What was the perceived effectiveness of U.S and UK government responses to the AIDS epidemic between 1981 and 1994?

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Abstract

The outbreak of AIDS in the early 1980s exposed weaknesses in government policies, healthcare systems, and societal structures as marginalized communities were disproportionately affected. This paper assesses and compares the perceived effectiveness of government responses to the AIDS epidemic between 1981 and 1994 in the United States and the United Kingdom. While both countries share strong political and cultural ties, their responses diverged significantly. We found that the delayed and politicized reaction in the U.S. led to widespread stigma and initially higher mortality rates compared to the U.K.'s more proactive approach. The research illuminates how governments balanced public health concerns with moralistic attitudes and finds that lack of urgency and inadequate funding hampered the U.S. response relative to the U.K. Ultimately, earlier involvement and sustained commitments to research, treatment access, and destigmatization campaigns could have saved lives in both countries. During the early AIDS epidemic, pervasive homophobia and discrimination hindered governmental responses in both countries despite the UK's more preventative approach. AIDS activists in the U.S., such as ACT UP, were instrumental in pressuring the government to increase research funding, speed up drug approvals, and expand access to treatment. Pressure from these groups eventually prompted policy changes, but contrasts in healthcare systems affected medical responses. The media played a fundamental role in shaping the narrative around AIDS in both countries, but collaboration in the UK drove more prevention. This paper exposes government short comings by examining how AIDS victims felt the effectiveness of the government's response.

Introduction

In 1981, the CDC reported "5 young men, all active homosexuals, were treated for [...] pneumonia” (CDC, 1981), marking the onset of a health crisis that would claim millions of lives worldwide. The CDC took over a year to officially name and define the disease, another to identify the routes of transmission, and another for the U.S government to say the word ‘AIDS”. Acquired Immunodeficiency Syndrome (AIDS), the most advanced stage of the Human Immunodeficiency Virus (HIV), weakens the immune system leaving individuals vulnerable to other illnesses.

The epidemic exposed the shortcomings of government policies, healthcare systems and wider societal structures. From the discovery of AIDS in 1981 to the first U.S government funding in 1983, more than 1,600 cases were reported, and more than 600 lives were lost. By 1994, AIDS had become the leading cause of death for all Americans between the ages of 25 and 44 (CDC, 1993). AIDS disproportionally affected marginalized communities, notably homosexuals and drug users, leading to politicized and discriminatory responses. The stigma also hindered drug development causing many to die seemingly avoidable deaths. While AIDS was serving as a death sentence worldwide, governments reacted with varying degrees of urgency and effectiveness.

To assess the effectiveness of government policies, this paper will examine their impact on individuals themselves. Furthermore, to better understand the differences in government approaches and policies, we will compare the US and the UK, two countries with strong political and cultural ties that exhibited contrasting responses. We will therefore investigate the perceived effectiveness of government responses to the AIDS epidemic between 1981 and 1994 in the U.S using the UK as a counterexample.

Methodology

Our research unfolded in two phases over the course of six weeks: first, the examination of key government policies and second, an investigation of activist responses to understand perceived effectiveness. We opted for a qualitative approach to the research question as quantifying the effectiveness of government policy limits the nuances of personal and social factors that shaped individuals’ experiences.

To research government policy, the Gale Archives of Sexuality and Gender, specifically the LGBTQ History and Culture since 1940 collection, were used alongside archives from the London School of Topical Hygiene and Medicine, the National Library of Medicine HIV/AIDS Collection and the National Institute of Allergy and Infectious Diseases HIV/AIDS Collection. The archives provided original policy documents, correspondences, and reports allowing for a comprehensive understanding of policies, their context and rationale. In addition, personal interviews were conducted with regional doctors and historians. The interviews, unlike the archives, allowed for follow-up questions, clarification, and nuance.

