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The Rayford Case: Institutional Rhetoric That Changed the Origins of AIDS in the United States

Institutions in power have controlled the way societies have responded to pandemics, but arguably none more devastating than the AIDS pandemic. The AIDS pandemic was continually shaped by medical biases and social norms that influenced health care, the media, and the history of AIDS in the United States. Powerful institutions in medicine such as hospitals have used preconceived notions to pin the pandemic on marginalized groups of homosexuals. By wrongfully blaming the homosexual community for the pandemic, institutions were able to control society's reaction in the wake of the pandemic. In this essay, I will explore the historical events leading up to the AIDS pandemic that show the systemic and sexual biases that were held among American physicians. I will next transition into the facts the AIDS pandemic, showing how there were no medical link between sexuality and the AIDS pandemic, yet the medical community fed the narrative that would eventually shape into the American media. Finally, I will show the real impacts that these power institutions caused on one young man's life. By analyzing the AIDS pandemic in the context of medical institutions in power, I seek to expose the ways medical biases control societies in the wake of chaos and hardship, ultimately changing the lives of the very people they are supposed to serve and protect.

Researchers estimate the first strain of HIV emerged in present day Democratic Republic of the Congo, near Kinshasa in the early 20th century. It was believed to have transmitted to humans from chimpanzees, likely in part from the rapid colonization and urbanization of central Africa. Several strains suggest the wild sooty mangabey carried the virus across West African

populations in the 1960s, transmitted by bushmeat practices (Wall, 2013). Likely someone involved in the hunting, handling, or cooking practice was bitten or cut, resulting in blood-to-blood contact (DeNoon, 2001). The origins of this theory are still debated and scrutinized to this day. For the scope of this essay, I will focus on how exactly the virus ended up in the United States. Many theorize the virus moved through the Caribbean islands from African to countries like Haiti, the Bahamas, Barbados, and Bermuda (Crewdson, 1987). Haitians had a large outbreak during the 1970's, leading many to believe Haitians first brought the virus to the shores of south Florida. Others suggest that Haitians servants imported from Kinshasa during the 1960's and 1970's came in contact with vacationing American homosexuals, who picked up the virus in the middle of the 1970's and eventually brought it back home (Crewdson, 1987). Early on in the pandemic, the rhetoric surrounding the virus showed explicit bias towards the male homosexual community. However, Haitian men and women were equally infected with HIV, including many heterosexuals (Crewdson, 1987). The timeline of AIDS in the United States may be completely wrong – especially after considering the strange case of a teenager in Missouri.

In 1966, fifteen-year-old Robert Rayford walked into City Hospital in St. Louis, Missouri complaining of groin discomfort. Rayford's legs and genital were covered in warts and sores, with severe swelling of the testicles and pelvis. Doctors suspected Rayford had a severe case of the sexually transmitted disease chlamydia. Doctors believed he was the recipient of anal sex through, "circumstantial evidence," though they never asked Rayford if he was a homosexual or even performing a rectal examination. Dr. Marlys Hearst Witte, a physician involved with the case explained, "We knew from the very first that he wouldn't let us do a rectal examination on him" (Crewdson, 1987). Though the doctors claim Rayford was uncomfortable opening up about his sexuality, Rayford seemed fine boasting that he was, "the stud of all time," blaming his

illness on sleeping with local woman (Crewdson, 1987). “[Rayford] dated his physical disability from an instance of sexual relations with a neighborhood girl,” according to autopsy documents (Crewdson, 1987). Doctors found chlamydia on Rayford, but in an unsuspecting place: his bloodwork. “The Chlamydia, for instance, shouldn’t have been in his blood. Chlamydia should stick to the site where it enters the body,” said Dr. William Drake, the pathologist who performed Rayford’s autopsy (Crewdson, 1987). Doctors were able to treat Rayford's over the next few months, but by early the Spring of the following year Rayford’s immune system became dysfunctional. He developed a fever and died of pneumonia. Though the doctors were shocked, they had no problem diving into the tissues of a lifeless black teenager. “When he died, Marlys and I just stood there and took everything,” said Dr. Memory Elvin-Lewis, a microbiologist who studied Rayford’s samples. “Blood and lymph and tissue and you-name-it” (Crewdson, 1987). Rayford’s obscene case would develop into a much larger pandemic across the United States in the following years.

