The Role of Activism During the AIDS Epidemic

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THE ROLE OF ACTIVISM DURING THE AIDS EPIDEMIC

The AIDS epidemic is widely seen as being recognized in 1981, though HIV had already been present in America for about 20 years. The disease was first identified in Los Angeles by an immunologist who described the disease as a rare lung infection, though the men first examined developed other infections as their immune systems began to shut down.\textsuperscript{1} HIV was originally called Kaposi’s Sarcoma (KS) before the HIV virus was discovered. The term AIDS was not actually used until September 1982 by the CDC. AIDS is a result of the contraction of the virus, HTLV-III, which causes the natural immunity of the body to be weakened. The weakening of the immune system causes those with AIDS to be more susceptible to illnesses that otherwise were not a problem. Scientists questioned whether the disease was spread through club drugs, saliva, mosquitoes, or any number of other sources, trying desperately to find the cause as the numbers began to grow.

The largest number of diagnoses were found in Los Angeles, San Francisco, and New York City. At the beginning of the epidemic, the largest number of cases were found in the LGBT community, especially among gay and bisexual men. For this reason, they were thought

to be the cause of the disease and that made anger towards the community increase along with the fear and panic that only grew with the increase of diagnoses. Media only served to aid this as new articles began to come out about the different cases as they were cropping up all over the nation. On July 3, the *New York Times* published the article ‘Rare Cancer Seen in 41 Homosexuals.’ After the article’s release, the term “gay cancer” began to be used by the public. Discrimination began to grow against the already marginalized community and employers and others began to shun and avoid those diagnosed with HIV. What progress the LGBT community had made after the Stonewall Riots was erased as the majority of the population saw HIV as a disease that was carried only by gay men: “Every advance since [the Riots] was met by an extreme and paranoiac counterforce. The 1970s produced the fiercest round of anti-gay legislation the nation had ever known.” The end of the first year of the epidemic showed the increasing upward trend of cases: “By year’s end, there [was] a cumulative total of 337 reported cases of individuals with severe immune deficiency in the United States—321 adults/adolescents and 16 children under age 13. Of those cases, 130 are already dead by December 31.” The Reagan Administration began to cut the research budgets ignoring the cries of the victims, which caused panic both within the community and in the general public to increase. It was not until September 17, 1985, that President Reagan even publicly mentioned AIDS and it was not until 2

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years later that he actually made a formal speech about AIDS. Meanwhile, the CDC began to estimate that thousands of people could be infected with the disease. It was still widely believed that only gay and bisexual men were infected and they were the ones that infected others. Intravenous drug users, lesbians, bi-women, heterosexuals, children, and those infected through blood transfusions were mostly ignored though there were plenty of victims in those categories.

For the most part, the disease was ignored. Mainstream media released some articles about the disease and the spread but it took several months from the beginning of the epidemic for the CDC to even release anything about AIDS. The early 1980s show a significant amount of discrimination against the LGBT community:

Employers were firing people diagnosed with the disease, insurance claims were being rejected, and landlords were locking patients out of their homes. Thousands of people urgently needed wills, because without them estates were being swept up by estranged family members who were stripping the surviving partners of everything, even the photographs and cherished ephemera from a shared life.6

The doctors that chose to focus on treating those infected faced significant discrimination despite the amount of risk they faced while trying to stop the epidemic: “After New York City physician Joseph Sonnabend is threatened with eviction from his office building for treating patients with AIDS, the state’s Attorney General and Lambda Legal join together to file the first AIDS discrimination lawsuit.”7 Media—even sources like The New York Times which are seen as reliable and generally unbiased—distributed information that made the situation worse for the infected and those treating them, such as in an article when they stated that the virus may be able

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6 France, 52-53.

to be spread through saliva. Since there was already significant anti-gay sentiment within the general public, the publishing of articles such as these served to increase the sense of fear around the disease and those infected. With those articles came more discrimination in getting work and even healthcare.

Meanwhile, places where gay people had become accustomed to using as safe places to engage in sexual relationships and find similar people, namely bathhouses and gay bars and clubs, were raided by police and shut down by cities to slow the spread of the disease. Soon, activists began to rise up, like Larry Kramer, who wrote the autobiographical play, *A Normal Heart*. The play is described as “scorching” and showed the pain in the life of those with AIDS trying to get treatment, dealing with loss, and hoping for help from those in charge:

> Political outrage may be what shaped this drama, inspired (very directly) by Mr. Kramer’s early days as an AIDS activist. But what emerges so stirringly from this production — which follows the shaky emergence of a political movement among gay New Yorkers to deal with AIDS — is its empathy with people lost in a war in which they have no rules, no map, no weapons. Everyone’s flailing, everyone behaves badly, and everyone is, if not likable, at least understandable. There is no rationing of compassion here, even for the enemy.