Activists, often from the group 'in trouble', draw on personal experiences to plan their actions which is insightful when investigating the felt effectiveness of government response. We looked at interviews from the AIDS Coalition to Unleash Power’s (ACT-UP) Oral History project. The interviews explained the reasoning behind actions, and thus we could identify where and how government policies were falling short in supporting AIDS victims.

By combining these two approaches, top-down focusing on government, and bottom-up focusing on activism, we explored the relationship between policy and lived experience. Each week of research fuelled further questions that led to us identifying three main analytical themes: major government responses, healthcare systems and the role of the media. These themes allowed us to investigate and compare the U.S and UK responses to the HIV/AIDS epidemic in its early and growth stages.

Major Government Responses

Government responses to the HIV/AIDS epidemic evolved significantly in the 80s and 90s. In the U.S, stigmatization and the view of the disease as divine punishment for homosexuals hindered effective policy and resource allocation. This led to a lack of serious responses and insufficient investment in research and prevention during the Reagan and Bush administrations. Consequently, the suffering of millions of HIV/AIDS patients in the U.S. persisted for the first decade of the epidemic. In contrast, the initial years of the UK response followed a similar pattern but transitioned into a more national and compassionate approach, focusing on helping rather than impeding the affected minority groups.

The discovery of HIV/AIDS in 1981 did not prompt an expected immediate national response. The Reagan administration remained largely silent during the four initial years of the crisis, despite protests and pleas for action. ACT UP took initiative, distributing information, condoms, and hosting public education sessions. It wasn't until 1983 that congress allocated $12 million for U.S. Health and Human Services Agencies, a move met with significant resistance from the Republican Party (Services, 2023).The response in the UK mirrored this initial lack of government involvement, with the NHS and gay self-help groups like the Terrence Higgins Trust handling treatment and response, emphasizing prophylaxis. However, the discovery of HIV transmission via blood products and needle exchange in 1983 triggered greater media and societal attention, slightly shifting the disease's stigma away from gay men. The years 1986-88 were pivotal years for governmental responses to the AIDS epidemic. In 1986, the U.S. Health Resources and Services Administration began its AIDS Service Demonstration Grants Program, allocating $15.3 million to the hardest hit cities of New York, San Francisco, Los Angeles and Miami for prevention efforts (Services, 2023). That same year, the United Kingdom held its first Parliamentary debate on AIDS, leading to a £20 million grant for media campaigns and free condom distribution (Berridge, 1996). In 1987 President Reagan made his first public speech on AIDS and in 1988 signed both the AIDS Research and Information Act and the Health Omnibus Programs Extension Act which authorised almost $700 million for AIDS public health care, research, and education (Institute, 1988). However, this major win for AIDS patients was hampered by the Helms amendment which prohibited federal funding for HIV/AIDS educational materials that promoted or encouraged homosexual activities. This amendment was a testament to the homophobic and conservative nature of the Reagan administration and the view of AIDS as a ‘dirty’ disease. The administration also banned federal funds for needle exchange programs, leading activists to establish illegal exchanges and eventually win in court under 'necessity of defence' (ACT UP Oral History Project, 2003 - 2010). In contrast, the U.K. continued with a national consensus for a liberal preventative approach by authorising pilot needle exchange programs in 1987 and permanent national funding in 1988 whilst the U.S adopted HIV as an excludable condition for entering travellers, a considerably more punitive approach (Acheson, 1988).

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By 1989, Reagan and Thatcher had been replaced by Bush and Major. The AIDS crisis had increased exponentially and the 10-year incubation period for HIV meant that many more reached the AIDS stage of the disease, the final and most lethal point. Consequently, the Bush administration signed the Americans with Disabilities Act in 1990, prohibiting discrimination against individuals with disabilities such as AIDS (Brady, 1992). Federal spending on AIDS in the US exceeded $4 billion by 1992, though these acts were pushed through by Congress rather than by Bush, due to the air of Republican conservatism during his administration (Brady, 1992). By 1990, £150 million was allocated for NHS AIDS treatments, with social services receiving £7 million in grants (Mellor, 1989). The UK's approach, marked by clearer government involvement and a focus on prevention rather than prohibition, was more effective in addressing the epidemic compared to the U.S under Bush's administration.

