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Examining Global Epidemics and Healthcare with a Focus on Marginalized Populations: Why the Approach to HIV Needs to be Intersectional

From the first case of HIV in the 1980s to the more recent Ebola outbreak in 2014, the way that the world responds to epidemics is dictated by who the disease or virus affects the most, and the value that society gives their lives. I will be discussing how different deep-rooted, systematic prejudices connect with each other and influence how society responds to significant outbreaks of disease. Primarily through the context of the HIV epidemic, I will examine how racism and transphobia in the culture of the United States intersect with each other and affect individuals' access to healthcare. First, I will examine the tendency of the United States (and the entire Global North) to prioritize white lives over black lives. I will then discuss the role of stigma in the prevention and treatment of HIV, and how it connects to the marginalization of certain communities today. I will be focusing on how black people and transgender people in particular are often left out of the picture in both access to healthcare and in general healthcare/HIV research. Finally, I will argue that understanding the intersectionality between different marginalized identities can help shape more positive responses to the current HIV epidemic, as well as other global epidemics in the future.

Racism and Fear in Epidemics and Healthcare

The pre-existing ideals in American society that prioritize white, straight, wealthy individuals from the Global North are glaringly apparent in our responses to mass death caused by disease. We decide whom we value and whom we will prioritize for aid based on race,

ethnicity, sexuality, gender, gender, and class. Epidemics are accompanied with fear and confusion. Especially in the beginning, when it may be unknown how contagious a disease is or how it can be transmitted, there is a sense of mistrust and terror since the threat is invisible. It is convenient and reassuring to “other” those who have the disease and to want to create anything, even invisible social walls, to build some kind of barrier between one’s self and the people who are already sick. Because being homosexual or using drugs were both considered aspects of immoral, high-risk lifestyles, so mainstream culture did not feel obligated to intervene at first with HIV. It seemed to some like a form of punishment for those that participated in these lifestyles. It is much easier to dismiss a life-threatening disease when it seems removed from mainstream, middle class America, because it could be said that, after all, those people “had it coming.”

Another recent and glaring example of this tendency is the Ebola outbreak that began in West Africa in 2014, which has already resulted in over 11,000 deaths in the region. Responses from organizations like the World Health Organization (WHO) were delayed despite locals in Sierra Leone, Guinea, and Liberia reporting the outbreak as an emergency. Doctors Without Borders claimed that the slow response cost thousands of lives that could have otherwise been saved.¹ The public in the United States and Europe only became truly engaged in the epidemic when they feared that the disease would hop from the continent of Africa and affect them personally. Once again, the Western world fell back on racist fear tactics that have existed since

1. Helen Regan, “Slow International Response to Ebola Epidemic Cost Thousands of Lives: MSF,” *TIME Magazine*, May 22, 2015, <http://time.com/3753684/ebola-medecins-sans-frontiers-west-africa-world-health-organization-slow-response-cost-lives/>

colonial times, painting the entire continent of Africa as a backwards place where disease and war are normal.²

This priority given to white lives over black lives is rooted in the history of the United States, from slavery to segregation to police brutality. Racism, especially in the United States, has started to become something that many white people regard as something from the past. The rhetoric of President Donald Trump, police brutality, and mass incarceration prove that the lives of people of color, especially the lives of black people, are not given equal value in our society. The mass incarceration in the United States is a consequence of the War on Drugs movement that began in the late twentieth century. This effectively criminalizing the poor and drug users, and blaming them for their own poverty, and has historically affected people of color more than white Americans.³ As of 2010, there are over 2.2 million people in prison in the United States and a disproportionate amount of them are black people.⁴ One in three black men in the U.S. will be incarcerated at some point in his lifetime.⁵ The effects of racism keep a significant percent of the African American population living in poverty, making them less likely to have health insurance and more likely to be hospitalized for preventable conditions such as bronchitis,

2. Laura Seay and Kim Yi Dionne, "The long and ugly tradition of treating Africa as a dirty, diseased place," *The Washington Post*, August 25, 2014.

3. Dorothy Roberts, "Social and Moral Cost of Mass Incarceration in African American Communities," *Stanford Law Review*, April 2004.

