African Grandmothers Tribunal—Seeking Justice at the Frontlines of the AIDS crisis

South Africa: Healthcare and Stigma

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Background

The South African Constitution guarantees equal access to healthcare, but equality of access is not a reality for all residents.\(^1\) Access includes both the physical availability of services and the circumstances that allow for service utilization.\(^2\) Although the era of apartheid has ended, the effects of that regime are still felt. Large regional and economic disparities continue and translate into unequal access to social services including healthcare.\(^3\) The South African medical system is stratified, consisting of community hospitals where free care is provided to all and semi-private and private institutions for those with economic means.\(^4\) The community clinics exist primarily in densely populated low-income areas and lack the resources to provide care for all of their patients.\(^5\) Generally, people who must rely on the public system have difficulty obtaining the healthcare they require.\(^6\) The South African health care system is also plagued by stigma against a number of minority groups. These groups experience even further difficulties and, as a result, are denied their constitutional right to healthcare.

HIV/AIDS

South Africa has the highest HIV/AIDS prevalence in the world, with approximately 5.6 million people affected and almost one third of women aged 25-29

\(^1\) Bronwyn Harris et al, “Inequities in access to health care in South Africa” Journal of Public Health Policy (2011) 32 102 at 103
\(^2\) Ibid.
\(^5\) Ibid.
\(^6\) Harris, supra note 1 at 103
have the disease. It predominantly effects the black population. A large amount of research has been done on HIV/AIDS stigma and how it affects those who suffer from the disease. There are three principle reasons for HIV/AIDS stigma: the infected are blamed for their condition and are criticized for making immoral choices; the disease is incurable and progressive; and, transmission is not well understood and therefore people are threatened by the presence of an HIV positive person. In the Western Cape Province, HIV is called “ulwazi” which translates to “that thing.” Disclosure and the resulting stigma can lead to a loss of employment and housing, estrangement from one’s family and community, increased risk of physical violence and even murder. Some health care professionals will refuse to treat people with HIV/AIDS because they don’t want to risk the possibility of infection. Upon disclosure of their status, many HIV positive people are rejected by their family and their community. HIV positive people report that they have been evicted confined to a specific part of their house, not being allowed to use utensils or being banned from food preparation, and being the object of gossip between their family and the community. The stigma is so destructive that, in a study performed in 1997, many infected teenagers stated that because the social rejection they were facing was so severe, they intended to spread the infection widely so

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9 Leah Gilbert, “My biggest fear was that people would reject me once they knew my status…Stigma as Experience by Patients in an HIV/AIDS Clinic in Johannesburg, South Africa” (2010) Health and Social Care in the Community 18:2, 139 at 140.
10 Ibid at 142.
11 Ibid at 139.
14 Ibid at 847.
that they wouldn’t die alone. People are afraid to get tested, to disclose their status (to their families, communities or sexual partners) or seek treatment. In these circumstances HIV/AIDS cases remain undiagnosed, untreated and transmission rates increase.

This intense social stigma reduces the accessibility of healthcare to HIV positive people in South Africa. Patients fear that the treatment process will lead to disclosure of their HIV status to their employers, family, or community. When at a clinic, HIV positive patients are given different color folders, seen in a different section of the clinic, and their HIV positive status is openly discussed by healthcare workers in public areas. While these practices may be developed for the efficiency of the health care system, they become devices that reveal a patient’s HIV status and subject the patient to discrimination. These clinics also have limited appointments, long waits, require long commutes, and are only open during regular business hours. This requires the employed to disclose their status to their employers if they wish to make regular clinic visits, which many will not do for fear of dismissal. The infected also fear that clinic staff will gossip in the community about their status. This is not an unfounded fear – the AIDS Law Project reported that the Health Professions Council of South Africa did not act against 28 doctors who had breached patient confidentiality surrounding HIV status.

It is very difficult to undergo treatment for HIV/AIDS without one’s family and community knowing. Living conditions do not provide opportunities to hide medication,

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15 Mfecane and Skinner, supra note 12 at 162.  
16 Gilbert supra note 9 at 139.  
17 Ibid.  
19 Ibid at 15.  
20 Bogart et al, supra note 14 at 848.  
22 Mfecane and Skinner, supra note 12 at 160.
clinics are staffed by community members, lack of transportation options make it impossible to receive treatment at clinics outside the community.\textsuperscript{23} If patients are afraid to disclose their HIV/AIDS status due to the stigma they will face, testing, treatment, and avoidance of transmission is almost impossible.\textsuperscript{24}