Healthcare

Access to healthcare while combating an epidemic is vital, yet the stigma surrounding AIDS hindered provision. Already marginalized communities, namely homosexuals and drug-users, were further discriminated against as the disease was seen as a consequence of their ‘immoral’ actions (ACT UP Oral History Project, 2003 - 2010). Based on the nature of the system, discriminatory attitudes emerged differently. The UK’s National Health Service (NHS) provided universal coverage based on medical needs and mainly funded through taxes. In contrast, the U.S system combined private facilities, government programs (Medicare and Medicaid), private insurance, and out of pocket-payments, lacking universal coverage.

Drug Developments

AIDS, a rapidly progressing and fatal disease with limited knowledge, posed a challenge for drug development. Moreover, the associated stigma discouraged pharmaceutical companies from investing in potential treatments. Regulatory hurdles, complex clinical trials, and the high cost of drug development further impeded progress. The first treatment against AIDS, azidothymidine (AZT), was approved in 1987, seven years after the identification of AIDS and 20,436 U.S deaths (World Health Organization, 2023). However, AZT proved to be toxic, costly, and often ineffective. FDA approval for other treatments was challenging, as clinical trials required patients to stop all medications. Until 1993, women and drug users were excluded from the CDC’s definition, delaying research whilst the first federally funded study on women took place twelve years after the identification of AIDS. With the profit-driven nature of private healthcare, ACT UP called out big pharmaceutical companies for waiting to buy out developers’ drugs, rather than pursue research (ACT UP Oral History Project, 2003 - 2010). The lacklustre development of treatments was marked by silence and limited government initiative and support.

In the UK, government-funded research drove progress. Research progressed in line with government policy and so in the years 1981-87 development was limited. The Medical research Council (MRC) did allocate funds to HIV/AIDS research in line with US events and CDC efforts. However, major drug developments occurred in 1987 with the release of AZT and a collaboration between the MRC and INSERM to test its effectiveness on domestic populations (Mellor, 1989). From 1989 to the early 1990s, the MRC led UK research, receiving substantial government funding, resulting in over 300 AIDS research projects (Acheson, 1990). However, it took another 8 years to discover and approve antiretroviral treatments, which impeded HIV replication, preventing progression to AIDS. UK drug development was a collaboration effort that joined international developments with domestic policy.

Access to treatments

Once treatments became available, accessibility and efficacy remained uncertain. Before medication was available to the public, it would go through clinical trials, which were often discriminatory. ACT UP argued that patients deserved access to experimental drugs and won dramatic regulatory changes through protesting slogans such as: ‘Hey FDA, how many people have you killed today’ (ACT UP Oral History Project, 2003 - 2010). A year later in 1989, the FDA released the ‘parallel track’, allowing terminal patients to take non approved drugs (Hutt, 1990). With, AZT costing over $10,000 per year, reduced to $6,000 following ACT UP’s 1988 Wall Street action, costs posed another obstacle (ACT UP Oral History Project, 2003 - 2010). Furthermore, high dosages, taken every four hours, maximized profits but decreased accessibility due to toxic side effects. With unaffordable emerging treatments, ACT UP smuggled small amounts of unapproved drugs from Canada and Mexico (ACT UP Oral History Project, 2003 - 2010) Interestingly, in 1988 the FDA legalized the importation of unapproved drugs for people with life-threatening illnesses, including HIV/AIDs (Grossman, 2021). ACT UP further called for congressional hearings on drug pricing and protested the pharmaceutical industry’s influence on elected officials.

