History of HIV/AIDS in Atlantic City Jessica Peoples Stockton University

This paper is the basis for what became the homepage for the website <u>A Mile in Their Shoes</u>, a website which displays the written ethnographies of HIV+ individuals across Atlantic City, NJ. This website was created by Dr. Laurie Greene and the Fall 2019 ANTH 2136 class at Stockton University.

#### What is HIV?

HIV is a retrovirus that hijacks cells with enzymes to make copies of RNA with DNA. This makes it harder for cells to target and enables HIV to make more viruses. Making 100 billion copies of itself every day, HIV mutates too quickly for drug development to keep up.

HIV can only be contracted through blood contact, such as having sex without contraceptives, sharing needles, or receiving a transfusion of infected blood. Although this is the case, HIV/AIDS was once the leading cause of death among Americans aged 25 to 44. Over the past four decades, scientists have made significant progress against the disease and the virus that causes it. At the peak of the epidemic, patients required thousands of dollars worth of medications and were given around three years to live. Today, someone diagnosed with HIV can expect to live approximately as long as someone without it thanks to the latest antiretroviral treatments.

## History of HIV/AIDS in Atlantic City

The history of HIV and AIDS in Atlantic City began at the peak of the AIDS epidemic in the 1990s. Initially known as GRID (Gay Related Immune Deficiency), reports of AIDS patients were on every news channel from California to New Jersey.

Community members did not initially express concern as they saw cases only in large, surrounding cities. It wasn't until individuals were officially diagnosed in Atlantic City that the community began to panic. This fear manifested into backlash and created an internalized stigma of the "gay cancer" that plagued South Jersey. Community members shunned the sick, and some refused to even say the name of an infected friend, fearing they might themselves become infected. As of 1990, the fatality rate of someone diagnosed with HIV/AIDS was 87 percent. Atlantic County currently has one of the highest rates of HIV/AIDS prevalence in New Jersey, totaling over 1,390 cases as of 2017. Within the county, the rate of HIV/AIDS prevalence is 515 per every 100,000 individuals.

#### **LGBTQIA+** in Atlantic City

Atlantic City has a strong history with the LGBTQIA+ community that dates back to the 1920s. The gay community began congregating on New York Avenue after being kicked out of eateries and bars across the city. Eventually, this community created their own inclusive bars, restaurants, and entertainment hot spots within the radius of four square blocks. The gay community thrived and reveled in their sexual and social freedom until the AIDS epidemic crept towards the east coast.

Within a few years, one-third of the gay community had died from HIV/AIDS or related illnesses, and the community they had grown together began to wither. Community members began dying so quickly that many recall attending funerals more often than they visited bars. As more community members passed, many bars and restaurants were forced to close because the entirety of their staff had become infected. The remainder of these institutions began fundraising for cremations, as religious authorities often refused to bury LGBTQIA+ individuals. As many

restaurants closed, LGBTQIA+ tourism diminished, weakening the entirety of Atlantic City. Although San Francisco, Los Angeles, and New York are known as the epicenters of the AIDS epidemic, the gay community of Atlantic City was devastated by the spread of the virus.

## Stigma and Other Effects of Disease

The stigma around HIV/AIDS is extremely prominent especially in the US, partly due to the stigma around homosexuality at the time of the epidemic. Stigmas surrounding HIV include queerness, addiction to drugs, prostitution, sexual transgression, irresponsibility, and/or pollution. Society designated stigmas can lead to various issues, such as poor self-confidence, poor coping mechanisms, and confidentiality of one's HIV/AIDS status. HIV-associated stigma also leads to more suicide-related deaths compared to deaths from physical health factors. The issue of this is confirmed by the simple fact that nearly all informants reported attempting suicide. HIV/AIDS is vastly underreported in the U.S. because of the societal response to testing and diagnosis, which increases the likelihood of individuals contracting HIV. At present, individuals have a one in 200 chance of contracting HIV.

The stigma surrounding HIV stems from the societal designation of high-risk groups. This designation has led to the notion that the HIV+ population are entirely made up of high-risk individuals, such as gay men, sex workers, or IV drug users. UNAIDS argues that HIV can be contracted by anyone, and that these individuals are simply most likely to contract HIV due to the lack of resources in marginalized groups.

HIV+ individuals also experience what is known as infectious inequality, a term used to explain the lack of medical care for sick individuals due to their extreme poverty, lack of resources, or lack of professional assistance. Professionals such as Dr. Paul Farmer, who is widely known as the father of medical anthropology, coined this term in order to acknowledge the inequities of illness and bio-medicine. Gay HIV+ individuals suffered greatly from such inequalities during the AIDS epidemic due to the harsh anti-gay attitudes of many politicians and healthcare professionals. Additionally, sex workers, low income drug users, and other less fortunate HIV+ individuals were often unable to afford what little HIV medication was available at the time. These issues continue today as healthcare institutions deprive low-income individuals of adequate facilities and treatment.