Dr. William Drake performed the autopsy of Rayford and found purplish lesions on Rayford’s left thigh, and several other growths inside the soft tissue of his body (Crewdson, 1987). Dr. Drake concluded the lesions were a malignant tumor called Kaposi’s sarcoma. Kaposi's sarcoma was a severely rare type of cancer that was affected by elderly Mediterranean or Ashkenazi Jewish ancestry, not a black teenager (Crewdson, 1987). “We knew that he had genital edema and severe proctitis, which is an unusual problem in a 14-year-old boy-the stigmata, almost, of homosexuality. At autopsy he had Kaposi’s sarcoma of the rectum and anus, which is an unusual place for Kaposi’s sarcoma to be” (Crewdson, 1987). Rayford’s tissues were frozen and tested five years later. “Antibodies were found in his tissue for Herpes simplex, Cytomegalovirus, and Epstein-Barr disease, three viruses that, along with bacterial Chlamydia,

are common among homosexual men, especially those with AIDS” (Crewdson, 1987). In 1984, there was no definitive test for HIV and the virus was still emerging throughout the United States. Dr. Witte sat on Rayford samples for another two years until HIV antibody tests became available, known as the Western Blot test (Crewdson, 1987). The Western Blot test is an antibody detection test where the viral proteins are separated and immobilized. The serum antibodies are bound to HIV-specific proteins. The bound proteins are run through an agarose gel in the electrophoresis process. The bound HIV proteins are counted to determine the test is positive or negative. It’s important to note the Western Blot test is an extremely sensitive test, and there are no universal criteria for interpreting the test (Selvage, 2011). The Red Cross counts a positive Western Blot test with three HIV proteins. The Pentagon requires two for a positive when testing military personnel. With Rayford's samples, all nine detectable HIV proteins were detected (Crewdson, 1987). Typically, an enzyme-linked immunosorbent assay (ELISA) and a Western Blot test are both used to confirm an HIV case. Therefore, a subsequent ELISA test was performed and identified HIV antigens in Rayford’s tissue sample, but not in the serum (Garry et al, 1988). Serum is the fluid and solute component of blood that does not play a role in clotting, or otherwise known as plasma (Medical Dictionary by Farlex, 2021). The ELISA test dilutes serum and applies it to a plate of HIV antigens. HIV antibodies present in the serum bind to the HIV antigens, and the plate is washed to remove unwanted serum. A subsequent antibody test is performed and followed by a second wash. An applied substrate changes the color of the sample, and each enzyme is counted (Goyal, 2004, p. 145). Like the Western Blot test, the ELISA test is both sensitive and requires counting to an undefined threshold. Rayford's samples passed both the Western Blot and ELISA test, which constitutes as a positive for the AIDS virus (Crewdson, 1987).

The post mortem testing of Rayford's samples show that he is one of the first individuals in the United States to die from AIDS. However, the testing and handling of his tissues may compromise the scientific integrity of the testing – especially after the samples were collected, stored, and transported after so many years. Steve Alexander, the director of immunology for the firm that manufactures the Western Blot test said, “The only alternative [HIV negative result] would be if someone contaminated the sample,’ he said. But he added that in cases of contamination it was unlikely that antibodies to all nine viral proteins would be detected” (Crewdson, 1987). Alexander says that fifteen-year-old preserved samples have been found to have HIV. Regardless of the preservation methods, the testing itself is arbitrarily counted. Aryn Martin's, “Can't Any Body Count?” explores the epistemic dangers of counting in analyzing the history of human chromosomes, “Counting requires constant attendance to and definition of object identity, and decisions about ‘what counts’ as a relevant object are products of skill, experience and immersion in a relevant community” (Martin, 943). Both the Western Blot and ELISA test, the early HIV tests were discretionary to the technician performing the test. Like Alexander stated, the only possibility that Rayford's tissues were negative for HIV were contamination. But if Rayford did in fact have one of the first known cases of AIDS in the United States, then how did he first get infected?