The play also “highlights the growing rifts between those...who are desperately banging on the doors of government and science in an attempt to stave off the annihilation of gay men, and those

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who focus instead on building new institutions that will care for the sick and the dying.”

Actor Rock Hudson brought positive attention to AIDS after coming forward about being infected. But despite the improvements, by the end of 1985, a majority of Americans still favored quarantining those infected with AIDS.\(^{12}\) This was partly due to the fact that there was an 89% increase of new AIDS cases from 1984-85\(^ {13}\) and the high mortality rate that came with a diagnosis—until drugs were developed the disease was nearly 100% fatal.\(^ {14}\)

It was ultimately the work of several activist groups that sprung up during the epidemic that brought the most amount of change. The activist group ACT UP (the AIDS Coalition to Unleash Power) which was well known and highly influential during the epidemic was created on March 12, 1987 by the same man that wrote \textit{A Normal Heart}, Larry Kramer. Kramer was a leading figure of the movement and a public face for the activist group. \textit{TIME Magazine} commended the group for “pressuring drug companies, government agencies and other powers that stood in their way to find better treatments for people with AIDS—and, in the process, improving the way drugs are tested and approved in the U.S.”\(^ {15}\) The activist group worked closely with Dr. Iris Long, PhD., a straight woman who was a retired chemist.\(^ {16}\) She reached out


\(^{13}\) “Timeline of HIV/AIDS.” January 16, 1986.


\(^{16}\) Sarah Schulman, interview by author, May 16, 2003, tape recording.
to the group and helped to teach them medicine and about the formulation of drugs so that they could start to develop their own attempts at cures. Some of these proved to be useful to an extent and activists brought it to the FDA and CDC in an attempt to get drugs pushed out sooner. Dr. Long also taught them how places like the NHS worked so that they could better target the groups that were slowing the process of drug creation for AIDS. One of the problems many AIDS activists had with the drugs that were released early on was that they were not easily available and most like AZT—the first of the drugs to be released—cost $10,000 a year, something that those infected usually could not afford. This resulted in the creation of underground drug trials and groups like People with AIDS (PWA) who worked to bring drugs that were not on the market or were from other countries to the United States.  

Soon it was discovered that although AZT was effective, it was toxic. ACT UP started pushing for the FDA to release new drugs, specifically DHPG, that were more readily available and would help with the blindness that many people with advanced AIDS were struggling with. The first big win for ACT UP in terms of the search for a cure, or something to at least combat the disease, was the release of DDI which was free and accessible.

ACT UP was known for their signs and slogans that they used at their protests to inform the public and increase the effectiveness of the the protests. “Silence = Death” was one of their most recognizable slogans and soon the pink triangle, which had been used to mark gay and bisexual men for persecution during the Holocaust, was adopted and became associated with the


group. The posters often held facts and specifics to target those they were protesting and teach even those that merely walked by. Their protests were so effective in part because they used methods that made sure that even those that did not have the time or resources to come and learn could get the point just from seeing some of the signs. One particularly powerful sign stated:

WE DIE -- THEY DO NOTHING, spelling out in fine print who WE are [People of color, whether we are Afro-American, Native American, Hispanic Latino, or Asian, women, men, IV drug users, partners of IV drug users, lesbians, gays, straights, the homeless, prisoners, and children affected by the AIDS crisis], who THEY are [Ronald Reagan, George Bush, Michael Dukakis, the NIH, the FDA, the U.S. Congress, the Congressional Black and Hispanic Caucus, our national media, our national minority leaders], and declaring, around the border, WE RECOGNIZE EVERY AIDS DEATH AS AN ACT OF RACIST, SEXIST, AND HOMOPHOBIC VIOLENCE.  

One demonstration that ACT UP is well known for was a protest done in conjunction with Women’s Health Action and Mobilization (WHAM!) in protest of “the church hierarchy’s public opposition to homosexuality, abortion, and safe-sex education.” The group promoted themselves by filming a documentary called *Stop the Church*: “It captured footage of the protest outside of St. Patrick’s Cathedral as well as disruptions within…[it recorded] protesters falling into the aisles as part of a mass ‘die-in,’ while others shouted at the cardinal as he began his homily, calling him a murderer.”

