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Resistance, Protests, and Movements

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The ACT UP Movement Research Paper: Silence = Death

Introduction

July 3, 1981. The front page of *The New York Times* reads, “Rare cancer seen in 41 homosexuals.” This would be the beginning of one of the most devastating epidemics in world history: HIV/AIDS. Human immunodeficiency virus (or HIV) attacks the cells within a person’s immune system and destroys the ability to fight off minimal disease (“HIV: The Basics” 1). If not treated efficiently, HIV can develop into Acquired Immune Deficiency Syndrome (AIDS). This was the case for much of the 1980s and 1990s. After the first cases of HIV/AIDS were discovered in the United States in 1981, panic ensued. The lack of education when it came to the disease led to over 700,000 HIV/AIDS related deaths to date. Since the first case was discovered, living conditions for HIV positive people have greatly improved. The development of PrEP and adhering to strict anti-retroviral therapy (ART) can make one “undetectable” and not able to spread HIV to others. Though living conditions have greatly improved today, the same cannot be said for the conditions in the 1980s and 1990s. HIV/AIDS is especially prevalent in gay men because it is spread through bodily fluids such as blood and semen. HIV is easier to spread through anal sex and gay men, at the time, were less likely to use protection. Today, HIV is still the most prevalent among gay men, specifically black and latino men (CDC). The ACT UP movement of the 1980s and 90s proved to be instrumental in creating real change for the LGBTQ+ community during one of the most taxing times in history. This research paper will

discuss the trials and tribulations the movement faced while also identifying tactics and strategies used by the organization.

Overview of the Movement

For the first few years of the epidemic, a lack of education and a general dismissive attitude resulted in confusion and suffering within the LGBTQ+ community, which led to the creation of the AIDS Coalition to Unleash Power or ACT UP; a radical activist group that targeted government officials and pleaded for the general public to pay attention. Without the creation of the ACT UP movement, it is hard to imagine how much more devastating HIV/AIDS would have been. David France of *The New York Times* describes the critical environment that led the ACT UP movement to fruition, “It’s also hard to remember that on the night ACT UP was founded, in 1987 — six years into the epidemic and 15,000 American deaths later — there was still not a single pill on the market to prescribe” (France). Ronald Regan had not publicly addressed the epidemic until 1985, 4 years into the crisis. The lack of attention was *very real* and was rooted in homophobia. Before the establishment of ACT UP, LGBTQ+ members provided “comfort to the sick: buddies to take you to hospital, lawyers to help you write your will” (Aizenman). Mike Petrilis, a survivor of the AIDS epidemic, and an American activist, exploded on these organizers saying, ““I don't want to write my will! I want a cure!”” (Aizenman). It wasn’t enough to have support for the dying; gay men wanted to *stop* dying. ACT UP is a major reason as to why conditions greatly improved for not only gay men, but every person living with HIV/AIDS today.

It’s important to understand why ACT UP was formed to begin with. The Gay Men's Health Crisis (GMHC) was founded in 1982. This was one of the earliest AIDS activism groups created. Because of the newness and unfamiliarity with the disease, GMHC struggled to get a

political hold on the crisis. As previously mentioned, there was little to no government intervention when it came to the AIDS crisis. After rumors of a “gay plague” spread around large cities such as Los Angeles and New York City, fear and disgust erupted in the straight community. It wasn’t until 1982 that Ronald Reagan’s press secretary even acknowledged the crisis, “When Kinsolving mentioned the disease was known as the ‘gay plague,’ the press pool erupted in laughter” (Montalvo). In 1982, Congress held its first hearing on the crisis, and only one reporter showed up and it made no national news coverage. In 1983, Reagan cut funding to the CDC when over 1,000 Americans were dying with the disease; leaving organizers frustrated. On September 17, 1985, Reagan addressed AIDS publicly for the first time calling it a “top priority” and allocating over \$150 million to AIDS research. Rock Hudson, a famous actor, died from AIDS in 1985, which launched the disease into the public eye.