The power dynamic that existed between the physicians and Rayford complicated the treatment he received and the science that followed. Though the AIDS pandemic was in its infancy, the doctors unjustifiably focused on his potential homosexuality. The doctors themselves talked openly about the stigma after Rayford's death, “So if you're asking me, do I think this boy lived in an environment or engaged in practices that one would now associate with transmission of AIDS, I would say I think that was rather likely. He could have been a male

prostitute. He certainly lived in the environment where that was possible” (Crewdson, 1987). Looking back at the doctor’s notes, there was nothing to suggest that he was a homosexual besides their comments regarding anal sex. However, no rectal examination was performed and no notes justify why they looked there in the first place, “We knew that he had genital edema and severe proctitis, which is an unusual problem in a 14-year-old boy-the stigmata, almost, of homosexuality” (Crewdson, 1987). The doctors openly bring up the stigma related to homosexuality, suggesting the dynamic between them was not appropriate for a doctor patient relationship. The relationship between the doctor and Rayford was also conflicted by race, "He was the typical 15-year old who is not going to talk to adults, especially when I’m white and he’s black," said Dr. Memory Elvin-Lewis (Crewdson, 1987). The unnecessary sexual and racial barriers between Rayford and his doctors were a result of a more systemic problem regarding medical institutions during their time. Years prior, homosexuality was classified as a mental disorder by the Diagnostic and Statistical Manual of Mental Disorders (Drescher 2015). Homosexuality held an unjustified bias in the medical community and prevented people like Rayford from receiving the care he deserved, “He was not a communicative individual. He knew the minute I walked into the room that I wanted something more from him—more blood, more lymph fluid, more something” (Crewdson, 1987). Ultimately, the doctor’s intimation comprised the trust Rayford had in disclosing his sexual past.

Many other possibilities should have been explored resulting Rayford’s infection of the virus. Rayford said he had never traveled outside of the Midwest, let alone the United States. At this time period, the AIDS virus was believed to exist in only African and Caribbean countries. Rayford having AIDS would mean that AIDS was present in North America prior to Rayford experiencing symptoms in 1966. This fact alone would completely change the origins of AIDS in

the United States. Some theorize St. Louis's international airport as a possible way AIDS initially spread to Missouri, likely from an African or Caribbean country. However, the theory still doesn't explain how Rayford became affected by AIDS. Rayford also said he had never received a blood transfusion. The only way for Rayford to have the virus was through sexual contact. Doctors postulated Rayford was a child prostitute, but never seriously considered sexually assaulted. This was a massive oversight within the doctors in this case, who effectively compromised Rayford's care based off their rhetorical biases and preconceived notions. Rayford's last tissue samples were destroyed in a New Orleans lab from Hurricane Katrina, ending any possibility of testing his samples in the future (Crewdson, 1987). However, arguably the stigmatization of sexuality influenced the science of the case more than the scientific tests themselves. Rayford's mixed responses regarding his sexual past offer the most insight, as well as the doctor's report following his rectal cavity. Regardless, there was a racial and sexualized barrier that existed between the patient and the doctors that created a ripple effect in the medical and scientific community in the following decades.

While there is little information to suggest the doctors were inherently biased within their analysis, their oversight shows a more systemic issue regarding sexuality in medicine in the United States. A close look regarding their statements after his death show they knew the relationship was stigmatized. Doctors hold a wealth of power in the United States based off their education, prestige, and care. I argue the stigma that AIDS was a "gay plague" was spread by the media, but created by the systemic biases that existed in the medical community during their education (Herek & Capitanio, 1999). The convoluted dialogue between Rayford and the Missouri doctors created a ripple effect throughout the reporting media, press, and news outlets. The public's speculation about AIDS consisted mostly with homosexuals, sex workers, children,

and those with connections to Africa. The first journalist to cover the pandemic was Lawrence Mass, a journalist for the *New York Native*. Mass wrote about gay men being treated for strange pneumonia. As the number of cases continued to build, news headlines ran like, "Alert over 'gay plague'" and "Gay plague' may lead to blood ban on homosexuals" (Kohler, 2020). Doctors treating patients promoted the idea of AIDS originating in homosexual communities was incited by homophobia, little to no information about the virus, and hatred towards the gay community and homosexual men (Kohler, 2020).

