## Perceptions of HIV in Cape Town, South Africa

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"You have to struggle with how you yourself are going to accept it and how your family is going to accept it, you know? How people that you are impacting are going to accept it" (Hampton, 2022, 1:53). This is just one musing from Sibusiso Jali, also known as Sbu, as he discusses the emotional and social impacts of receiving a positive HIV test. The documentary A Future Without HIV: Investigating South Africa (HIV Pandemic Documentary), which was directed by Meissa Hampton, follows several individuals living in Cape Town, South Africa as they discuss their personal experiences either living with or being tested for HIV. Throughout the documentary, doctors, community health workers, and other professionals discuss the social and political impacts of HIV. The human immunodeficiency virus (HIV) weakens the immune system by attacking and replicating in CD4 cells, which are a type of white blood cell. As the disease progresses, an individual may develop acquired immunodeficiency syndrome (AIDS). which is the latest stage of HIV. This stage may take up to 15 years to develop (WHO, 2022). While Sub-Saharan Africa accounts for 70% of new HIV infections, South Africa is considered the hotspot for this disease. Within this country, 5.6 million people are HIV positive (Hampton, 2022). Despite its high prevalence in South Africa, there is a significant amount of stigma surrounding this disease. Several theoretical concepts in medical anthropology, such as the meaning-centered and political-economic critical approaches can be used to explain perceptions of HIV in South Africa. In the documentary, stigma and other societal factors, such as gender roles, beliefs surrounding traditional medicine, political tension, and fear surrounding getting tested, affect how HIV is perceived by local communities.

While researching potential documentaries to analyze, A Future Without HIV: Investigating South Africa (HIV Pandemic Documentary) stood out due to its examination of the various factors that affect perceptions of HIV in Cape Town, South Africa. There are many aspects of this documentary that made it the optimal choice for this research project. For example, it provides narratives from healthcare professionals in order to present statistical information regarding HIV, it presents information regarding the historical and political events that have shaped HIV as it is today, it analyzes a specific community, and it thoroughly discusses the social factors affecting HIV and methods to prevent the further spread of this disease. This information directly relates to the research goals of this project. The first goal is to answer what social, political, and cultural factors that affect HIV perceptions in Cape Town. The second research goal is to determine the aspects of South African culture that prevent individuals from receiving HIV testing. While this documentary covers a wide range of factors affecting HIV in South Africa, a few of these, such as the role of traditional medicine and gender norms, are only briefly discussed. Therefore, studies that further analyze these factors are also included in this project. This reveals potential limitations of the research presented. Presumably due to the short length of the documentary (1 hour and 38 minutes), many of the discussions are brief. Therefore, these quick discussions of the factors affecting HIV may not provide a full understanding of how this disease is socially constructed.

Throughout the documentary, many aspects of social norms and conduct are examined.

While HIV is typically perceived to be a disease that only affects men, women are also at risk.

According to Dr. Catherine Sozi, "the epidemic in South Africa is a feminine epidemic"

(Hampton, 2022, 25:46). Additionally, the role of gender and romantic relationships are discussed as factors that affect HIV prevalence, particularly in women. Strict gender roles in South Africa are cited as reasons why women feel unable to engage in safer sexual behaviors. One reason why many individuals have negative perceptions of HIV is because the disease is associated with sexual promiscuity. Another factor affecting both the prevalence and perception of this disease is the use of traditional medicine. Oftentimes, traditional healers advise their clients not to take their HIV medication. This approach to HIV treatment also stems from ideology spread by President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang during the early 2000s. Additionally, the documentary describes HIV as a "social" disease, citing four main reasons why people refrain from getting tested. These include fear of self-knowledge, fear of death and dying, fear of discrimination, and fear of stigma. Due to the social nature of this disease, the most effective prevention methods will likely utilize support from one's community (Hampton, 2022).