Founded in New York City in March of 1987, the ACT UP movement would go on to become one of the most influential and radical advocacy groups of the 20th century. Whether it was die-ins or kiss-ins, ACT UP made their presence known. ACT UP was originally founded to urge the government to find a cure for HIV/AIDS through “inappropriate” demonstrations. One of the most iconic and persuasive tactics used by ACT UP were die-ins. The earliest use of the term “die-ins” came in 1970 after Earth Day protests in Boston. Since then, die-ins have been used to protest war, pollution, police brutality, etc. In a rhetorical sense, the use of “die-ins” is extremely beneficial. Humans have a hard time confronting death. In an iconic set of images from October 1988, ACT UP demonstrators laid outside of the FDA headquarters in Rockland, Maryland demanding the release of an experimental HIV/AIDS medication. Their signs read, “Never Had a Chance,” “Killed by the System,” and “I Died for the Sins of the FDA.” Less than a year later, the FDA approved a new drug and expanded access to others living with the disease.

Other tactics used by the ACT UP movement include letter/postcard campaigns, teach-ins, invading offices and distributing fact sheets, picketing, phone calls, and “zapping.” Zapping was a huge tactic used by the group through phone, fax, or even local newscasts. The ACT UP Historical Archive gives an example,

“One group wanted to pressure a local employer who was refusing to hire people with HIV. Members of the group had already spoken to company officials who refused to meet with them and were unresponsive to their demands. They decided to use a phone zap-to make as many phone calls as possible to the company's general number for as many days as possible and to keep whoever answered on the phone for as long as possible. Their goal was to interfere with the company's usual business” (ACT UP NY Archive).

ACT UP used tactics that would force people to listen. By interrupting newscasts or calling companies, they were reaching a broader audience than just the LGBTQ+ community and bringing awareness to a disease that had been around for over 5 years with little to no government intervention. Another iconic protest took place in 1989 in New York City and involved sneaking into the New York Stock Exchange. Journalist David Handleman describes the scene,

“It was September 14th, 1989; more Americans had already died of AIDS-related causes than the 58,000 that had died in Vietnam. And, sneaking into the New York Stock Exchange, wearing suits and fake trader ID badges, carrying chains, handcuffs and foghorns, Peter Staley and six colleagues from ACT UP — the AIDS Coalition to Unleash Power — were fighting a war too” (Handleman).

ACT UP was considered a militant group because of “radical” tactics used. The question now becomes: are the actions radical or are they well thought out? Creating monetary disruptions is the *most* persuasive form of activism; it makes people pay attention.

When discussing the ACT UP movement, it is difficult to forget about its co-founder: Larry Kramer. The *Making Gay History* podcast elaborates on Kramer’s legacy, “In 1982 Larry co-founded the Gay Men’s Health Crisis, now known as GMHC. Five years later he co-founded ACT UP, the AIDS Coalition to Unleash Power” (Marcus). Kramer speaks in an interview in 1989 about his experience growing up as a gay man and founding the ACT UP movement, “much too late” (Kramer). Larry Kramer was known for his big personality and temperament, and was the face of the movement. He was a playwright in New York City when the AIDS crisis began, and also co-founded the GMHC in 1982. Though Kramer is credited for the creation of ACT UP, many people were involved in organizing. In 1987, artists began to spray paint “silence=death” onto walls and scaffolding in lower Manhattan. ACT UP had one simple mission: acquiring life saving drugs from the FDA. Other prominent figures in the ACT UP movement include Eric Sawyer: a founding member that worked in the housing crisis and now works in The UN addressing AIDS issues, Mazine Wolfe: a leftist organizer from the 1960s that taught new members the ropes of activism, and Tim Bailey who joined in 1988 and was a crucial member until his death in 1993 from AIDS. There was a diverse array of members with the ACT UP movement which shows how AIDS just about affected everyone in one way or another. Robert Vazquez-Pacheco, a member of ACT UP who witnessed the death of his boyfriend in 1986 describes the AIDS epidemic as, “[Losing] villages of gay men. It’s like what happened in Rwanda or places where people just disappear” (The Men and Women who Started Act Up).

This frustration was the main reason ACT UP was formed and still has over 70 chapters around the world.

A major success of ACT UP included being able to lower FDA drug restrictions so everyone who needed them could receive care. Filter Magazine mentions that,

“ACT UP won a four-year campaign to get the CDC to change the definition of AIDS to include symptoms that affected only women. And this change not only got women benefits, but it allowed women to get into experimental drug trials” (Szalavitz).