The group and other AIDS activists fought against the Catholic Church throughout the epidemic because they spoke out and condemned the use of

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condoms saying that it was a sin to use contraception. Activists had been working to slow the spread of AIDS by promoting the use of condoms and other forms of protection and the arguments of the Church only added to the trouble activists faced trying to prevent the spread. The very first protest done by ACT UP was staged at Wall Street where they demanded more rights and more help, such as:

...having the FDA immediately release potentially life-saving investigational drugs to everyone with AIDS or AIDS-related complex; immediate abolition of government-funded double-blind studies; availability of drugs at affordable prices; a massive public education to stop the spread of AIDS; policy to prohibit discrimination in AIDS treatment, insurance, employment, and housing; and establishment of a coordinated, comprehensive, and compassionate national policy on AIDS.

ACT UP also organized other large scale protests like when, “Over 1,000 members and supporters of the activist group ACT UP engage in a massive sit-in that shuts down FDA’s Rockville, MD, offices for the entire day to protest the slow pace of the federal drug-approval process for treatments for HIV/AIDS. There are 176 arrests.”\(^{22}\) This protest resulted in the FDA releasing new regulations to speed up their processes and work toward more results.

In 1992, ACT UP, WHAM!, and other AIDS activist groups held a protest outside the White House in which they took the ashes of their friends and loved ones that had died of AIDS and dumped them over the fence and onto the lawn. Many there called Bush, Quayle, Reagan—and others that have been involved in the administrations during the epidemic—war criminals, calling for them to be put in jail, and accusing them of committing genocide.\(^ {23}\) They


used chants such as, “History will recall, Reagan and Bush did nothing at all” and “150,000 dead, how many more?” to make the point of the protest clear and target those inside the White House as they marched past.\textsuperscript{24} The protestors climbed the fences to thrown urns, boxes, and signs with photographs and names of the dead onto the lawn. Soon they were met by mounted police officers who tried to control the crowds and force the protestors away from the fences. This resulted in the chant of “shame, shame, shame” being taken up by those marching.\textsuperscript{25} After the confrontation, one protestors got a bullhorn and announced to the police officers and the crowds, “We are gathered here today, to pay our last respects to the Bush Administration.”\textsuperscript{26}

The era had other activists that fought their way with legal battles, like teenager Ryan White. White was a hemophiliac from Indiana that contracted HIV through a blood transfusion. He brought national attention to the disease when he was refused entry to his middle school after being diagnosed. He worked for the rights of those with HIV/AIDS within the education systems and against the discrimination that those like him had to face. Even with court hearings, it was not an easy battle. His mother remembers after the fact just how difficult it was:

We had the CDC on our side, and all these medical professionals and all these famous infectious disease doctors. And that we would have them in the courtroom and they would testify. But what happened was the parents group and the school board and everybody, they had doctors testifying that they wouldn’t let their kids go to school with Ryan and they wouldn’t treat Ryan if he’d been a patient of theirs. They wanted to believe that somehow, someway, you’ve done something bad, or wrong or you wouldn’t have got this disease. And we definitely felt that.\textsuperscript{27}

\textsuperscript{24} \textit{Ibid.}, 5:29-5:57.


\textsuperscript{26} \textit{Ibid.}, 8:38-8:47.

\textsuperscript{27} “Jeanne White-Ginder: Transcript for “Fight to Go to School,” (accessed 17 March 2019); available from https://hab.hrsa.gov/livinghistory/voices/jeanne_transcript3.htm
Just a few weeks after his death, the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act was passed and named in his honor and greatly expanded the amount of care to those living with HIV/AIDS: “Between FY 1990 and FY 1991, HRSA spending on HIV/AIDS increased more than 13-fold, from $16.5 million for AIDS Service Demonstration Grants, to $220.6 million for the Ryan White CARE Act as a whole.”\(^\text{28}\) The passing of the bill was a win for activists and those living with AIDS as hospitals were becoming overcrowded and resources were wearing thin under budget cuts. About the debating of the bill, Senate Chaplain, Reverend Richard C. Halverson, DD, stated “rarely will the Senate be called upon to deal with an issue more complicated by prejudice, fear, and emotion, nor more presently or potentially destructive, than the issue of AIDS.”\(^\text{29}\) Soon after, other bills began to be passed:

The House bill, known as the AIDS Prevention Act of 1990, had as its centerpiece two provisions aimed specifically at getting more people tested for HIV and helping those in all stages of HIV disease get access to early intervention in hopes of slowing disease progression. One provision would have sent funds to the Centers for Disease Control and Prevention to provide State grants for HIV counseling, testing, and treatment. The other was aimed specifically at giving states the option of providing Medicaid to people with HIV.\(^\text{30}\)

The legislation that was passed was the beginning of the government at last getting involved and working with the activists of the era to slow the devastation of the disease.