Although HIV is typically viewed as a disease that only impacts men, young women in South Africa are also at a high risk of contracting this disease. Around 70,000 adolescent girls and young women were infected with HIV in 2019, and the overall prevalence of this disease in women aged 20-24 was 15.6% as of 2022 (Govender et al., 2022). In Cape Town, most relationships are between men and women, with heterosexual couples contributing to over 60% of new infections. In addition, regular condom usage has been cited as an effective HIV prevention strategy (Speizer et al., 2018) However, in Cape Town, embedded gender roles make it difficult for women to advocate for safer sexual behaviors. Nokubonga describes how due to

men's role as the head of the household, they provide women with many necessities, such as clothes and money. Therefore, if a man does not want to use a condom, "you feel like you can't say no" (Hampton, 2022, 27:05). This exchange of sex for material goods highlights how women in Cape Town are at an economic disadvantage. The documentary discusses how they will not be in the position to deny sex until they gain economic independence, which can only be accomplished once levels of poverty and education for young girls change. Through economic independence, young women would be able to make their own money, and therefore care for themselves without a man (Hampton, 2022). Due to this economic and gender inequality in Cape Town, it has been found that HIV prevention strategies are more effective when they target both the male and female partners. One program called the Couples Health CoOp (CHC), which focused on improving couples' communication and risk reduction skills, resulted in both improved condom usage and gender norms (Speizer et al., 2018). Another factor that contributes to HIV prevalence in Cape Town is the association between HIV and sexual promiscuity. Due to the stigmatization of sexual behavior, individuals are less likely to disclose past partners when engaging in sexual relationships. Therefore, they may not view condoms as necessary, further contributing to the spread of HIV (Hampton, 2022).

In Cape Town, traditional medicine practices may prevent individuals from utilizing antiretroviral (ARV) medications for HIV. Sbu discusses how traditional healers, who are known as "sangomas," do not believe HIV medication is necessary, and encourage their clients to cease its use. This can further contribute to the spread of HIV (Hampton, 2022). As stated by Ndou-Mammbona (2022), over 80% of the population in rural South Africa utilizes services

from traditional healers. Generally, individuals only seek care from biomedical professionals if they are experiencing serious symptoms. Due to this delay in treatment, individuals may not be diagnosed with HIV for long periods of time, which may negatively affect disease outcomes. In addition, some individuals believe that others in their community bewitched them to believe they have HIV. Some healers also cite lack of adherence to cultural rituals as an explanation for HIV deaths. One healer named Khakhu discusses how she believes people die from HIV because they have dirty blood. Therefore, she uses a knife to remove this dirty blood from her clients. However, these knives are used on everyone and not regularly sterilized, which contributes to infections and anemia (Ndou-Mammbona, 2022). In Cape Town and other areas of South Africa, the meaning-centered approach may be used to explain local perceptions of HIV causation. Due to local beliefs surrounding HIV, this disease may be interpreted as the sum of the various meanings applied to it. For example, while healers may have different opinions regarding the cause/treatment of HIV (such as the role of bloodletting or bewitching others), most seem to agree that Western treatment methods, such as ARVs, are not useful. When considering the high percentage of individuals who visit traditional healers, the use of ARVs in rural communities is most likely not seen as "normal," and therefore is not considered a necessary step in HIV treatment.

Another factor that influences HIV perceptions, particularly surrounding the use of traditional medicine, is the political ideology spread by President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang during their time in office. While HIV first began to spread around 1980, it was primarily considered a disease that only affected the United States. This

changed in 1994, when the epidemic first became a serious issue in South Africa. When Mbeki was elected president in 1999, he denied the severity of the disease and questioned if HIV truly caused AIDS. He stated, "It seemed to me that you could not blame everything on a single virus" (Hampton 2022, 16:59). The Health Minister at the time, Manto Tshabalala-Msimang, also participated in this denialism, suggesting that traditional medicine was cheaper and should be sold as an HIV treatment. Lucilla Blakenburg, Co-Director of Community Media Trust (CMT), cites this as "almost an unwillingness to believe science" (Hampton, 2022, 17:42). Both President Mbeki and Health Minister Manto Tshabalala-Msimang did not want the West to tell them how to handle the epidemic. Therefore, they denied South Africans access to ARVs. However, CMT, which was an organization that advocated for access to these drugs, used protests and civil disobedience to fight for their right to ARVs. Unfortunately, the years of denialism and lack of access to medication resulted in the deaths of thousands. In 2006, around 567,000 people died from AIDs (Hampton, 2022). These political factors draw attention to theoretical explanations for HIV perceptions during this time.

