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Sociocultural Impact of AIDS Understanding on Prevention Education and Treatment Accessibility

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Sociocultural Impact of AIDS Understanding on Accessibility to Vital Resources

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ABSTRACT

The first fifteen years of the AIDS Crisis (1981-1996) were characterized by an immense need by those impacted both for legitimization of diagnoses and access to treatments which targeted both the HIV virus itself and resulting opportunistic infections (OIs). However, early epidemiological trends and the social perception that AIDS was a disease of white gay men resulted in much of the initial focus to center this population and their experience of the disease. This contributed to an incomplete understanding of the natural history of the virus, a failure to identify OIs more common in women and IV drug users (IVDUs), and barriers to vital services. In addition, most clinical trials-which were the only legal avenue to experimental treatments before 1989- excluded or limited the participation of diverse populations. Among those who did have access to clinical trials, as well as many others whose lives were directly affected by the epidemic, the cycles of hope (as treatments emerged) and despair (as their ineffectiveness and toxicities were revealed) was mentally and physically taxing, and in many cases fatal due to the limits of the therapy.

METHODS

The current investigation involves archival materials related to Gay Men's Health Crisis (GMHC) available in personal archived and the NYPL Special Collections, and articles (both journalistic and medical) from the time. GMHC was the first and largest AIDS service organization, formed in 1982 to address the expanding needs of people with AIDS (PWAs). Deeply rooted in gay identity, the organization was conflicted in their responsibility to serve all PWAs. Both oral history interviews with GMHC staff and volunteers conducted and/or analyzed as part of this project and internal documents shed light on this tension. Source material was analyzed to identify the obstacles associated with access to diagnoses, treatments, and educational resources across differing risk groups of PWAs, including gay men, women, and IV drug users.

RESEARCH QUESTIONS

How did the emergence of HIV/AIDS primarily among gay white men influence the early investigation and understanding of the disease?

How did exclusionary criteria within AIDS clinical trials limit access? How did the changing treatment landscape impact the emotional toll on all PWAs?

Who was GMHC for? How did their organizational identity influence educational efforts and the clients they served?

EARLY AIDS UNDERSTANDING: "GAY CANCER"

- CDC, 1981: labels of "Gay Cancer" and "Gay Related Immune Deficiency" show the early perception of AIDS (termed in 1982) within a gay male context
- 1984: Multicenter AIDS Cohort Study begins, studying AIDS progression in nearly 5,000 gay men, 94-95% of whom are white
- 1993: Driven by lack of knowledge and pressure from activists, the CDC and the NIAID initiate the Women's Interagency HIV Study, the first of its scale
- The WIHS was much more diverse; 80% of cohort identified as Black, Latina, or Hispanic
- Women included different risk groups than gay men: about half contracted HIV through IV drug use, and about a third from heterosexual transmission
- Due to the near-decade space between these studies, however, vital data for women was not collected in the early years. This led to an underdiagnosed population who were unable to receive vital services such as Medicaid/insurance coverage and disability benefits

EMERGING TREATMENTS: A STORY OF HOPE & DESPAIR

- Until 1996, there was no long-term treatment for HIV/AIDS
- PWAs had to act as their own medical advocates and navigate treatment options
- AZT, the most popular AIDS drug, had a 2-year survival rate of only 47%
- Many PWAs were distrustful of AZT and debated its efficacy
- *PWA Coalition Newsline* writer Rob Schnick: *"people who say AZT is no good don't know science from a hole in the ground."*
- AZT was extremely expensive: $8,000 a year in 1989. It wasn't alone.
- Aerosolized Pentamidine, used to treat common OI *Pneumocystis carinii* pneumonia (PCP) was a great expense as both the medicine and a nebulizer had to be purchased, with superior nebulizers not covered by Medicaid
- By 1993, the Concorde trials more publicly exposed the limitations of AZT. AZT was highly toxic, and pentamidine wasn't without its risks, as it had the fatal potential to encourage PCP spread in other parts of the body
- GMHC client describes being *"overwhelmed by hopelessness and negative attitude [...] has had a negative reaction to AZT and pentamidine aerosol"*

CHANGING DEFINITION OF AIDS

Key:

- OI commonly experienced in gay or bisexual men
- OI commonly experienced in women
- OI commonly experienced in IVDU
- Little information found or uncommon OI

1987

A negative test ruled out an AIDS diagnosis, unless *Pneumocystis carinii* pneumonia was present or the CD4 count was less than 400/mm^3

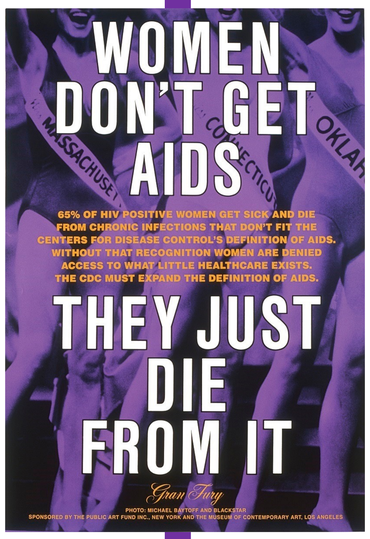
If test is inconclusive:

- Cryptosporidiosis
- Cytomegalovirus
- Kaposi's Sarcoma
- *Mycobacterium avium*
- Extrapulmonary Cryptococcosis
- *Pneumocystis carinii* pneumonia
- Toxoplasmosis
- Herpes simplex virus
- Esophageal candidiasis
- Pulmonary Candidiasis
- Brain Lymphoma
- Progressive multifocal leukoencephalopathy

With a positive test:

- Extrapulmonary TB
- Wasting Syndrome
- Salmonella septicemia
- Isoporiasis
- Histoplasmosis
- Non-Hodgkins Lymphoma
- AIDS-related dementia

In 1990, the CDC published an analysis of death certificates among women with HIV/AIDS, finding that HIV+ Black women had an incidence of mortality nine times higher than white women, and that 65% of women died without an AIDS diagnosis.



While the 1991 International AIDS Conference was taking place, the AIDS Coalition To Unleash Power (ACT UP) published this full-page ad in the New York Times.

1993

The 1993 definition was more inclusive of women as it was the first to include gynecological symptoms. As a result, the annual percent change in AIDS deaths for women increased from approximately 11.5% in 1992-93 to 30% in 1993-94. The criterion below assumed a positive HIV test and ranked symptoms, with only the most severe (category "C") allowing for an AIDS diagnosis.

New conditions of HIV+ women were included in the "B" category.

- Persistent vulvovaginal candidiasis
- Cervical dysplasia/ cervical carcinoma
- Pelvic Inflammatory Disease

AIDS Diagnosis Recommended in the presence of conditions listed in 1987, and/or:

- Cytomegalovirus Retinis
- Invasive cervical cancer
- Pulmonary TB
- Recurrent Pneumonia
- CD4 T- lymphocyte count <200 cells/uL

EXCLUSION FROM CLINICAL TRIALS, WHICH WERE THE ONLY GLIMPSE OF HOPE

- Until 1989, participating in a clinical trials was the only way to access experimental AIDS and OI therapies
- Exclusion of women and IVDUs resulted in disproportionately white and male trial participants
- The first large-scale AZT and Aerosolized Pentamidine trials were almost exclusively men
- Under FDA guidelines, from 1977-1993, women of 'child-bearing potential' could not participate in trials unless expensive fetal toxicity studies were conducted
- IVDUs were often excluded because they were seen as unreliable subjects. Also, lack of clinical trial advertising and clinics centered in white neighborhoods limited IVDU access
- At the time of approval, no AZT trials had included IVDUs, resulting in the discovery of serious adverse effects only after individuals had consumed the drug
- Even for white male PWAs, clinical trial access was limited by uncontrollable factors such as extent of AIDS progression or use of other prescription medication
- PWAs in placebo trials didn't know if they were receiving the drug, or if their AIDS was being purposely left untreated

WE SERVE EVERYONE! WHO? HOW? WHY?

Who was GMHC for?

Former employee of GMHC's Education Department James Holmes identified early responses to AIDS were centered on gay men and didn't consider other risk groups: *"It wasn't that nuanced at that particular time. This was a crisis, people were dying [...] the demographic of what the interest of GMHC was -at that time- was gay men."*

When managed growth was implemented in 1992 as a means to cap the weekly client intakes at 25, it was met with concern about how this would impact clientele demographics. In a letter, client services volunteer Matt Baney expressed *"a gay man should not be bumped for someone else because his diagnosis came later in the month."* That "someone else" implied IVDUs.

Struggles with inclusivity

Amber Hollibaugh, founder of the *Lesbian AIDS Project (LAP)* describes the difficulty in convincing GMHC of its necessity. *"There's been a struggle in GMHC to deal with women's issues,"* Hollibaugh identifies, which includes both staff and clientele. *"You can't serve women the same way you serve gay men."* Beginning in 1992, the LAP sought to serve lesbians where they were: *"in prisons, in drug rehabilitation programs, in halfway homes, in shelters…"*

As expressed in focus groups which formed as a response to GMHC's ambivalence with diversity, educational services were not as accessible to women, IVDUs and people of color. Black clients were concerned over lack of educational outreach in their neighborhoods, drug users conveyed feelings of IVDU-phobia, women with children found GMHC's event times inconvenient, and nearly every group identified lack of transportation as a barrier to GMHC's services.

CONCLUSION

The research presented here offers insight into the heightened challenges of accessing vital resources during the AIDS epidemic among marginalized PWAs, such as women and IV drug users. Lessons from the AIDS pandemic have informed much of the recent COVID-19 response and vaccine development, yet disparities affecting exposure rates and treatment access still exist today which disproportionately affect marginalized communities. In considering the history of the AIDS crisis, it's important to look forward and ask, *how can we confront future pandemics in efficient and equitable ways?*

EXPANDED DISCUSSION, CITED