A large part of ACT UP was attempting to break the stigma surrounding the AIDS epidemic and homosexuals as a whole. By staging die-ins and kiss-ins, activists were able to humanize themselves and connect to others through pathos and other types of rhetorical strategies. It's also important to note that though the ACT UP movement was mainly made up of gay men, they advocated for visibility within the straight community as well. While the ACT UP movement was monumental to the development of AIDS research, it's also important to recognize the lack of diversity within the movement. Most of the main organizers discussed previously are all white and mainly men.

The ACT UP movement was one of the most influential and important movements in the late 20th century. The HIV/AIDS epidemic ravaged throughout the world, and mainly affected gay men, and as a historical movement, it is worthy of study. The hundreds of oral histories archived, the rhetorical nature of die-ins and kiss-ins, and the radical nature of the movement as a whole aided in the fight against HIV/AIDS while also slowly removing the stigma surrounding people in the LGBTQ+ community.

Major Takeaways

My major takeaway from this research paper is basically how little I knew about it in the first place. Being part of the LGBTQ+ community myself, I never looked into the movements that played a part in my privileged position today. There was an intense sense of urgency within this movement because of the impending AIDS epidemic spreading and becoming worse. I learned how effective the tactics used were in implementing healthcare for people suffering from HIV/AIDS, and how impactful social movements can be when the purpose of them is to make others as uncomfortable as possible. Die-ins, kiss-ins, and community rallies forced the general public to pay attention to the AIDS epidemic and were otherwise ignorant.

Research Questions

- How did major players of the ACT UP movement further their activism careers after the ACT UP movement shrunk?
 - Considering that ACT UP still protests and has chapters, are they still involved within the movement? What other movements were founded by key members of ACT UP?
- What was the larger impact of the oral history project that was briefly mentioned in the research paper?
 - The oral history projects are a huge part of the ACT UP movement, but I would really like to look deeper into them since there's over 100. It would be beneficial to see the perspectives of each person involved in the movement.

Personal Reflection

The movement "ACT UP" was overall monumental to AIDS relief overall. The shocking nature of the movement itself helped the issue of HIV/AIDS to the forefront of healthcare in the

United States. I admire the willingness of the community to put themselves in danger in order to save lives; basically taking on the role of the government. The difference is, gay men, especially, had no choice but to protest and educate the general public. If I was alive during the 80s, I definitely would have been someone participating in the movement considering my politics. I do, however, believe that the ACT UP movement was very much nondiverse. The movement was made up of different sexualities, but the main leaders of the coalition were rarely people of color. It's not a secret that black gay men are still disproportionately affected by HIV/AIDS, yet the movement was necessarily the most cognizant of this issue. The diversification of the movement was even mentioned at the time, and I probably would have been a big advocate for that considering HIV/AIDS affected and still can affect anyone. Later in the movement, women and children began to be included which added some diversity, but not to the extent that it was needed. I think the tactics used by the group were very effective, smart, and intentional. Die-ins and kiss-ins were vital to the framing of the movement, whether positive or negative (all press is good press). The radical nature of this movement helped to push them into the public eye and continue spreading their messages. I also liked that ACT UP focused on educating the public about what HIV/AIDS is, how it's spread, and who can get it.

Conclusion

When looking at the AIDS epidemic, it is vital to cover the ACT UP movement. Without the development of the ACT UP movement, certain medications, health coverage, and the stigma surrounding the disease may have been completely different; HIV-positive people may have never gotten the healthcare they needed to survive. There is just no way to know. By using phone and TV zapping, die-ins, kiss-ins, pamphlets, and AIDS education, ACT UP was able to create real difference in demolishing the stigma around the LGBTQ community. Six years into the

crisis, ACT UP was created; too late if you ask the organizers of the movement. The activists within the movement were fed up with the mistreatment from government officials and high drug prices. Generations of gay men were lost between those six years, and because of the neglect from government officials, thousands of Americans died well into the 90s and 2000s. This movement was extremely important for many reasons: (1) the dismantling of the stigmas surrounding the AIDS epidemic, (2) lowering the overall amount of AIDS cases due to sex education, (3) being able to connect the general public to the emotional aspect of the epidemic. As we look back critically to Regan's neglect and ignorance, remember the organization that is responsible for causing real, tangible differences when it came to the epidemic.

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