

## ARTICLE

# Transgender issues in South Africa, with particular reference to the Groote Schuur Hospital Transgender Unit

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This article gives an overview of transgender issues in South Africa, with a particular focus on the work of the Transgender Unit, Groote Schuur Hospital, Cape Town, South Africa. The article presents current definitions, diagnostic considerations and healthcare options in the area of gender dysphoria, and then outlines the history, mandate and role of the Transgender Unit. It concludes with some of the current challenges in the field of transgender healthcare and makes recommendations for the way forward.

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## Definitions

There has been ongoing and critical debate around the diagnostic classification and terminology of disorders related to transgender identity. This has resulted in shifts in placement and renaming of these diagnoses in various editions of the *International Classification of Diseases and Related Health Problems* (ICD) and the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). Successively termed transsexualism,<sup>[1]</sup> gender identity disorder<sup>[2]</sup> and now gender dysphoria (GD),<sup>[3]</sup> a defining criterion is the person's discontent with their assigned gender.

In helping clinicians to work in a sensitive and respectful manner with patients from sexual minority groups, such as the transgender community, the following definitions have been provided:

- **Sex** is biologically defined and refers to the biological characteristics used at birth to assign an individual to a sexual category: natal sex – male or female.
- **Gender** refers to the roles, behaviour and attributes that are labelled as masculine or feminine by society.
- **Gender identity** refers to one's personal sense and experience of gender. In most people it is congruent with the natal sex.
- **Transgender** describes individuals whose natal sex, gender identity and gender expression are incongruent. This may be associated with variable levels of distress (GD), e.g. a person assigned male at birth may identify and present as female (transwoman) and a person assigned female may identify as male (transman). Gender identity can also be on a continuum between male and female.
- **Transition** refers to the process of physical and psychosocial adjustment undertaken by some persons with GD to achieve greater congruence between the natal sex and their experienced gender.
- **Gender dysphoria** refers to variable levels of mental distress associated with gender incongruence.
- **Gender reassignment therapy** (gender alignment or gender affirming changes or interventions) refers to any or more of a number of endocrine and surgical interventions to enable physical feminisation or masculinisation to facilitate transition.

## Diagnostic considerations

In both the ICD-11 and DSM-5 revision processes, the challenge has been to find a balance between providing diagnostic categories that facilitate access to healthcare and medical insurance for the transgender community, while protecting these individuals from the potential stigmatisation that may arise from being diagnosed with a mental disorder in order to receive this treatment.

There are concerns that the combined stigma of being transgender and having a mental disorder diagnosis creates a doubly burdensome situation for an already vulnerable population, which could in turn compromise their health and human rights.<sup>[4]</sup> For example, transgender people may be more likely to be denied primary healthcare in general medical or community-based settings given the perception that they must be treated by psychiatric specialists.

The barriers to obtaining transition-related services, as well as stigma and discrimination, have resulted in some transgender people, out of desperation, exposing themselves to significant harm, including HIV infection, in seeking non-conventional treatments.<sup>[4]</sup> It is important that clinicians (and their diagnostic frameworks) be responsive to the needs, experiences and human rights of this vulnerable population, and facilitate the provision of accessible and high-quality transgender healthcare.<sup>[4,5]</sup>

## Healthcare options

### Clinical assessment

The initial evaluation and diagnosis are made by a mental healthcare professional, who assesses the individual's gender concerns in accordance with standard criteria. Differential diagnoses are excluded, eligibility for therapy is considered and capacity to give informed consent is confirmed. After evaluation, information is provided regarding transition options and possible medical interventions. Any co-existing mental health concerns are addressed and the patient is then prepared and referred for hormone therapy and/or surgery.

### Endocrine/hormone therapy

Endocrine therapy involves a rigorous risk evaluation with clinical and laboratory assessment followed by a regimen of cross-sex hormones, maintained and monitored throughout the patient's life.

Previously exclusively the domain of the endocrinologist and the mental health specialist, the diagnosis, evaluation and cross-hormone therapy can now in many cases be managed by a general practitioner competent in gender transition therapy, or in consultation with a transgender unit.

## Sexual reassignment surgery

Best practice recommendations, clinical experience over five decades, and expert professional consensus have consolidated gender reassignment therapy as part of the management of GD.<sup>[6]</sup> It is therefore no longer considered experimental. These therapies, when the diagnostic criteria are fulfilled, are not elective, cosmetic or lifestyle surgeries, but reconstructive and medically necessary. Surgery consists of ablative/reconstructive procedures to the primary or secondary sexual anatomy. Some procedures (e.g. gonadectomy) can be performed by a general surgeon or gynaecologist. While the prevalence of GD in adults is estimated to be more than 0.01%, relatively few people present for therapy, possibly influenced by lack of information, limited resources and high levels of stigma.

## Psychotherapy

Psychosocial support and psychotherapy are also potentially valuable interventions that may assist in supporting the individual's right to autonomy and self-identification. Transgender individuals are no longer required to live as the self-identified sex or undergo mandatory psychotherapy to progress to sexual reassignment surgery. The mental health practitioner's past role as gatekeeper has been replaced with being primarily evaluative and supportive.

Adolescence adds a further dimension with the onset of irreversible, perhaps unwanted, changes. Non-intervention has the potential for much harm. Puberty can be delayed until the patient has a greater level of maturity and has reached the age of consent. Gender-non-conforming children, their families and teachers often require considerable psychosocial support.

