



Ghent University Hospital, Belgium
Ghent University, Belgium

Correspondence to: G T'Sjoen
Guy.T'Sjoen@ugent.be

Cite this as: *BMJ* 2022;379:o1949

<http://dx.doi.org/10.1136/bmj.o1949>

Published: 03 October 2022

SELF-CARE INTERVENTIONS FOR SEXUAL AND REPRODUCTIVE HEALTH RIGHTS

Integrating transgender care into mainstream medicine—an essay by Guy T'Sjoen and Joz Motmans

All healthcare professionals will find themselves supporting care for a transgender or gender diverse person at some point, and education and research need to be widened, write **Guy T'Sjoen** and **Joz Motmans**

Guy T Sjoen, Joz Motmans

Population estimates show that transgender and gender diverse identities or experiences can no longer be considered a rarity. The prevalence of transgender identities is cited as 0.3% to 0.5% among adults and 1.2% to 2.7% among children and adolescents¹; data from the 2021 Canadian census, to pick one example, showed 0.33% of the 30.5 million citizens identifying as transgender or non-binary (box 1).^{2,3} These numbers can be understood through the evolving awareness of gender diversity in societies, the improved legal framework in many regions around the world, access to information over the internet and through social media, and the existing possibilities for gender affirming care.^{4,5}

Box 1: Gender diverse terminology

- Transgender or trans are umbrella terms used to describe people whose gender identities or gender expressions are not what is typically expected for the sex to which they were assigned at birth.
- Transgender women, trans women, or women of trans experience are people who were assigned male at birth and who have gender identities as women. They may, or may not have undergone any transition.
- Transgender men, trans men, or men of trans experience are people who were assigned female at birth and who have gender identities as men. They may or may not, have undergone any transition.
- Gender diverse is a term used to describe people with gender identities or expressions that are different from social and cultural expectations attributed to their sex assigned at birth. This includes people who identify as non-binary, gender expansive, gender non-conforming, and others who do not identify as cisgender.

As more people feel comfortable in outing themselves, more transgender and gender diverse people are seeking psychological or medical care, with rising referrals reported by gender clinics.⁶ Moreover, it is almost inevitable that anyone working in healthcare will sooner or later have at least one transgender patient under their care. Emergency staff may be confronted with a trans person brought in after a car crash; a general practitioner may be puzzled with gender reversed lab results; a radiologist may see unexpected organs on magnetic resonance imaging. All healthcare professionals therefore need at least some knowledge on the composition of diverse

bodies, and on the health needs of this patient population so that even simple care is not delayed.

Moreover, healthcare professionals have an important role in supporting gender diverse people to care for themselves through provision of reliable information or access to medication, self-testing, and other self-care practices. This can help to improve health outcomes and support their mental health, among other benefits. But the lack of access to supportive quality care inhibits people's ability to effectively self-care. Feeding into this is the poor knowledge and education of healthcare professionals that can affect clinical judgement and communications with transgender and gender diverse people.

The first commitment of all healthcare workers is to quality of care with compassion, with the goal of improving lives. Inappropriate curiosity, such as asking about their genitals or surgery history when this is not relevant for the specific medical issue being treated—often cited as the most common experience of transgender and gender diverse people seeking healthcare—should be avoided.⁷ A non-judgmental and open approach is important, and attention to sensitivities in language can contribute to building trust with patients.^{8,9} A single patient should never be the only source of information, and healthcare professionals need to be as well informed about transgender and gender diverse health issues as their patients. As such, knowledge and education around transgender care should no longer be managed by the few specialised interdisciplinary gender care facilities.

Getting started

Many healthcare professionals have not received any training on transgender health as it is not systematically included in curriculums. Results from an online survey among European healthcare professionals showed that only 52.7% reported some form of training on transgender health and that training led to increased confidence.¹⁰ GPs had significantly lower confidence than nurses, psychosocial care providers, and other medical specialists. Ninety per cent of healthcare professionals believed that training would raise their competence, and this belief was significantly higher among professionals who had received some training.¹⁰

Healthcare professionals who are more specialised in transgender care often start working in this field through personal interest or after meeting a transgender and gender diverse patient. They rarely get a chance to dedicate more than a few hours a week to train in aspects that may help. This is why most gender clinics are made up of part time and largely self-taught “gender specialists.”