**Effect on Treatment**

HIV stigma significantly reduces the success of anti retroviral treatment (“ART”). This treatment was not available in South Africa until 2004, largely due to the incorrect and stigma driven response of the administration of President Thabo Mbeki (1999-2008).\textsuperscript{25} Mbeki refused to accept free ART or grants to support the treatment until 2004, insisting that the AIDS epidemic was caused by extreme poverty rather than a single virus.\textsuperscript{26} This response to the epidemic and the denial of its magnitude resulted in a poor understanding of the disease, a lack of preventative strategies and an increase in HIV related stigma and discrimination.\textsuperscript{27} ART treatment became available after 2004 but as of 2010 only 1.4 million of the people who have HIV/AIDS are taking the treatment.\textsuperscript{28} It is only available to 28% of people who need the treatment.\textsuperscript{29} Most HIV related deaths occur before ART begins.\textsuperscript{30} ART treatment requires strict adherence and frequent clinic visits, especially in the early stages.\textsuperscript{31} Due to the stigma surrounding infection, HIV positive patients seeking ART try not to disclose their status and treatment to employers and families, which makes compliance very difficult.\textsuperscript{32} The South African ART program

\textsuperscript{23} Ibid at 148.  
\textsuperscript{24} Ibid at 148.  
\textsuperscript{25} Visser and Sipsma, supra note 7 at 205.  
\textsuperscript{26} Ibid at 205.  
\textsuperscript{27} Ibid at 206.  
\textsuperscript{28} Bogart et al, supra note 14 at 843.  
\textsuperscript{29} Gilbert, supra note 9 at 140.  
\textsuperscript{30} Bogart et al, supra note 14 at 843.  
\textsuperscript{31} Bogart et al, supra note 14 at 846.  
\textsuperscript{32} Gilbert, supra note 9 139.
demands that before a patient can begin ART, they must have disclosed their HIV status to at least one person, as a signal that they have accepted their condition and will comply with the treatment.\textsuperscript{33} Given the hesitation to disclose their HIV status as discussed above, this may another barrier to the success of ART in South Africa. In addition to long clinic waits and transport times, antiviral pills need be taken with food, and many patients cannot afford to eat before attending the clinic.\textsuperscript{34} Because compliance with the requirements of ART is most likely to reveal someone’s HIV status to their family, community, or employer, many of those infected with HIV/AIDS remain untreated.

Healthcare professionals are also subject to HIV/AIDS stigma. Nurses may be stigmatized by their families and their community, who fear that they may have been infected with HIV/AIDS in their workplace.\textsuperscript{35} They are also working under staff shortage pressures because 16\% of the nursing population is infected with HIV/AIDS.\textsuperscript{36}

\textbf{Women and Reproductive Health}

Women in South Africa are particularly vulnerable to HIV/AIDS because of gender inequality and are subject to greater stigma if infected.\textsuperscript{37} This gender inequality permeates South Africa, where women are discriminated against and subordinated within the family and society.\textsuperscript{38} They are often wrongly portrayed as the main transmitters of the disease, and infected women are characterized as promiscuous, dirty, and irresponsible.\textsuperscript{39} The majority of women live in rural and remote areas, where

\textsuperscript{33} Coetzee et al, \textit{supra} note 21 at 149.
\textsuperscript{34} \textit{Ibid} at 146.
\textsuperscript{36} Mfecane and Skinner, \textit{supra} note 12 at 157.
\textsuperscript{37} Visser and Sipsma, \textit{supra} note 7 207.
\textsuperscript{38} \textit{Ibid}.
\textsuperscript{39} \textit{Ibid}.
treatment is more difficult to obtain. The United Nations Committee for Elimination of All Forms of Discrimination against Women ("CEDAW") reports that women with HIV are at a higher risk of violence and discrimination. In 2004 Lorna Mlofane was raped and subsequently murdered after her rapists discovered she was HIV positive. CEDAW’s report on South Africa in 2011 stressed the need to address the link between HIV stigma and violence against women.

HIV positive women who become pregnant also experience stigma and discrimination because of their HIV positive status. The 2010 National HIV and Syphilis Prevalence Survey found an HIV prevalence of 30.2% amongst pregnant women. While HIV positive women may choose to have a child, many unplanned pregnancies also occur. Under South African law a woman can obtain a legal abortion in the first 12 weeks. After this period, consent of a doctor is required. However, despite this relatively liberal policy, access to abortion is scarce in rural communities and over 4.2 million unsafe abortions are performed each year. Women are also not often provided with adequate contraceptives or sufficient information about the interaction between contraceptives and ART, resulting in unwanted pregnancies in HIV positive women.

Preventing mother to child transmission (PMTCT) services are available to prevent transmission from mother to child, but like ART, receiving this treatment may

41 Ibid.
42 Mfecane and Skinner, supra note 12 at 160.
43 Concluding Observations of the Committee on the Elimination of Discrimination against Women, supra note 40 at para 36.
46 Medical consent will be given if the children is a product of rape or if it endangers the mother’s life. For more details please see the Choice on Termination of Pregnancy Act, supra note 43.
48 Ibid at 92.
force women to disclose their status and face discrimination.\textsuperscript{49} Transmission from mother to child can occur during pregnancy, labor and delivery, or during breastfeeding.\textsuperscript{50} Both CEDAW and the Strategic Plan for Maternal, Newborn, Child and Women’s Health 2012- 2016 (MNCWH) focus on the importance in increasing PMTCT services.\textsuperscript{51} However pregnant women are afraid to disclose their status for fear of abandonment, ostracism, domestic violence or being blamed for their condition.\textsuperscript{52} As a result, women tend to opt out of being tested, fail to disclose their serostatus if diagnosed, opt out of PMTCT programs and miss scheduled visits.\textsuperscript{53} The stigma against HIV positive women with children is so severe that a despite PMTCT recommendation to do so, many women won’t use formula instead of their own milk because they fear being questioned on their decision and discovered as HIV positive.\textsuperscript{54} A study conducted in 2004 showed that HIV positive women who became pregnant experienced further discrimination from health care workers and their community.\textsuperscript{55} They are perceived as


\textsuperscript{50} Ibid.