4. "What's At Stake: Mass Incarceration," *ACLU*, accessed on March 7, 2017, <https://www.aclu.org/issues/mass-incarceration#current>

5. "Racial Disparities in Criminal Justice," *ACLU*, accessed on March 7, 2017, <https://www.aclu.org/issues/mass-incarceration#current>

dehydration, or type two diabetes.⁶ Because of these many different factors, black lives are not given as much value or priority in healthcare in the United States or abroad. This hierarchy has been and still is glaringly apparent in the HIV epidemic. Although significant progress has been made in terms of treatment for the virus in the past 30 years, it still affects millions of new people each year, primarily those who are a part of already marginalized communities.⁷

HIV in the United States

Some of the first known cases of HIV occurred California in 1981, affecting primarily homosexual men. There was an unusually high amount of cases in otherwise healthy homosexual men developing a rare, usually fatal disease *Pneumocystis carinii pneumonia* (PCP) and a cancer *Kaposi's Sarcoma*, and later that same year cases of *Pneumocystis carinii pneumonia* (PCP) were also being found among people who injected recreational drugs. The cause of the deficiency was believed to be caused by sexual deviance and was referred to as the Gay-Related Immune Deficiency (GRID) initially until September of 1982, when the CDC first used the term "AIDS" (Acquired Immune Deficiency Syndrome).⁸ Because the virus affected primarily homosexual men and drug users at first, responses from the public and the Reagan administration were slow and dismissive. President Reagan did not acknowledge the AIDS epidemic until 1987,

6. Joshua Collins, Tonette Rocco, and Lawrence Bryant, *Health and Wellness Concerns for Racial, Ethnic, and Sexual Minorities*, (New York: John Wiley and Sons, Incorporated, 2014), 7.

7. Richard Parker, "The Global HIV/AIDS Pandemic, Structural Inequalities, and the Politics of International Health," *American Journal of Public Health*, March 2002, 92 (3): 344

8. "History of H.I.V. and A.I.D.S. Overview," *AVERT.org*, last modified February 20, 2017, <https://www.avert.org/professionals/history-hiv-aids/overview>.

after 21,000 Americans had already died from the virus. Before that, the only mention of the disease by others in his administration had consisted of homophobic jokes at press conferences.⁹

One of the first cases that gained national attention and public sympathy was that of Ryan White, a white teenager from Indiana who suffered from hemophilia and had contracted AIDS from a blood transfusion. White and his family faced significant discrimination in their community in Indiana, where there were protests against him attending the school from people fearing that even sharing a handshake with White could infect them with the virus too. Eventually, White was able to transfer to another school in Indiana that welcomed him. As more information was released about the mysterious new virus, he became a beloved spokesperson for HIV/AIDS in the United States. He was supported by many well-known celebrities and politicians at the time, from Elton John to the Reagans. White used his platform to fight against the stigma against homosexuals and drug users as well as a better system for testing the national blood supply for HIV, and The Ryan White CARE Act providing over \$2 million in funding for the virus was passed in 1990 in his name.¹⁰ However, it is also important to consider why White was given a platform and eventually received national sympathy. He was from a white, middle-class family in the Midwest, and had contracted HIV in the “purest” way possible- a blood transfusion.

The Stigma of HIV

9. Caitlin Gibson, “A disturbing new glance at the Reagan’s administration’s indifference to AIDS,” *The Washington Post*, December 1, 2015.

10. Howard Markel, “Remembering Ryan White, the teen who fought against the stigma of AIDS,” *PBS*, April 8, 2016.

Now much more is known about the transmission of HIV and that it can affect anyone, regardless of their sexual orientation, but its history of impacting marginalized populations still remains true today and contributes to the connotations of immorality that continue to accompany the virus. Out of the over 36 million people living with HIV worldwide, only about sixty percent of them know their status.¹¹ The stigma that people with HIV face in their communities is a significant factor that keeps them from getting tested and going in for treatment services.¹² If individuals are so afraid of the repercussions of having HIV that they do not disclose their status to their partner, this can lead to their partner and future children contracting the virus as well. This poses a risk not just to the individuals themselves, but also to their family members and others in their community.