The NHS and Whitehall focused on prevention rather than prohibition allowing for those who contracted HIV/AIDS to receive care in specialised wards and through their General Practitioner. Patients had immediate access to healthcare through Genito Urinary Medicine Clinics (GUMC) which offered confidential HIV-AIDS testing and guidance. Before 1987, AIDS wards offered bedside care aligned with NHS principles. After the discovery of AZT in 1987 and antiretroviral drugs in the 1995, drug treatments became part of NHS prescriptions and came at a subsidised cost. (Berridge, 2023) The main barrier to accessing treatments in the UK were the patients themselves, particularly intravenous drug users who often feared criminal persecution. To address this, the government introduced needle exchange programmes in 1986, emphasising prevention. The NHS’s nature facilitated greater treatment availability due to low out of pocket cost and the preventative consensus of the healthcare system.

Medical Institutions

Although treatments emerged and patients could access them, they still needed to go through medical institutions and professionals to receive care, a challenging task. The first U.S AIDS service provider was founded by Gay Men’s Health Crisis, a non-profit in 1982. The first dedicated U.S in-patient ward was established in San Francisco General Hospital in 1983 with an all-volunteer staff – from nurses to janitors – and only 12 beds (Cook, 2011). Four years later the American Medical Association declared that doctors have an ethical obligation to care for people with AIDS, implying that the social stigma surrounding homosexuals likely dominated over certain healthcare professional's role in care giving. Government grants to support medical institutions were infrequent; for example, in 1988, the U.S. Health Resources and Services Administration granted $4.4 million for the first paediatric AIDS service, while the 1988 Helms AIDS amendment hindered homosexual community-based AIDS education (Helms, 1988). These grants reflected the general notion of 'innocent' victims, being children and haemophiliacs, and the 'guilty', being homosexuals and drug-users.

These groups were treated differently by the medical community (ACT UP Oral History Project, 2003 - 2010) Homosexuals lacked trust in the medical institutions, fearing discrimination and viewing doctors as proxies for expensive drugs. ACT UP played a pivotal role in advocating for compassionate care and addressing mental and emotional needs. Some patients explored alternative treatments, like acupuncture and dietary changes, fostering support communities and peace of mind (ACT UP Oral History Project, 2003 - 2010). The U.S. government played a limited role in reducing the AIDS stigma, while activists and volunteers led efforts to destigmatize the disease, both through direct regulatory changes and shifts in individual attitudes towards patient-centred care.

In the UK, AIDS patients developed a more trusting relationship with medical institutions thanks to specialized wards and government initiative, decreasing the AIDS stigma. GUMCs were important institutions who provided AIDS education and lifestyle change advice, alongside confidential HIV testing and free condoms. For advanced treatments, specialized HIV-AIDS wards like the London Middlesex Hospital's unit, inaugurated by Princess Diana, were available. However, some emotional challenges emerged, as certain East-Asian staff declined serving patients due to personal beliefs (Berridge, 1996). Nonetheless, other staff members provided support, and rotating nurses and doctors ensured care across high-mortality wards. The British healthcare system's preventive approach facilitated the swift adaptation of institutions and doctors to combat the epidemic effectively.

Relationship Between the Government and the People

The government's primary duty is to provide for its people, yet the interaction between these two parties always involves intermediaries. The government is not made up of all the people, but rather elected representatives and communication flows through the media creating a distance between the two. We will consider the media as the interpretative middle ground between the government and the people, who are represented by activists. Both parties push stories to create a narrative that matches their public agenda. In both the U.S and the U.K the media played a significant role in politics, shaping the way people with AIDS were treated.

In the U.S, activists' sought media coverage to raise awareness about the epidemic the government was silent about. ACT UP conducted independent research to gather information on AIDS and government policies. They strategically planned actions in front of relevant institutions, for instance drug approval in front of the FDA, AIDS definition in front of the CDC, Bush's lack of response in front of his residence (ACT UP Chronology in Brief , 1987-2012). Protesting at the root cause made responsible parties clear, however, its success regarding the public was determined by media coverage. Garnering media attention was challenging due to prevalent homophobia at the time.