\textsuperscript{51} Concluding Observations of the Committee on the Elimination of Discrimination against Women, supra note 37 at para 36 and “Strategic Plan for Maternal, Newborn, Child and Women’s Health (MNCWH) and Nutrition in South Africa 2012-2016” (2012), online: National Health Department of the Republic of South Africa <https://extranet.who.int/nutrition/gina/sites/default/files/ZAF%202012%20MNCWHstratplan.pdf> at 12. In 2011, CEDAW recommended that the South African administration “take measures to broaden and strengthen PMTCT services in order to achieve its target rate of 5% for mother to child transmission.” In additional to improving the general quality of material care, addressing the HIV infection is listed as the most important intervention for reducing maternal mortality by the MNCWH, a policy initiative outlined by the South African government to be implemented from 2012-2016. The MNCWH plan proposes to reduce HIV transmission from mother to child by increasing PMTCT services, preventing HIV among young women, and decreasing unplanned pregnancies in HIV positive women.

\textsuperscript{52} Thorsen et al, supra, note 49 at 44.

\textsuperscript{53} Ibid.

\textsuperscript{54} Breastfeeding by an infected mother increases the risk of infection from 5-20% (of an HIV infected mother who does not breastfeed) to 20-40% (of an HIV infected mother who does breastfeed). Those women who desire to follow the PMTCT guidelines are often not able to afford formula. For more information see Thorsen et al, supra note 49.

\textsuperscript{55} De Bruyn, supra note 47 at 92.
irresponsible for having conceived a child.\textsuperscript{56} The stigma against HIV positive pregnant women is so extreme that both members of the general population and medical professionals have argued that women should be sterilized before they can be eligible for ART.\textsuperscript{57}

**Tuberculosis**

People who suffer from tuberculosis also experience stigma and discrimination.\textsuperscript{58} The disease is associated with poverty, filth and squalor.\textsuperscript{59} Confidentiality of patients at clinics in compromised by long waits, designated waiting areas, doors that are left often during consultation and a color coded card system used by clinic staff.\textsuperscript{60} The effect of the stigma has a similar effect as it does on HIV patients – avoidance of diagnosis and testing, reluctance to disclose their status and to be treated.\textsuperscript{61}

**Migrants**

Discrimination also occurs against minorities and migrants, of which South Africa has recently seen a significant number due to the recent conflicts in Zimbabwe.\textsuperscript{62} These individuals have difficulty accessing social services, health care, and other necessities such as sanitation and clean water.\textsuperscript{63} Although the *National Health Act* and the South African *Constitution* guarantee access to live saving health care regardless of

\textsuperscript{56} Ibid at 96.
\textsuperscript{57} Ibid at 95.
\textsuperscript{58} For more information on TB stigma please see: Murray et al, “High levels of vulnerability and anticipated Stigma Reduce the Impetus for TB Diagnosis in Cape Town, South Africa” (2013) *Health Policy and Planning* 28 410 at 415
\textsuperscript{59} Ibid.
\textsuperscript{60} Ibid.
\textsuperscript{61} Ibid.
\textsuperscript{63} Ibid.
immigration status, it is difficult for migrants to access anything more than this basic care.  

Migrants experience particular difficulty when trying to secure ART. Although the National Strategic Plan on HIV, STIs and TB (2012-2016) specifically includes non-citizens, they often encounter discrimination when they pursue treatment, with reports of migrants who are denied treatment because they are foreigners. They also face insurmountable commutes to clinics, especially if they are in detention, staying in a remote area or awaiting deportation.

The Special Rapporteur on the Human Rights of Migrants strongly encourages South Africa to implement the recommendations of the World Health Assembly resolution WHA61.17 on the Heath of Migrants. This demands that member states “promote migrant-sensitive health policies, establish an information system to assess migrants; health, and promote equitable access to health promotion, disease prevention and care for migrants.” Additionally, South Africa should ratify covenants that it has signed designed to protect the rights of migrant people.

64 Ibid.
66 Ibid. For more information on the report please see the Department of Health’s website at http://www.doh.gov.za/docs/stratdocs/2012/NSPfull.pdf
68 Ibid para 61
69 Ibid at para 62
70 These include the International Covenant on Economic, Social and Cultural Rights, the International Covenant on the Protection of the Rights of all Migrant Workers and Members of their Families, and the International Convention for the Protection if all Persons from Enforced Disappearance and the Optional Protocol to the Convention against Torture. For a list of other unratified conventions, as well as those South Africa has ratified in the area of Migrant rights, please see Report of the Special Rapporteur on the Human Rights of Migrants at para 6-9.