Access to Gender-Affirming Care in South Africa – A Landscape in Transition

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Until recently, access to gender-affirming care in South Africa has been very difficult, especially in the public health sector. Not only does this have an impact on gender affirming possibilities for trans and gender diverse (TGD) people, but it also has an impact on TGD people's mental health. This landscape is gradually transforming, with great developments in improved access to care as well as new models of care.

Health Disparities

Compared to cisgender people, TGD people internationally experience significant health disparities and an increased burden of disease (Reisner et al. 2016). Specific health risks include increased risk of mental health challenges, violence and victimization, substance use, and a disproportionately high prevalence of the Human Immunodeficiency Virus (HIV), as evidenced by South African research which will be discussed below.

A recent survey on the realities of violence, mental health and access to healthcare related to Sexual orientation, Gender Identity and Expression (SOGIE) found alarming rates of mental health challenges amongst South African TGD respondents: depression as measured with the CES-D 10 (63%), anxiety as measured with the GAD-7 (39%) and suicide attempts in the past year (16%) (Müller, Daskilewicz and the Southern and East African Research Collective on Health 2019).[1] Experience of sexual violence in the past year was reported

1 CES-D 10 is Centre for Epidemiological Studies Depression Scale (CES-D-10), a validated screening tool. GAD-7 is Generalized Anxiety Disorder 7-item scale, a validated screening tool. AUDIT is Alcohol Use Disorders Identification Test, a 10-item screen-

by 35% of trans women and 28% of trans men. Alcohol use that was classified as hazardous/harmful/dependence with the AUDIT instrument, was reported in 46%, with drug use that was classified as harmful/dependence with the DUDIT instrument in 25% of respondents. A Cape Town study found that 57% of gender non-conforming participants (who identified as female or 'transgender') had tested HIV positive compared to 31% of the male-identifying participants (Jobson et al. 2018). Some trans women in South Africa turn to commercial sex work for survival (Samudzi and Mannell 2016). A study of South African sex workers found that the trans women were 2.4 times more likely than cis female respondents to have unprotected sex, which increases HIV risk (Richter et al. 2013). At the time that the data for this study was collected (2010), public health messaging about HIV in South Africa was mostly heteronormative, with very limited public health interventions focusing on trans sex workers.

Legal and Policy Framework in South Africa

The Bill of Rights in the South African Constitution guarantees every citizen rights regardless of one's "race, gender, sex, […] sexual orientation [or] age"; the respect and protection of their inherent dignity; the right to life; freedom and security of their person including protection from inhumane and degrading treatment; and the preservation of "bodily and psychological integrity," including sovereignty in decisions regarding reproduction and control over the body (Hatchard 1994). The Promotion of Equality and Prevention of Unfair Discrimination Act of 2000 protects individuals on the basis of gender, while explicitly differentiating between gender and sex (Republic of South Africa 2000).

Section 27 of the South African constitution states that everyone has the right to have access to healthcare services, including reproductive healthcare (Hatchard 1994). It further declares that the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights.

Before 2003, it was not possible for a trans person to change their gender marker in their identity document in South Africa. This changed with the Al-

ing tool developed by the WHO. DUDIT is Drug Use Disorders Identification Test, an 11-item validated screening tool.

teration of Sex Description and Sex Status Act 49 of 2003, which prescribes a process requiring two medical reports stating that "gender reassignment" (the wording in the Act) has taken place (Republic of South Africa 2003). While on paper the law says it is possible to change one's gender marker, the implementation of Act 49 has been very inconsistent (Hamblin and Nduna 2013; Klein 2012). A Legal Resource Centre report describes the unjust delayed and improper processing of applications, as well as unfair and baseless rejections, and argues that the implementation issues of the Act amount to unjust administration and violate the right to equality, dignity, privacy and just administration (Mudarikwa, May and Martens 2017).