Most people currently living with HIV are in developing nations, but access to treatment and services still remains a significant problem in the United States as well, especially for already marginalized communities. As of 2013, more than 1.2 million people had HIV in the United States, and one in eight of them were unaware of their status.¹³ Cases of HIV declined by nine percent between 2010 and 2014 in the United States, but there are still specific population groups that account for a significant percentage of new cases. In 2015, 45 percent of new cases were with African American individuals, despite them only making up about 13 percent of the country's overall population. The LGBTQ community is also disproportionately affected, with

11. "The Global HIV/AIDS Epidemic," *AIDS.gov*, accessed March 11, 2017, <https://www.aids.gov/hiv-aids-basics/hiv-aids-101/global-statistics>.

12. "Stigma," *UCSF: Center for AIDS Prevention Studies*, accessed March 11, 2017, <http://caps.ucsf.edu/library/stigma>.

13. "HIV in the United States: At a Glance," *AIDS.gov*, accessed March 12, 2017, <https://www.aids.gov/hiv-aids-basics/hiv-aids-101/statistics>.

67 percent of all new cases being attributed to transmission through male-to-male sexual contact.¹⁴ Even though there has been a great amount of progress with HIV care since it first emerged in the 1980s, there is still a trend with who it affects and who is lacking in adequate healthcare. Heterosexual individuals continue to have one of the lowest rates for new cases, which drops even more if the individual is also white.¹⁵ Healthcare organizations around the world, from the CDC to the WHO to UCSF, are still putting a significant amount resources and effort into preventing and treating HIV in the United States and abroad. However, because white heterosexual people are not as commonly infected with the disease, it is not usually seen as a priority in the middle-class American mind.

Transgender People with HIV: Stigma, Causes, and Prevention

HIV has carried stigma since the first major outbreaks in the 1980s occurred among homosexual men. The United States has come a long way in rights for LGBTQ people in the past half century, but there is still a long way to go. Transgender people in particular are at a high risk. “Transgender” refers to individuals “whose gender identity, expression or behavior is different from those typically associated with their assigned sex at birth.”¹⁶ It was only within the past 25 years that homosexuality and being transgender have stopped being treated as mental

14. “HIV/AIDS: Basic Statistics,” *Centers for Disease Control and Prevention*, last modified on November 30, 2016, <https://www.cdc.gov/hiv/basics/statistics.html>.

15. “New HIV Diagnoses in the United States for the Most-Affected Subpopulations, 2015,” *Centers for Disease Control and Prevention*, last modified on November 30, 2016, <https://www.cdc.gov/hiv/basics/statistics.html>.

16. “Transgender Terminology,” *National Center for Transgender Equality*, last modified January 15, 2014, <http://www.transequality.org/issues/resources/transgender-terminology>.

illnesses by doctors.¹⁷ With current debates about bathroom laws and with rates of violence against transgender people continuing to rise, individuals in this community still face significant discrimination and social barriers. In 2017, there have already been at least seven transgender people killed because of their identity, all of whom were transgender women of color.¹⁸

Transgender people in particular experience prejudice and challenges, especially with access to healthcare. They are 1.4 percent more likely to have a college education than someone in the general population, but are twice as likely to be unemployed and four times as likely to be living on under \$10,000 a year.¹⁹

People who identify as transgender, especially those who have transitioned from male to female (MTF), have been greatly impacted by HIV. The fear and discrimination that often infiltrate their lives because of their identity cause transgender people to be more likely to suffer from mental illnesses such as anxiety, depression, and substance abuse.²⁰ This sense of instability in their lives can also cause Male-to-Female individuals in particular to participate in more risky sexual behaviors, such as unprotected anal intercourse, multiple casual male partners, or sex

17. Walter Bockting, "Transforming the Paradigm of Transgender Health: a Field in Transition," *Sexual and Relationship Therapy*, 24 (2): 104. doi: 10.1080/14681990903037660. (2009)

18. Alex Schmider, "GLAAD calls for increased and accurate media coverage of transgender murders," *GLAAD*, last modified February 27, 2017.

19. Jack Harrison, Jaime Grant, and Jody Herman, "A Gender Not Listed Here: Genderqueers, Gender Rebels, and Otherwise in the National Transgender Discrimination Survey," *The Williams Institute*, April 1, 2012.