## The Transgender Unit, Groote Schuur Hospital

The rendering of gender reassignment services according to recognised international professional guidelines,<sup>[7]</sup> and in terms of all the provisions set out by the National Department of Health,<sup>[8]</sup> is legal, ethical medical practice in South Africa. This is further supported by the recognition and provision in South African law for a person's alteration of sex description.<sup>[9]</sup>

Provisions for dignity, equality and access to healthcare as contained in the South African Constitution<sup>[10]</sup> should equally be applied to health service provision for transgender people. Transgender healthcare, however, is not well accommodated in the National Department of Health's programme or curriculum.<sup>[8]</sup> In the public sector it is limited to a single comprehensive service at one transgender clinic and partial services at a few other centres.

## History

From the 1970s Groote Schuur Hospital, Cape Town, South Africa, has offered an intermittent psychiatric, surgical and endocrine service to transgender patients, but poor co-ordination of the various departments, turnover of personnel and unreliable appointment systems frustrated patients and staff. With transgender individuals becoming increasingly informed and aware of their transition options, and with an escalation in referrals by local civil society organisations (CSOs), the need to establish a co-ordinated, transgender health service was identified. In 2009, a multidisciplinary

unit was formed, currently comprising two psychiatrists (child and adult), a psychologist, a plastic surgeon, two endocrinologists, a family physician, a social worker, a sexologist, a transgender advocate from civil society and a co-ordinating nurse. Patients could further access gynaecology, urology and laser therapy services.

## Mandate and role

The primary mandate of the Unit is to provide a comprehensive package of care for the transgender patient and to facilitate follow-up support in the local community. A secondary role is offering telephonic technical support to providers of psychological and endocrine services at distant sites. With increasing numbers of younger people presenting, the team also provides clinical services and advice to gender-diverse children and adolescents, their families (helping them cope with their child and their own feelings towards a gender-variant or gender-non-conforming child), and schools.

The Unit has a role in advocating the acceptance and integration of the transgender person in the community, workplace and school. To this effect and in partnership with CSOs, members of the Unit work with families, employers and teachers, and provide the documentation required to change legal gender markers through the South African Department of Home Affairs. The Unit also has an important role in advocating equal access to healthcare, including gender reassignment therapy.

Although limited by resources, it supports a small number of transgender-related research projects by both under- and postgraduate students. It uses the World Professional Association for Transgender Health version 7 (WPATH version 7)<sup>[7]</sup> standards of care clinical framework and guidelines, which follow a therapeutic model of informed consent and harm reduction. Members meet regularly to address issues directly affecting the clinical management and co-ordination of healthcare for the transgender patient, but also consider broader aspects of transgender health advocacy, training and research.

Since 2009, the Unit has assisted 102 patients. Of these, 83% had realised they were gender diverse as adolescents or when younger, while 20% had co-existent psychiatric disorders. Over 60% were employed. Almost half were white, 40% coloured and about 10% black. These patient percentages are not representative of the South African demographic distribution, and may demonstrate the influences of level of education, access to information, and variable cultural proscription on gender affirmation.

## Role of the mental health professional

Historically, mental health professionals have acted as gatekeepers to transition services for transgender people. This is problematic for those who do not otherwise have a mental disorder or desire mental health treatment, or do not have access to this resource. In South Africa, the lack of adequate training of mental health professionals creates an additional barrier to both access and quality of care.

However, mental health professionals can play an integral role in the assessment, ongoing support and treatment of many transgender people as they move through their transition process. This involvement should always be guided by standards of care, and where possible, multidisciplinary consultation regarding clinical necessity.

Patients are primarily referred by local CSOs such as Gender Dynamix and the Triangle Project (a lesbian, gay, bisexual, transgender and intersex service organisation), community health clinics, district and regional hospitals, private psychiatrists and psychologists, as well as general practitioners from non-major

urban and rural areas. Many referrals to the Groote Schuur Unit are from outside the Western Cape Province, i.e. the Eastern and Northern Cape, KwaZulu-Natal and Gauteng provinces.

## Challenges facing the Transgender Unit and transgender services in South Africa

### Limited funding and resources

The greatest challenge currently facing the Transgender Unit is the effect of limited resources on staffing. The surgical component is under the greatest pressure, with limited theatre time available, making provision for only 2 - 3 completed gender reassignment operations annually. The monthly referral rate of 3 - 4 clients translates into a surgical waiting time of up to 15 - 20 years, which is a source of great distress for patients. As public awareness of transgender issues increases and patients present earlier, the Unit encounters greater patient numbers and a growing proportion of adolescents. To fulfil its mandate of providing transition services to patients and offer technical support to the region, further funding is needed.

### Limited professional training and research

The lack of undergraduate and limited postgraduate training in transgender issues severely restricts the number of trained carers. There is also a need for increased interest and involvement of reconstructive and other surgeons in the treatment of transgender people. Lack of local transgender research limits the development of evidence-based interventions.

### Patient needs

With so few facilities, rural patients are severely disadvantaged by logistical considerations. The social stressors of high levels of stigma, discrimination and persecution further burden the health of transgender people.

## Conclusions and recommendations for the way forward

With new standards of care enabling devolvement of endocrine management to primary or secondary healthcare settings, the Transgender Unit is already putting in place a supportive

framework and guidelines to enable general practitioners to offer patients transition therapy. Innovative ways are also being sought to expand the surgical expertise base, including using surgeons from transgender units abroad to train local surgeons. The inclusion of aspects of transgender issues in the undergraduate curriculum and development of a CPD-accredited course in transgender health are under consideration.

As the Unit currently also treats patients from outside the Western Cape Province, there are legitimate grounds to motivate for quaternary funding from the National Department of Health. The paucity of localised transgender research provides scope for further projects using our existing data.

Advocacy efforts are being explored to achieve wider access to healthcare for transgender individuals. A process is underway to engage with medical aids to provide more inclusions for transgender therapies.

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