

A Commentary on the 40th Anniversary of the First Official Reporting of HIV/AIDS

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Content warning: The following article includes wording that may be triggering for those of the LGBTQIA+ community. The terminology has been included to provide historical context in an effort to encourage the destigmatization of HIV/AIDS and its association with marginalized communities.

“It makes me think... What happens when a flower wilts? Does it just die away and it’s forgotten?” - Kitty Rotolo

June 5th, 2021, marks 40 years since the first five gay men in Los Angeles, California, were diagnosed with the opportunistic pathogen *Pneumocystis carinii pneumoae*, leading to the recognition of the HIV and AIDS epidemic. A month later, 41 gay men were identified with other opportunistic infections and Kaposi sarcoma. This trend sent waves of fear and uncertainty through the medical community, and in the surge of confusion, stigma, and ignorance, public health response was lacking, while some medical providers denied care to those diagnosed with what was originally coined “Gay Cancer” and then “Gay-Related Immunodeficiency Disease” or GRID. It is vital that the medical community reflects on our historical response to public health concerns, especially as they relate to marginalized communities that have been affected by the HIV/AIDS epidemic, and now the current COVID-19 pandemic.

With obstacles to medical care, the rates of very ill AIDS patients dramatically increased in the 1980s. Government funding for research related to the illness was minimal, and the gay community became wrought with deep anger and sadness as the bodies of their chosen families became innumerable.

When HIV testing later became widely available, the understanding of asymptomatic carriers provided new insight for the gay community as well as the heroic providers, researchers, and advocates caring for people living with AIDS. Battling a lack of government support and significant social stigma, researchers and drugmakers established zidovudine (AZT) as the first FDA-approved medication in the management of HIV/AIDS; however, the benefit was minimal. Significant and often intolerable adverse drug effects aside, the medication was incredibly expensive. Gay men of economic privilege were the only ones with immediate access to it, worsening the disparity between those with money and those without.

In 1997, Combivir, the first fixed dose combination antiretroviral therapy, became available for use. Since then, more than 30 drugs for HIV treatment have been developed and most are well-tolerated, including antiretrovirals that are now FDA-approved for preexposure prophylaxis (PrEP). Today, thirty-four years after AZT, despite significant advances toward the development of an HIV vaccine, HIV continues to be a significant and costly public health issue.

The CDC estimates that 1.2 million people are living with HIV in the United States currently, 38 million worldwide. While the rates of infection have globally declined in the last decade, certain communities continue to be the last to receive life-saving treatment and prevention measures. Although Black Americans represent only 12 percent of the U.S. population, they accounted for 43 percent of new HIV

diagnoses in 2018 and an estimated 42 percent of people living with HIV.¹ In April of 2021, the CDC released further emerging information about disparities in HIV management in seven U.S. cities. Forty percent of transgender women in the study were found to have a known HIV positive status. Additionally, 62 percent of Black transgender women were found to have HIV, in contrast to their white counterparts at only 17 percent.² White patients are more likely to be prescribed PrEP than Black patients, even when controlled for insurance status and having had a discussion about PrEP with a health care provider.³ Healthcare providers are professionals at the helm of providing HIV screening, prevention, and treatment. We must take seriously the responsibility to ensure equitable access to care.

The timeline and lives lost from the start of the HIV/AIDS epidemic is unsettling and the latest statistics untenable. They remind us of the ramifications of public health action that is too little, too late. For those affected by HIV, the fear and misinformation associated with the COVID-19 pandemic and the delay in critically needed services are also grim reminders, and parallels have emerged.

Like HIV, COVID-19 became linked to a subset of the population. Like gay men, Asian-Americans became targets of violence, thought of as vectors for disease. Those who test positive for COVID-19 may be looked down upon, shamed, and told, “they brought it upon themselves because they weren’t careful enough.” Masks have become the new condoms, public health politicized. Minority communities are bearing the brunt of the COVID-19 pandemic, further exemplified in analysis by the American Public Media research lab of recent CDC reports: Pacific Islander, Latinx, Indigenous and Black Americans have a COVID-19 death rate of double or more that of white Americans, who experience the lowest age-adjusted rates.⁴ There is an onus on the individual to stop the spread, to “follow the rules,” wear a mask, maintain a distance of six feet, and stay home, rather than systemic responsibility. As any student of public health can attest, human behavior is not easy to change and many precautions become unsustainable without a communal sense of responsibility among the population and their governing body.

The epidemiology and societal implications of both crises show us the dangers and devastating public health implications when a diagnosis becomes stigmatized, shameful, and subject to misinformation. On this day we mourn the 33 million lives lost worldwide due to HIV/AIDS - lives that were stolen by medicine’s inadequacies and leadership’s reluctance to act in the face of stigma and homophobia. On this day we also look to the future, where the 38 million global citizens living with HIV will have adequate access to quality medication regimens and management of their chronic condition; a future where the U.S. Department of Health and Human Services has met its goal of ending the epidemic. As healthcare providers and advocates for the public’s health, on this day we vow to never forget this history and to learn from our mistakes. We vow to never shame a patient for a diagnosis, but instead we will educate both the patient and ourselves to provide culturally competent, comprehensive, and unbiased care.



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