20. Jeffrey Herbst, Elizabeth Jacobs, Teresa Finlayson, Vel McKleroy, Mary Spink Neumann, and Nicole Crepaz, "Estimating HIV Prevalence and Risk Behaviors of Transgender Persons in the United States: A Systematic Review," *AIDS and Behavior* 12, no. 1 (2008): 1-17, doi: 10.1007/s10461-007-9299-3.

work.²¹ These behaviors put them at a greater risk for contracting HIV, and the lack of understanding about their identity in the broader healthcare system can create a barrier that keeps them from accessing treatment. For instance, some transgender individuals will inject hormones as a part of their transition process. This is a unique risk because HIV research and outreach about using clean, safe needles usually revolve around the injection of recreational drugs. If transgender people cannot afford hormone treatment or have a doctor who does not understand their gender identity, they will sometimes buy hormone injections illegally or use some “leftover” hormones from friends who have had the treatment already. This puts them at risk for using contracting HIV through infected needles. There is not as much research about transgender people and their risk for HIV, which needs to be remedied so that there can be more education and outreach that can aid this population in getting the services they need to prevent and treat the virus.

While there has been extensive research done about the experiences of individuals in the LGBTQ community, particularly gay and bisexual men, there are not as many available statistics about transgender people and HIV. There has been minimal research aimed at finding any specific intervention or prevention methods focusing on the connection between transgender people and the high rates of dangerous behaviors that put them at risk. The study “Estimating HIV Prevalence and Risk Behaviors of Transgender Persons in the United States: A Systematic Review,” published in *AIDS and Behavior* in 2008, attempted to fill this gap. Research about the prevalence of risk factors for transgender people in the United States was done over a period of 13 years (1990-2003), consisting of interviews, self-administered surveys, or focus groups.²² The

21. Ibid.

22. Ibid.

prevalence of risk factors were coded separately for male-to-female people (MTF) and female-to-male (FTM), a distinction I understand makes the data easier to synthesize but also risks oversimplifying individual's experiences and making assumptions about their identities. This aspect could be a contributing factor to the lack of research about transgender people with HIV. Most of medicine still operates on a binary system with gender, dividing care by individual's born sex and reproductive organs. There is not as much space dedicated to individuals who are intersex, in transition, or who identify as anything outside of the narrow female versus male model.

Based on the binary that this study implemented when doing this research, it was found that MTF transgender individuals are generally at a higher risk than FTM individuals in the United States. FTMs were significantly less likely to participate in risky behaviors that increased their chances of contracting HIV, such as having unprotected intercourse or injecting recreational drugs. Within those binaries, it was found that African American MTFs had the highest rate of infection of HIV, followed by Hispanic MTFs and white MTFs.²³

The barriers that keep transgender people, especially transgender people of color, from accessing healthcare services can be fatal. Being diagnosed with HIV is no longer a death sentence like it once was 20-30 years ago. People with HIV can take a combination of medicines called antiretroviral therapy (ART), which helps control the virus and keep it from turning into AIDS. ART gives patients the chance to live longer, healthier lives and lowers their risk of passing on the virus to others. However, getting started on ART and consistently taking the medication requires having a dependable healthcare provider. Transgender people are at an

23. Ibid. p. 5

increased risk of being unemployed and uninsured because of job discrimination, making them less likely to have access to dependable healthcare that could provide them with the life-saving treatment.²⁴

It is essential to understand the intersectionality of racism and transphobia when conducting research about HIV in the United States. Transgender women of color especially are at an increased risk for violence against them because of their identity. Without considering the complex relationship between the race and gender identity of transgender people in our country, we will be unable to prevent HIV from spreading in their communities and unable to get those already infected on the life-saving antiretroviral therapy. The healthcare system in the United States fails people from marginalized communities. There is currently not enough being done to understand how discrimination impacts whose lives are prioritized during epidemic outbreaks or healthcare in general. Unless we address the discrimination these individuals face on a daily basis and better educate healthcare professionals, we will be unable to eradicate the HIV virus in the United States and provide the most vulnerable populations of people with the healthcare they need.

24. "Health & HIV," *National Center for Transgender Equality*, accessed on March 9, 2017, <http://www.transequality.org/issues/health-hiv>.

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