In an effort to analyze powerful medical institutions and the role they played in the AIDS pandemic, I will use a body of work by Michel Foucault. Foucault worked to extend the definitions of power to include the institutions that shape and influence society. Foucault argued society operates in a series of constant power struggles from unequal parts, usually from unequal parts of knowledge. Foucauldian views on power use truth as medium to control others. More specifically, truth in any form whether be scientific, medical, or journalistic creates an inequality between groups of people. Truth is therefore weaponized to promote power, serving as an inequality to those in power and those subjected to power. Foucault analyzed sexuality and the methods used to suppress personal freedoms, especially within the context of the institutions. The medical communities' jadedness regarding sexuality influenced the rhetoric doctors had with patients, and the level of comfort patients have in discussing these topics. The similar level of awkwardness and discomfort plagued Rayford and the doctors, preventing the origins of his past from helping contributed to his illness. The unequal comprehension of medicine causes a natural imbalance of power in medicine between patient and doctor. The doctor, having authority to prescribe pharmaceuticals, surgeries, and therapies, holds a wealth of administrative power. Foucault would use the term biopower to describe pharmaceuticals and surgeries, a term used to

describe the technology of power for managing people (Foucault, 1976, p. 140). While these imbalances of power are somewhat natural and often unavoidable for doctors (education, intelligence, etc.), what isn't is the rhetorical interactions between the patient and doctor. The comments regarding the Rayford's race and sexuality was entirely propagated by the medical communities' response to these topics. Rhetorical biases would constitute as biopolitics in Foucauldian terms. Biopolitics describes the exertion of the state over the processes of life, whether it be blood banks, health care, or the press (Foucault, 1976). In the context of Rayford's case, biopower was used in the medical community to control and manage the homosexual community. Whether intentional or not, the medical community's slow acceptance of the gay community inherently affects their ability to properly diagnose and treat patients. The state, which controls large scale functions over health care, indirectly impacted the training of doctors, which resulted in microaggressions over the years. Then when a worldwide pandemic occurs, their medical efficacy is compromised on a professional level. Though little was known about the disease itself, the rhetoric adopted by doctors trickled throughout society in the following years. As doctors set a scientific precedence and standard for health care, the media reports the details of their findings. The newspapers attempted to spread information, when it was biased from the source. With sciences and especially medicine, the black and white testing is seldom the problem with patient care. It is the unfortunate sociological issues like race and sex that inherently affect the minds of those in power. There is little evidence that Rayford's doctors actually meant to cause any harm in their practice. However, it was their ignorance that is culpable with an emerging virus that ruined their efficacy to discover truth and promote adequate care.

The biopolitics between Rayford and the attending physicians captured a sad part of the AIDS pandemic. Though the AIDS pandemic largely took the public by surprise, the remnants of sexual and racial bias impacted people for decades, specifically within health care professionals. Thankfully, the medical community has acknowledged their faults with the gay community and made efforts to change. Overall, the power that institutions, governments and organizations do influence and affect our personal liberties — whether be sexual, with health care and all relating domains. However, society must allocate its attention towards the better treatment of others, extending powers to groups that seek to leverage inequality and place power back in the hands of the people — not the institutions that promise the change. After all, institutions were created by humans in an effort to control and regulate one another. The measures that its control extends is determined by our tolerance of it. Rayford's case shows the complexity of health care in the modern world, highlighting the human aspects that are often overlooked when it comes medicine. Small changes in the way we approach sexuality can have a transformative impact on the world we create for the people we love.

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