and colorful surreal art by James Romberger and colorist Marguerite Van Cook to vividly recreate the New York City street scene of the early 1980s. Joyce Brabner’s *Second Avenue Caper: When Goodfellas, Divas, and Dealers Plotted against the Plague*, illustrated by Mark Zingarelli, is a more traditional black-and-white graphic novel recounting the typically desperate stories from the early days of the epidemic. Originally published in French in 2001, and translated into English by Anjali Singh, Frederik Peeters’s *Blue Pills: A Positive Love Story* is an autobiographical black-and-white graphic novel telling the story of a heterosexual couple who are serodiscordant (i.e., one is HIV-positive, one is HIV-negative).

## Literature

Many fictional works address the AIDS crisis in a thoughtful way, and a number of short story collections are particularly fine. In *Vital Signs: Essential AIDS Fiction*, Richard Canning collects eighteen short stories by authors such as Ann Beattie and Dale Peck. Canning’s informed historical introduction places these works in the context of the literature on AIDS. Rebecca Brown’s *The Gifts of the Body* is a collection of intimate, compassionate short stories told in the voice of a home healthcare worker caring for AIDS patients. *The Way We Write Now: Short Stories from the AIDS Crisis*, edited by Sharon Oard Warner, includes Susan Sontag’s seminal AIDS short story “The Way We Live Now.”

There are also many books of memorial poetry addressing the grief and loss of the epidemic. *Poets for Life: Seventy-Six Poets Respond to AIDS*, edited by Michael Klein, features the work of Eve Ensler, Wayne Koestenbaum, Thom Gunn, and Walter Holland, among many others, and includes essays by Paul Moore Jr., Joseph Papp, and Carol Muske. Tory Dent published two award-winning collections of poems about living a life HIV-positive, *What Silence Equals* and *HIV, Mon Amour*. *Persistent Voices: Poetry by Writers Lost to AIDS*, edited by David Groff and Philip Clark, includes poems by forty-five poets, among them William Dickey, Assotto Saint, and Pulitzer Prize winner James Merrill. The poems in *Diva*, by the openly gay Cuban American physician Rafael Campo, touch on memories of Cuba and the deep sense of sadness and loss of patients and their caregivers.

## Visual Arts

*Not Over: 25 Years of Visual AIDS*, written by Robert Atkins et al. and edited by Nelson Santos, provides a history of the Visual AIDS organization, which was founded in 1988 and created the Red Ribbon Project and the annual “Day without Art” project. The book includes images of Visual AIDS projects, collaborations, and printed matter; the organization’s eponymous website includes an online gallery of artists’ works. *Loss within Loss: Artists in the Age of AIDS*, edited by Edmund White, makes real the void created by the loss of many New York artists in the early days of the epidemic. The book was funded by the Estate Project for Artists with AIDS. In *Muses from Chaos and Ash: AIDS, Artists, and Art*, Andréa Vaucher interviews HIV-positive artists and explores the effect the disease has on their creative works. Included are filmmaker Marlon Riggs, photographer Robert Mapplethorpe, painter Keith Haring, and author Hervé Guibert, to name just a few. David Wojnarowicz, discussed above, showcases his art in *David Wojnarowicz: Brush Fires in the Social Landscape*. Like Wojnarowicz, artist Mark Morrisroe was a former street hustler. Morrisroe used many types of photographic processes and toward the end of his life created experimental abstract images using x-rays of his own PCP-filled lungs. His work is reproduced in *Mark Morrisroe*, which chiefly comprises illustrations and is edited by Beatrix Ruf and Thomas Seelig. The book is well designed and beautifully printed. The renowned photographic collective Magnum produced *Access to Life*; edited by Annalyn Swan and Peter Bernstein, the photography project shows the improvement in people’s health, lives, and finances since beginning antiretroviral treatment in 2007. In it, photojournalists report from Haiti, Russia, and six other countries. Each section includes brief biographies of the participants, large-format black-and-white and color photographs, and HIV/AIDS statistics from the country. The volume is accompanied by a DVD and includes a preface by Desmond Tutu.

## Theater, Film, and Performance

HIV/AIDS has been a frequent subject of the performing arts. Larry Kramer, discussed earlier in this essay as the founder of ACT UP, started his career as a screenwriter and later became a playwright. His award-winning, semiautobiographical play *The Normal Heart*, chronicling the early days of AIDS in New York, was staged Off-Broadway in 1985 and later revived on Broadway and adapted by HBO. That play’s follow-up, *The Destiny of Me*, is slated for a Broadway revival and an HBO treatment. Both plays are available in print (in one volume), and *The Normal Heart* is available on DVD. *The Way We Live Now: American Plays and the AIDS Crisis*, edited by M. Elizabeth Osborn, collects ten plays and play excerpts that illustrate the theater world’s response to the AIDS crisis. Included in the anthology are William Hoffman’s play *As Is* (a treatment of Sontag’s short story “The Way We Live Now”) and works by Harvey Fierstein and Terrence McNally. In *How to Make Dances in an Epidemic: Tracking Choreography in the Age of AIDS*, Dave Gere looks at how the loss of many dancers and choreographers (Alvin Ailey and Rudolf Nureyev among them) to AIDS affected the dance world. Jonathan Larson’s Broadway musical *Rent* looks at poor young New Yorkers living with HIV and their relationships. The play was made into a film and is available on DVD. Tony Kushner’s award-winning *Angels in America: A Gay Fantasia on National Themes*—probably the best-known dramatic response to the AIDS crisis—affirmed the political Right’s impression of all gay and/or HIV/AIDS-related art as sacrilegious. Comprising two plays—*Part One: Millennium Approaches* and *Part Two: Perestroika*—*Angels in America* examines AIDS, sexuality, and Reagan-era politics and is available on DVD as an HBO miniseries. The film *Philadelphia*, which is about the discrimination and legal battles facing those living with AIDS, was released in 1997 and is likely to have been the first cultural encounter many Americans had with HIV/AIDS. Derek Jarman’s *Blue*, a poetic film and audio diary about his AIDS-induced blindness, was filmed against