In South African healthcare, recent years have brought a shift to include LGBT health in healthcare policy recommendations. Trans people were identified as one of the most-at-risk populations in the 2012–2016 National Strategic Plan for HIV, STIs and TB (SANAC 2012). In the subsequent 2017-2022 Strategic Plan, the language changed from "most-at-risk populations" to "key populations", for HIV and STIs, using the UNAIDS and WHO definitions. This identifies trans people as one of the key populations. This document sets the goal of: "Reach[ing] all key and vulnerable populations with customised and targeted intervention services" (SANAC 2017). In December 2019, the Essential Medicine List of the Department of Health for the first time included hormones specifically for treatment of 'gender dysphoria' (NEMLC 2019).

Despite progressive legislation, conservative social attitudes persist in South African society, including in healthcare settings. In a recent representative population survey, 66% of South Africans reported that they are 'disgusted' by gender non-conformity (Gabriel 2016). This survey estimated that over the previous 12 months, around half a million (450,000) South Africans have physically harmed people that they believed to be women whom they deemed to be dressing or behaving in ways that were too masculine. Likewise, 240,000 have assaulted people who they believed to be men, whom they deemed to be dressing or behaving in ways that were too feminine. Approximately 700,000 South Africans verbally abused (shouted at or teased) gender non-conforming people.

Experiences of TGD Persons in Accessing Care in South Africa

While some of the studies report on sexual as well as gender minorities, there is a small but growing body of evidence specifically on trans experiences. In

a South African study of queer people's experiences, participants reported feeling keenly aware that the physical spaces of the healthcare facilities that they had visited overwhelmingly suggested that they were by and for heterosexual and gender-normative people (Meer and Müller 2017). Participants pointed out that the more non-normative one appears, the greater the vulnerability to homo- and transphobia is. This is of particular relevance to trans persons who do not fit into the binary expression of gender (Meer and Müller 2017). A qualitative study analyzed the experiences of 16 LGBT health service users accessing South African public sector healthcare (Müller 2017). This study found that all participants reported experiences of discrimination by healthcare providers based on their sexual orientation and/or gender identity, such as disrespectful treatment, verbal harassment and religious judgment. A recurrent theme in this study was delayed health-seeking behavior, or the avoidance of health facilities by people who identify as LGBT. Barriers to accessing care include fear of experiencing discrimination, homophobia, or secondary victimization, as well as with an understanding that public facilities often do not or cannot provide care for LGBT-specific health concerns. As a result of health rights violations that they had either experienced themselves, or had heard about from friends and peers, many participants expressed their fear of judgement and discrimination when accessing public health facilities. This resonates with the minority stress model that describes three processes, where the second process described is negative expectations that delay health seeking behavior and also exacerbate the impact of discrimination when it occurs (Hendricks and Testa 2012).

A case study of barriers faced by trans persons when accessing health services in Gauteng reported condescending attitudes by health workers as well as an observation that staff members were not adequately equipped with the necessary skills to offer adequate health services to trans people (Nkoana and Nduna 2012). A qualitative study done in Gauteng and Mpumalanga found that respondents experienced discrimination in the South African medical system due to the wide prevalence of a rigid understanding of gender and sexuality (Husakouskaya 2013).

A key survey on trans people's access to sexual health services in South Africa reported that many of the participants experienced health workers as discriminatory and hostile (Stevens 2012). This survey described multiple layers of discrimination in South African healthcare facilities, ranging from verbal abuse to denial of care. It is important to note that such discrimination is not only perpetrated by individual healthcare providers. Rather, it is

a structural problem deeply rooted in the health system itself (Müller 2016). The health system is experienced as heteronormative and cis-normative with little understanding of non-conforming sexualities and gender identities.

Qualitative studies in South Africa have described the negative experiences of trans people when trying to access healthcare. A study of 17 young trans persons in South Africa described discriminatory treatment in the health sector, especially for trans persons who feel they are not easily 'read' according to their gender identity (Sanger 2014). In the Western Cape a study of 10 trans women described an imbalance in the power relationship between healthcare practitioners and trans women, with experiences of ill-treatment and breaches of confidentiality (Newman-Valentine and Duma 2014). In Kwazulu-Natal, participants reported that when they asked for gender-affirming services, they were met with confusion from healthcare workers who were unable to offer care, advice or appropriate referral (Luvuno, Ncama, and Mchunu 2019). Participants reported experiences of violation of bodily privacy through healthcare worker voyeurism and deliberate exposure of the trans-status of the patient to other patients. Their experience was that all health problems were turned into problems concerning gender identity, even if the patient was seeking care for a different, unrelated reason, with one participant reporting that even though she went to the clinic for a broken bone, she was made to undress (ibid.).