Transgender healthcare is a relatively new field, so healthcare professionals need to spend more time offering not just good quality care but dealing with policy makers and administration, not to mention the time and effort it takes to argue for space, time, specialist staff, and recognition for transgender and gender diverse patients within existing healthcare frameworks.

Outdated guidelines on frequency of outpatient visits for patients receiving hormone treatment also create an unnecessary workload.^{11 12} Three monthly follow-up sessions on starting treatment have often in reality been reduced to only two visits in the first year, at three and 12 months, as few problems are raised at follow-up and treatment strategies rarely need adjustment. These decisions have been partly determined by the long waiting lists. In some countries the waiting times for specialised gender clinics are now up to three to five years,¹³⁻¹⁵ making it necessary to rethink the organisation of care.¹⁵ Our centre in Ghent, Belgium, for example, saw 487 patients for an initial appointment in 2021. But a further 863 people contacted our service (an increase of 170% compared with 2016) and had to be put on the waiting list. At the same time, in many regions of the world no care is available at all or clinics are few, apply restrictive criteria, or require long travel times.⁷

A lack of available care and barriers to accessing it may add to a higher prevalence of mental health problems such as suicide and depression among trans and gender diverse people,¹⁶ and may lead some to self-manage with unprescribed gender affirming hormone treatment.¹⁷ Care professionals see substantial numbers of patients who self-medicate, especially trans women taking contraceptive pills.¹⁸ This is largely because of waiting lists, unavailability of care, or distrust in healthcare professionals.⁷ Health professionals may get irritated with patients or turn them away if they declare self-administration (or self-initiation) because they do not meet the requirement of being without hormone treatment at presentation for mental health evaluation. Patients may then have to start again at the bottom of a waiting list for another centre or to turn to private (and more expensive) practices. Although it is understandable that doctors will not accept responsibility for treatments not started through the health system, respect and dignity for all is crucial. These patients need reassurance about the effectiveness and safety of their treatment and may want professional guidance and adaptation of their treatment. Nevertheless, to minimise health risks, it is crucial to motivate patients to adhere to prescription drugs and to avoid the risks of inappropriate dosing and counterfeit medicines on the black market.¹⁹

The increased visibility of transgender and gender diverse people, and especially the increase in referrals of children, has resulted in a more critical approach to transgender care and severely polarised opinions. This may partly explain why many healthcare professionals hesitate to get involved. Members of specialised gender teams need to build a network with colleagues in other disciplines, including primary care, so that continuation of care is not hindered and established gender clinics can stop being the bottleneck of care. International networking among other trans care providers is also needed to share new insights, fresh ideas, and learn from one another's experience.

Mainstream educational programmes

Research shows that healthcare professionals working in transgender care services have mostly sought knowledge from less reliable sources on the internet²⁰ or from more specialised conferences, published papers, or guidelines.¹⁰ This implies that postgraduate training is much needed for healthcare professionals licensed some years ago.

A recent review of transgender health content in medical education found that most current training consisted of single session interventions facilitated by instructors with a range of professional experience; half covered more general LGBT+ content, and half was trans health specific.²¹ The authors detected several facilitators (such as scaffolding learning throughout the curriculum, drawing on expertise of transgender people, and engaging learners in skills based training) as well as barriers (lack of educational materials, lack of faculty expertise, time or cost constraints, and challenges in recruiting and compensating transgender guest speakers).

The original guidelines and care protocols for transgender care were written in the late 1960s and have been regularly rewritten since.¹¹ The shift from experience based approaches to more evidence based approaches is notable over the past decade. An update of the World Professional Association for Transgender Health's standards of care²² is due to be published in autumn 2022. Based on a strong peer reviewed process, it will provide information on current knowledge and practices. As a result, many aspects from current training programmes will need further debate and update. Topics that are heavily debated focus on the one-size-fits-all gender affirming hormonal therapy, and the need for specific protocols for treating non-binary people. Other topics include the time required for different stages of transitioning, such as length of mental health counselling, the requirement for hormonal therapy before irreversible surgical interventions, and the age restrictions in adolescent care.

Quality care is rapidly evolving in this field and needs to move beyond purely medical knowledge and content. The broader social and psychological wellbeing and quality of life aspects determine health as well, hence the need to work interdisciplinarily in trans care facilities. For example, many restrictive concerns about the safety and effectiveness of gender affirming hormonal therapy need to be revised. One example is the monitoring of liver function tests, which were once described as mandatory but are not necessary if there is no other medical indication.²³ Hormonal therapy in fact has few serious side effects, although you will still find long lists of (relative and absolute) contraindications and safety measures in current guidelines.