The lack of empathy in these establishments also enables structural violence to take place within social and medical institutions. Structural violence refers to a form of violence where institutions may harm individuals by preventing them from meeting their basic needs. Similarly to infectious inequalities, structural violence is caused by harming disadvantaged individuals through complications in medical care, economic hardships, and stigma-based discrimination. Discrepancies in any of these affect the individual's ability to access treatment and maintain a stable living environment. The social effects of both structural violence and infectious inequalities enable anthropologists to predict an individual's social experience with an illness as it relates to housing, employment, and social behavior.

Medical anthropology uses the study of culture and medicine to better understand factors influencing health. This field of anthropology aims to study factors such as perceptions of risk, cultural practices shaping biomedicine, use of pharmaceuticals, political ecology of infectious diseases, availability of healthcare resources, and the experience of illness. These experiences can be studied to increase the medical knowledge around HIV/AIDS, which may allow an increase in the quality of medicine and a decrease in the cost of treatment.

The study of medical anthropology is also useful in order to understand how the medical system affects those suffering from illnesses like HIV. During the epidemic, medical research on HIV (or what was then known as GRID) was limited due to a lack of funding or interest. What little research was being done at the time was halted during a disagreement between French and U.S. researchers regarding the discovery of the origin of HIV and new treatment methods. As concepts such as structural violence and infectious inequalities develop, anthropologists are able to conduct more research on the effects of disease as dictated by medical and social entities.

### What Is Being Done?

Today, in the State of New Jersey, there are over 37,000 people living with HIV. Community members began to fight against HIV/AIDS and the lack of testing, treatment, and preventative efforts being made by the U.S. government in the late 1980s. At the start of the epidemic, very little funding was being collected for AIDS efforts due to the lack of support from political leaders and the Center for Disease Control and Prevention (CDC). Additionally, research was slowed considerably due to tension over intellectual property between French and U.S. research teams. During these quarrels, gay activists rose above the stigma to advocate and fundraise for initiatives like ACT UP. ACT UP, also known as the AIDS Coalition To Unleash Power, is a political group founded out of New York working to end the AIDS epidemic.

Mortimer Spreng, President of the South Jersey AIDS Alliance, has contributed to the development of several community responses to the AIDS epidemic by hosting and performing in fundraisers benefiting gay HIV+ individuals and AIDS research. Spreng hosted A Day Without Art, an exposition designed to show how LGBTQIA+ artists have influenced society. This exhibit included blacked out magazines and newspapers with only blank space, and was reflective of what the world would look like if they lost these artists to disease.

Spreng also participated in the Miss'd America Pageant, an annual drag beauty contest that has taken place in Atlantic City since the 1990s. This contest is a spoof of the Miss America Pageant where contestants in drag compete with swimsuits, evening gowns, interviewing, and talent. This contest has raised hundreds of thousands of dollars for local LGBTQIA+ charities and initiatives, and is responsible for founding and funding the South Jersey AIDS Alliance. Other benefits in Atlantic City include Drags R Us, Drag Wars, and the Fashion Store.

It was a crucial effort to design organizations funded to aid all HIV+ individuals because of the variety of individuals affected by HIV and AIDS. In response, many HIV+ individuals turned to activism after becoming mentally and medically stable. After years of fighting, New Jersey has developed a great deal of resources available to those affected by HIV and AIDS in Atlantic

City. Some of the most notable institutions include the South Jersey AIDS Alliance (SJAA), PRIDE at AtlantiCare, the Institute for Human Development (IHD), and the John Brooks Recovery Center. These organizations offer the use of resources like Oasis and The Nest, and are funded to help HIV+ individuals rise above their illness.

# Why Step Into Their Shoes?

The AIDS epidemic of the 1980s significantly impacted the lives of the LGBTQIA+ community, sex workers, and IV-administered drug users in Atlantic City. Since the peak of the epidemic in the 1990s, those affected by AIDS have suffered from a long-lasting stigma that has affected their willingness to get tested, disclose their HIV+ status, or begin a treatment program. This project aimed to uncover the severity of stigma and other issues associated with the prevention, intervention, and treatment of HIV by conducting fieldwork in Atlantic City.

This initiative was also designed to gain a better understanding of the issues HIV+ individuals meet on a daily basis. Without grasping these issues, it is impossible for researchers and professionals to identify and meet the needs of these individuals. HIV+ informants from Atlantic City were interviewed over a month period concerning their HIV+ status and the effect it has had in all aspects of life, including lines of support, familial and romantic relationships, housing, diet, and employment. This is neither a comprehensive nor strategic sample, but rather the beginning of a collection of experiences of illness from the HIV community. This sample includes a vast array of individuals with random variation of sexuality, substance use habits, and contraction.

These interviews give HIV+ individuals the opportunity to share their story with others. Stigma surrounding a disease such as HIV can often muffle those affected by it, but this initiative aims to open discussion of HIV as it affects the mental well-being of the individual.