The political-economic critical approach can be applied to the lived experience of HIV during Mbeki's presidency. Due to the policies implemented on the macro level of the government, many individuals' lives were lost. This explains how while Mbeki and Tshabalala-Msimang seemed to believe in the validity of their statements against HIV and the use of ARVs, their policies and procedures still resulted in negative outcomes for their citizens. Additionally, this emphasizes how power structures set in place were able to affect South Africans' individual health experiences. While not every individual was personally affected by

this disease, they presumably knew someone who was either living with HIV or had died from its effects. In addition, public outcry regarding the lack of access to ARVs highlights the anger South Africans experienced in response to the political climate at the time. Finally, this historical perspective of HIV emphasizes the importance of targeting health at the policy level. Without policy interventions, individuals would not be able to access necessary health tools, such as ARVs in South Africa.

Along with political tension, social factors contribute to a negative perception of HIV, which then decrease the likelihood that an individual will receive testing for this disease. According to focus group discussions and a literature review conducted by Scott Burnett, the group director of an HIV prevention program called loveLife, there are four main fears that contribute to this fear of getting tested. First is the fear of self-knowledge, which refers to the belief that one has acted in a manner that led to an HIV infection. Next is the fear of death and dving. Although HIV can be managed through ARVs, many individuals in Cape Town still associate the disease with its final and most deadly stage, AIDS. In addition, people fear discrimination from their family, friends, and community. Due to negative perceptions of HIV, infected individuals fear that their family will evict them from their homes, will not understand their diagnosis, or will react poorly. Finally, individuals may avoid testing due to perceived HIV stigma. Because HIV is associated with stigmatized behaviors, such as men having sex with men, the injection of drugs, and women having multiple sexual partners, it is oftentimes viewed negatively by the community. This demonstrates how social ties in Cape Town may play a vital role in HIV prevention (Hampton, 2022).

In the documentary, HIV is described as a "social disease" that depends on the interaction of individuals with their friends, family, and communities. Therefore, HIV interventions that utilize social and peer influence may be more effective than other potential methods. According to one professor, Dr. Sinan Aral, "Social support has a powerful and unique ability to directly counteract social stigma. In the end, this is a social disease. It needs a social cure" (Hampton, 2022, 1:08:19). This concept of a social cure may be interpreted using a framework known as the social influence theory. According to this theory, three processes affect an individual's beliefs, attitudes, and behaviors. The first of these processes, *compliance*, occurs when an individual complies with the beliefs or desires of a group due to perceived benefits/rewards. When this occurs, the individual often seeks to avoid disapproval from the group, even if they disagree with the sentiments shared. Next, identification refers to when an individual engages in a behavior so that they may gain or maintain a relationship with others. Finally, *internalization* refers to when an individual engages in a behavior because it aligns with their intrinsic values (Liu et al., 2020). This theory may be used to explain how individuals in Cape Town internalize stigma surrounding HIV. As stated by Dr. Aral, individuals may not trust health advice given by the government, organizations, or companies, but they are likely to trust advice from their friends and family. The influence of social support in Cape Town draws attention to how applied medical anthropology may be used to prevent HIV. This subfield, which is especially useful for planning effective interventions, can be used for the prevention of many diseases, particularly HIV. Due to the social factors that affect HIV, one cannot combat this disease through just a biomedical approach. Therefore, it is necessary to have applied medical anthropologists who

have spent significant periods of time with a community and understand how to effectively combat negative perceptions of disease (Joralemon, 2017).

There are many factors that affect HIV perceptions in Cape Town, South Africa. These include gender roles, traditional medical practices, political oppression, and fear surrounding getting tested for HIV. Medical anthropology can be used to inform the socio-cultural meanings of this disease through theories such as the meaning-centered approach and the political-economic critical approach. This is necessary not only for the planning of disease interventions, but also for a full understanding of how a community such as Cape Town interacts with HIV. While factors such as the fear of death, self-knowledge influence an individual's decision to be tested for HIV, the fear of discrimination and stigma arguably play the most important role. Due to the social nature of this disease, individuals internalize the beliefs and attitudes that their peers have towards HIV. Because these beliefs are often negative, this further contributes to the fear of getting tested for the disease. Ultimately, although HIV is a prominent issue in Cape Town, medical anthropology may be used to determine the most effective methods of intervention for this disease.

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