a blank blue screen, with voices—accompanied by music and text—speaking about friends, physical changes, and spiritual quandaries. *Zero Patience*, a sexually explicit New Wave musical, has a unique AIDS-related plot involving the ghost of AIDS “patient zero” and is an example of inspiring, low-budget filmmaking.

Ethnomusicologists Gregory Barz and Judah Cohen look specifically at the African continent in their edited volume *The Culture of AIDS in Africa: Hope and Healing in Music and the Arts*, which examines how music, theater, and other performance arts help African communities address AIDS. And in *Community Theatre and AIDS*, Ola Johansson looks at a Tanzania-based research project and how traditional art forms like community-based theater allow the participants to speak of HIV prevention and issues like fidelity, prostitution, and condom use.

Compiled and edited by Thomas Avena, the anthology *Life Sentences: Writers, Artists, and AIDS* brings together various media and artists. Among the interviews Avena includes is one with singer Diamanda Galas, a classically trained pianist and singer, who discusses her *Plague Mass*, a challenging, militantly fierce work in the style of Greek funerary music expressing the rage and sorrow caused by the AIDS epidemic. Also included are an interview with photographer Nan Goldin, poems by Essex Hemphill and Tony Kushner, and short stories.

### Looking Forward

Although new HIV infections have fallen by almost 40 percent since 2001, UNAIDS reported that an estimated 1.5 million people worldwide died from AIDS-related illnesses in 2013. In the Western world, the sense of urgency about AIDS has decreased since combination therapy became available in the mid-1990s. An unexpected consequence of the success of combination therapy is that people have become complacent about safe-sex methods—and the need to use them consistently—which has led to a resurgence in new infections. As the Kaiser Family Foundation’s 2011 survey *HIV/AIDS at 30: A Public Opinion Perspective* makes clear, in the United States the stigma of HIV infection continues.

Many international agencies are working on vaccine development, prevention strategies, structural remedies, and poverty relief in the hope that by scaling up prevention and treatment programs they will eventually outpace and even eliminate the disease. Nathalia Holt’s recent *Cured: How the Berlin Patients Defeated HIV and Forever Changed Medical Science* describes the cases of two men who were declared “functionally cured” of HIV infection, in one case following a painful and expensive bone marrow transplant of HIV-resistant stem cells. Although the technique appears to have worked in one patient, the economic feasibility and logistics must be assessed. *Biomedical Advances in HIV Prevention: Social and Behavioral Perspectives*, edited by Lisa Eaton and Seth Kalichman, focuses on biomedical technologies currently being researched (e.g., topical microbicides/gels and vaccines) to help end the spread of HIV. Pre-exposure prophylaxis (known as PrEP) and post-exposure prophylaxis (PEP) are other treatment options being explored. *Rethink HIV: Smarter Ways to Invest in Ending HIV in Sub-Saharan Africa*, edited by Bjørn Lomborg, ranks HIV prevention and treatment policies using a cost-benefit analysis. A priorities ranking report put together by the aids2031 Consortium, *AIDS: Taking a Long-Term View*, suggests that researchers take a fresh, proactive approach as well as a long-term approach. The international organization UNITAID, launched by the United Nations in 2006, is using innovative financing to encourage pharmaceutical companies to participate in the Medicines Patent Pool, which allows drugs to be used on an open-access basis by researchers in developing

countries. And fast-track programs such as that initiated at USAIDS support scaling up HIV prevention and treatment programs with an eye toward ending the epidemic as a public health issue within the next few decades.<sup>[1]</sup>

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[1] UNAIDS, *Fast-Track—Ending the AIDS Epidemic by 2030*,  
[http://www.unaids.org/en/resources/documents/2014/JC2686\\_WAD2014report](http://www.unaids.org/en/resources/documents/2014/JC2686_WAD2014report)

## Conclusion

As this essay shows, the range of HIV/AIDS literature is broad and spreads across many disciplines. Publication of monographs in the clinical sciences has slowed, with journals providing the most up-to-date research. Most of the monographs fall under the heading of public health, although the sociology literature on HIV/AIDS is steadily growing as a generation of survivors reaches more milestones. Stopping the disease will involve using all the techniques available—education, prevention, treatment, and research—and overcoming financial impediments. The disease is still active, and academic interest in it will continue. One hopes the literature will eventually move from such immediate topics as treatment and prevention to historical observations.

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