The epidemic also saw many other forms of effective activism, like the AIDS Memorial Quilt. The first panel was created in February by Cleve Jones in memory of Marvin Feldman and was designed to be 3 feet by 6 feet or the size of a traditional grave plot. By October, the number of panels reached 1,920 and was displayed for the first time at the Washington Mall. Today, there are more than 48,000 panels and the quilt weighs 54 tons. This particular form of activism was effective due to its symbolic nature. The larger it got, the easier it was for homophobes, government officials, and others in denial of the enormity of the situation to understand just what this epidemic was doing to the population.

By the end of 1988, nearly 62,000 people in the U.S. had died of AIDS or AIDS-related illnesses. Among those, there were many people that are seen as highly influential individuals to the movement and to the era in general. Joseph Beam, best known for his work on the editing of *In the Life* which was a collection of writings that was done by gay black men to show the impact of HIV and AIDS on their community. Broadcast journalist Max Robinson, the first black news anchor in the United States and a founder of the National Association of Black Journalists, also died of AIDS, as did openly gay and Black entertainer, Sylvester.

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31 The NAMES Project Foundation, “About the AIDS Memorial Quilt,” (Atlanta, GA: 2019, accessed 13 January 2019); available from https://www.aidsquilt.org/about/the-aids-memorial-quilt


Throughout most of the epidemic, most of the attention was on gay and bi men, and often just those that were white. There were some ACT UP protests to raise awareness for women and people of color that were infected with HIV/AIDS. In 1993, Congress enacted the National Institutes of Health Revitalization Act. This act gave the Office of AIDS Research control and oversight for all of NIH AIDS research and required that NIH as well as other organizations that worked on AIDS research to expand their involvement of women and minorities within their research. This act was a win for ACT UP because one of their problems with the NIH was their exclusion of women and people of color. The act saw a new start for treatment and research to be done on people that were not cis-gender, white men. A few months later another study was funded that focused on women with HIV/AIDS, called the Women’s Interagency HIV Study. Later, the exclusion in NIH was targeted again: “The U.S. Department of Health and Human Services (HHS) issues guidelines requiring applicants for grants from the National Institutes of Health (NIH) to address "the appropriate inclusion of women and minorities in clinical research." In 1995 there was a 63% increase in the amount of diagnosed women with HIV/AIDS since 1991.

By October 1995, there have been 500,000 reported cases of HIV/AIDS in America and 320,000 deaths. But in 1996, there was a decline in the amount of new HIV/AIDS cases, the first time there was a decline in the number since the beginning of the epidemic in 1981. The

34 “A Timeline of HIV/AIDS,” June 1993


36 amFAR, 1995.

same year, the AIDS Memorial Quilt was shown in full at the Washington Mall for the last time. This was the year that marked what is seen as the official end of the epidemic. While there are still new cases each year afterward and thousands of deaths still, there is a steady decline due to education, legislation, and treatment. In the midst of the epidemic, AIDS became the leading cause of death for those aged 25-44.\textsuperscript{38} At the end of 1996, there were 581,400 cases of HIV/AIDS and 362,000 deaths.

The epidemic was a debilitating period for the entire county with the majority of cases focused in the LGBT community, especially African American and Latinx people within the community. The AIDS epidemic in the United States reveals what will happen if the oppressed become angry enough that they take the situation into their own hands and change their destiny. The LGBT+ community in the 1980s was present but was not accepted by all of society and so the community thrived underground in large cities like New York, San Francisco, Los Angeles, and Miami. When AIDS broke out and was found primarily among young, gay men, the public panicked, resulting in the community having to make a decision: go deeper underground and protect themselves as best they could, or use the crisis as a point to push off from and begin to get more rights and recognition. The epidemic did not result in LGBT people getting all their rights, that is not even true for modern day, but they had shown what a powerful force they were when united. The work of activists like Spencer Cox, Larry Kramer, Mark Harrington, Ann Northrop, and Iris Long was what saw the decrease in deaths from AIDS and it was their perseverance and courage that held the government and other institutions accountable. The epidemic revealed the corruption and hate within society during the late 1900s, from negligent

government officials, discrimination in science, the effects of media on stigma and the public as a whole, and the mass panic that can come from the unknown. It was the activism during the epidemic that brought an end to the crisis. Without the strong and unapologetic force that they held in the public eye, the bills that were passed that helped the sick and the dying would not have been passed. The activists were not afraid of looking bad to the public because they already knew they were hated whether it was because they were gay, black, drug users, having sex outside of marriage, or any other reason hurled back into the faces of those that were dying. They used their reputations to their advantage and made it into a weapon, carving themselves a space in society, unafraid to scream the controversial truth. It was the panic and the force of thousands of angry protestors and scared citizens taking the matter into their own hands and working to find drugs that would work and in the meantime spread education and provide support that allowed the AIDS epidemic to come to an end.
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