A survey on the realities of violence, mental health and access to healthcare related to SOGIE reported disturbing findings regarding access to healthcare (Müller, Daskilewicz and the Southern and East African Research Collective on Health 2019). Of the South African TGD respondents, 48% reported having been called names or insulted in a health facility because of their gender identity and 39% reported that they had been denied healthcare because of their gender identity (ibid.).

Landscape in Transition

South Africa has a quadruple burden of disease, that has been described as colliding of epidemics: HIV and tuberculosis; chronic illness and mental health; injury and violence; and maternal, neonatal, and child health (Mayosi et al. 2012). In this context, gender-affirming care has not been regarded as a high priority. Access to gender-affirming care is severely limited and unequal within South Africa, with a 2017 publication reporting access to care in public

hospitals in only 4 of the 9 provinces (Spencer, Meer and Müller 2017). The researchers found that while a small minority of healthcare providers offer gender affirming care, this is almost exclusively on their own initiative and is usually unsupported by wider structures and institutions. A specific concern is the limited access to gender-affirming surgery, with waiting lists of 15-20 years (Wilson et al. 2014). Of the South African TGD participants in the survey on the realities of violence, mental health and access to healthcare related to SOGIE (Müller, Daskilewicz and the Southern and East African Research Collective on Health 2019), only 28% used hormones. Participants were significantly more likely to report using hormones if they had medical aid or health insurance ($p < .05$).

Medical aids (health insurance) in South Africa do not generally fund gender-affirming care, although the case for 'medical necessity' has convincingly been argued by the Legal Resource Centre (Mudarikwa, May and Martens 2017). Gender affirming private healthcare is not easily accessible in South Africa, due to unaffordability for most people (Koch et al. 2019).

The landscape is gradually changing with more public hospitals and general practitioners providing access to hormones, and a project to pilot four primary care clinics for trans people to access HIV prevention and treatment as well as hormones by WITS RHI. Not-for-profit organizations have advocated for improved access to care and have provided training for health professionals in gender-affirming care. The argument has been made for inclusion of gender-affirming care in health science curricula for training of health professionals in all disciplines (De Vries, Kathard and Müller 2020). The Psychological Society of South Africa has developed guidelines for psychology professionals working with sexually and gender diverse people (McLachlan et al. 2019). Trans people were involved in the core team who developed the guidelines. These guidelines can be used for mental health advocacy (Pillay et al. 2019). Widespread training on the guidelines has taken place and is ongoing. The guidelines are based on 12 statements that focus on equipping professionals with ethical, sensitive and affirming ways when engaging with sexually and gender diverse people (Victor, Nel, Lynch and Mbatha, 2014; PsySSA 2017). These guidelines also provide a framework for understanding the challenges that are created living in a patriarchal, hetero-cis-normative society and the impact that it has on gender diverse people (McLachlan et al. 2019).

New Models of Care

New models of care are evolving. The informed consent model, with a participatory approach, plays a vital role in the field of gender-affirming healthcare in South Africa (McLachlan 2019). The participatory approach endeavors to establish each TGD person as an agent of change within their community, as well as in public healthcare. The TGD individual does not only become the driver of their own medical transitioning, but also an ambassador for the trans and gender diverse community.

The participatory approach enables the TGD person to have autonomy in their transitioning. Through access to healthcare trainings and being empowered with knowledge and skills, the TGD person is able to engage within the community, not only about their own needs, but also establishing safe spaces for the TGD person. Gender affirming healthcare workers support the TGD person in their transitioning and they are seen as equal partners in the gender-affirming healthcare space. This approach not only enables the TGD person to be heard, but also to actively engage with the process of healthcare reform.

Conclusion

For many years the landscape has looked very bleak for TGD people in South Africa. Today, there are signs of hope, oases of possibility for improved access to care. Most encouragingly, trans people and organizations are playing an active role in educating trans communities and healthcare workers, and in developing guidelines for the delivery of gender-affirming care. The authors are hopeful that access to care will continue to improve in years to come.

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