With the aim of mainstreaming transgender care, GPs need to be trained and educated about the necessary (and often) lifelong follow-up of transgender patients taking gender affirming hormonal therapy. A recent study found just 50% of surveyed GPs are willing to take on such care, with willingness related to religious identity and perceived capability of providing routine care.²⁴ Training of healthcare professionals is also important for supporting self-care of people taking hormonal therapy.

Research and funding support

Transgender healthcare is a relatively new specialty, as are many of its interventions. Thus, work with transgender and gender diverse patients also means engaging in clinical research. Gender clinics have to divide their attention between seeing many patients and setting up research efforts, well aware that time spent in research will only increase the ever expanding waiting list. Research is,

however, needed so that gender clinics obtain the scientific information to train and support their colleagues.

Funding agencies have been slow to adapt their frameworks to accommodate research into transgender healthcare, making it difficult. Nevertheless, more progressive examples such as the National Institutes of Health's sexual and gender minority research office exist.¹ The reason so many clinical research questions remain today is because the right questions haven't been asked or questionnaires were not adapted to the studied population and clinical researchers did not find access to substantial funding.

To keep our finger on the pulse and to avoid mistakes from the past, new holistic population health surveys should include questions on gender identity to discover a detailed and realistic sample. Equally important, medical research is too often blind to part of a reality that includes a socioeconomic context, stigma, and minority stress, among other issues. Insights from broader general health surveys should ideally inform healthcare professionals about new developments, including concerns that have not yet entered the consultation room. For example, the medical world has been blind too long to the specific health needs of people with non-binary identities. The life stories of transgender and gender diverse people and real life data collected with a scientific approach may hopefully influence those opposing trans related care, and may trump the many ill-advised opinions out there.

Current transgender research is mostly confined to people who are receiving clinical care. A challenge will be to also reach people unknown to or outside the healthcare system. Access to online communities and recruitment through collaboration with peer recruiters will open these doors. Research on trans health also needs to apply specific ethical considerations.^{25 26}

Doing better

It is unacceptable to ignore the needs of the growing number of transgender and gender diverse people who wish to access gender services. This requires reorganisation of transgender care so that it is not only available in overloaded specialty services. We call on governments to invest more in training programmes for healthcare professionals, both as a structural component in the curriculum and in lifelong learning programmes. Research shows clearly that education increases confidence and competence, and well informed healthcare providers will lower many obstacles transgender and gender diverse people experience in accessing care. Putting care into the mainstream is the only way to cope with the increases in demand we witness, and to decrease self-medication and the terrible effects that long waiting lists have on the mental health of transgender and gender diverse people.

At the same time, more long term follow-up research is needed. Studies have often excluded participants who had started hormone treatment before their first visit. This is no longer tenable given the high percentage of new patients who already self-administer hormones. The inclusion and exclusion criteria for (expensive) endocrine research have been strict. Including people who self-administer would be a leap forward in breaking down these research walls, by including a broader spectrum of people taking gender affirming hormonal therapy and thus creating larger databases. Comparing their data on first encounter to those of study participants with similar duration of prescribed hormone treatment within a provided context (such as the European Network for the Investigation of Gender Incongruence²⁷) will elucidate differences in safety and effectiveness. Psychosocial variables must also be included in this type of research.

The need for more education and more research puts an important responsibility on educational committees and research funding agencies to push this long ignored field forward.

Biographies

Guy T'Sjoen is a clinical researcher and principal investigator for the endocrine part of the multicenter ENIGI (European Network for the Investigation of Gender Incongruence) study. He is as past-president of EPATH their representative at the WPATH board (European and World Professional Associations for Transgender Health).

Joz Motmans is the president of EPATH and the coordinator of the Transgender Infopunt, the Flemish expertise centre on transgender topics.

Competing interests: We have read and understood BMJ policy on declaration of interests and declare the following interests: GT has received scientific grants from Ipsen, Bayer Shering and Sandoz. He is associate editor for the *International Journal of Transgender Health* and the *Journal of Sexual Medicine*.

Provenance and peer review: Commissioned; externally peer reviewed.

This article is part of a series proposed by the UNDP/UNFPA/Unicef/WHO/World Bank Special Programme for Human Reproduction (HRP) and commissioned by The BMJ. The BMJ retained full editorial control over external peer review, editing, and publication of these articles. Open access fees are funded by HRP.

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