As stories gained traction, ACT UP discreetly shared findings with reporters, making them believe the story was their own idea (ACT UP Oral History Project, 2003 - 2010). ACT UP became a reliable source for compelling stories and gained more control and influence over the media. They established strong media connections, informing reports ahead of actions and promising big stories. Reporters would show up and ultimately made the action a big story by publicizing it. These narratives would influence the public's opinion on AIDS and politicians, conserved about their image and power, often responded with promises or policies. Activist used media to manipulate and put pressure on the government by targeting their public image.

The U.S government holds a legacy of silence in the beginning on the AIDS epidemic. President Reagan's administration downplayed the crisis, with his press secretary stating that there was no concern for the crisis and Reagan himself not mentioning the word 'AIDS' for four years. The Bush administration prioritized spending on the Gulf War over AIDS, overshadowing the crisis in media headlines. Activists protested that the war was at home against AIDS. While some policies and grants were implemented, they often went unnoticed as they were deemed technical and small-scale and thus didn’t grab the public’s attention in headlines. Independent organizations, including the CDC, attempted to raise public awareness through the media, launching AIDS related public service announcements in 1987 (National Institute of Health and Human Services, 2016).

In the early 1980s, UK media associated HIV/AIDS with homosexuals, fuelling homophobia and discrimination. However, in 1985, as it became clear that intravenous drug users and haemophiliacs were also at risk, media attention shifted towards protecting the nation’s blood supply rather than blaming the homosexual community. This transition led to a collaborative "wartime" era between public media and the government, with the 1987 Mass Media Campaign against AIDS (Berridge, 1996). The campaign included distributing leaflets to every UK household, "AIDS Week" on BBC and ITV news channels and emphasizing safe sex practices like condom use (Mellor, 1989). This effort extended to cinema through pre-film educational videos. Consequently, AIDS was no longer discusses as moral issue, reflecting the UK’s preventative approach that seeped into the media. However, in 1988, the introduction of Section 28 prohibited local authorities from ‘promoting homosexuality’, sparking renewed homophobia and weakening the influence of gay advocacy groups (The National Archives, 2022).

Reflection

The AIDS crisis is often associated with homophobia, evident in the U.S government's silence, slow drug development, and societal discrimination. Our research, however, revealed a hidden layer of discrimination against people of colour and women.

Lack of representation of women in discussion, research and policy making made it difficult for them to access treatments, testing and prevention methods. Furthermore, politicians wanted to protect women of childbearing ages, yet pregnant women with AIDS did not have access to effective prevention methods as they were not readily available. In 1998, AIDS was no longer the leading cause of death for all Americans aged 25-44, but it remained so for African Americans, accounting for 49% of U.S. AIDS-related deaths (CDC, 1993). Their AIDS-related mortality rate was nearly ten times higher than that of Whites and three times higher than Hispanics. Although this group was disproportionally affected by AIDS, they were not well represented in activist groups like ACT UP. ACT UP was predominantly a white male group who were suddenly stripped of their privileges fueling the anger and motivation of the group but narrowed their focus on finding a cure (ACT UP Oral History Project, 2003 - 2010). ACT UP's members brought their own prejudices from society into the group. The lack of representation in the leaders of ACT UP made it even more difficult to push ideas to the front lines.

Conclusions

During the early AIDS epidemic, pervasive homophobia and discrimination hindered governmental responses in both the U.S. and the UK. Despite the more liberal and preventative response of the Thatcher government to AIDS in the medical and policy arenas, the atmosphere of governance mirrored that of Reagan's administration: that of reluctance and dismissal. Both administrations in the early years sought to distance themselves from the growing epidemic and only enacted policy in the years 1987-89, at which point pressure from activist groups, such as ACT-UP, was too mainline to ignore. Furthermore, the major differences in healthcare provision between the two resulted in contrasting medical responses. The UK's NHS, with its established GUM clinics, provided fast and affordable healthcare, while the semi-privatized U.S. system left certain populations without adequate care, prompting criticisms of federal funding for Medicaid and Medicare. Finally, the media was an effective means of elevating the AIDS issue to the headlines for both countries, especially in the UK where collaboration led to widespread prevention.

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