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Alleviating gender dysphoria: a cross-service analytical framework

Objectives: The aim of this paper is to address a core gap in the research literature relating to trans and gender diverse (TGD) people of ways to alleviate gender dysphoria in service provision which could be applied in health and other areas. **Methods:** A national Australian Study on TGD people combining key informant interviews (n=14), survey (n=340) and in-depth interview (n=12) data was used to conceptualise a framework for alleviating dysphoria. **Results:** The framework presented in this manuscript can be used by researchers and service providers in various fields to design study protocols, assess organisations and enhance their everyday practice. The two important areas included in the framework are the context of the experience and characteristics of systems. **Conclusions:** The framework described in this manuscript can facilitate an efficient assessment of a service's current practices, inform a practitioner's daily practice and be used by researchers to appropriately design studies.

It provides an analytical framework that can be used across multiple settings developed from this process.

Keywords: gender diversity, service, framework.

Introduction

Health and wellbeing issues of the trans and gender diverse (TGD) population have gained increasing attention within research alongside growing societal awareness and acceptance of gender diversity. Broadly, TGD people are defined as those whose gender does not align with their sex assigned at birth and people who identify with a gender outside of the binary of man/woman¹. As a community, TGD people are estimated to make up 0.1-0.7% of the population². International research has documented consistently that TGD people experience disparities in their health and wellbeing when compared with general populations and many barriers when accessing healthcare, existing at the structural, interpersonal and individual level³⁻⁷. The disadvantage face by TGD individuals is attributable to discrimination and stigma affecting their opportunities – for example, they are at greater risk of homelessness and low income⁸,

and rates of depression and anxiety have been found to be at rates up to six times that of general populations ⁹. Internationally, the evidence consistently finds that the majority of TGD people experience discrimination and harassment based on their gender, including verbal, written physical, sexual and exclusory actions ^{4,6}. Many TGD people therefore conceal their identity out of fear.

The stigma associated with diverse genders stems from the dominant societal view of gender which views this as binary and, more broadly, a limited understanding of gender diversity ¹⁰. In order to affirm their gender, many TGD individuals seek healthcare services to aid with medical and/or surgical therapies, and they therefore have frequent interactions within healthcare systems, commonly experiencing poor treatment and care ^{6,8,9}

Many TGD individuals 'gender dysphoria', a term coined in the 1970s ¹¹. Although contentious for reasons relating to medicalisation and pathologisation of diversity, the term gender dysphoria is broadly accepted within the TGD community ¹². From the community perspective, the phrase is used to describe discomfort that is associated with one's body or the way other people perceive one's gender identity; whether at a social, physical or emotional level ¹³. There are varying degrees to which TGD people experience gender dysphoria which can be a source of significant distress for many in the community ¹²; though some individuals report not experiencing it . Management of gender dysphoria can include: medical and surgical care; psychotherapy; change in gender role or expression; peer support; voice therapy; hair removal; binding of chest tissue and other body contouring methods; or changing legal documents ¹.

Gender dysphoria may be especially overwhelming in a healthcare setting during invasive procedures or settings that are highly gendered (e.g. cervical screening)

¹⁴. Several practical guidelines exist specifically related to gynaecologic and cervical screening for TGD people, as well as LGBT-general guides to primary healthcare ¹⁵⁻¹⁷. Additionally, other guidelines exist for front-line healthcare staff on best practices for affirmative care of TGD people (especially relating to communication and organisational aspects) and legal guidelines for TGD-affirming hospital policies ^{18, 19}. Missing from these practice frameworks/guidelines and the research literature more broadly are TGD people's perspectives on ways to specifically alleviate dysphoria in all clinical encounters that may trigger dysphoric distress. This article, using data from a national Australian survey and interviews with key informants and TGD people, provides an analytical framework for alleviating gender dysphoria across multiple settings, both clinical and in research, to address this gap.

Methods

Data used to understand and develop a framework for alleviating gender dysphoria were taken from several different stages of a study on health and cancer care for TGD Australians approved by the lead author's university ethics committee (HEC18034 and HEC18341). A community reference group was formed at the beginning of the study and has been involved in study design, recruitment, reporting and dissemination.

The first stage of the research comprised key informant interviews; to inform the main data collection. Participants included a diverse cross-section of fourteen participants who were TGD community members and leaders, and/or professionals who were selected based on their experience working and/or researching with the TGD population. Participants were identified through research publications, gender services networks, a conference and community advocacy groups across Australia. Recruitment

for the semi-structured, key informant interviews continued until data saturation was reached..

Using insights gleaned from the key informant interviews and community reference group input, a survey and interview guide were then developed. The online survey was conducted in 2018-19 and involved 537 TGD Australians aged over 18. The survey sample was a convenience sample obtained through online Facebook advertising. Organisations and people associated with the TGD community also shared the post amongst their networks, generating a snowball sample. The interviews involved twelve TGD people who had a diagnosis of cancer (aged from 18-60, four trans women, four trans men, three non-binary people and one genderqueer person).

The current manuscript has as its' main focus of analysis answers from survey participants to the open-ended question 'what do you think could be done in healthcare to minimise the body discomfort (dysphoria) that may be felt during certain procedures (e.g. ones that involve genitals)?'. The data was analysed thematically, following steps outlined by Clark and Braun ²¹. Using NVIVO 12, the first author analysed the survey data inductively to allow for the emergence of themes which were true to the participant's sentiments. The first phase involved reading and making notes on the data. In the second stage, preliminary codes were created and the data were coded according to these. In the final stage, codes were grouped into themes and these were refined. During all phases, the research team discussed all coding and thematic decisions. Once the themes from the survey data were clear, the first author used these to analyse the key informant and in-depth interview data with deductive thematic analysis methods. This provided a selection of quotes that expanded upon the themes from the survey participants.

In total, 340 survey participants (63.3% of total survey participants, 537) reported the factors that they felt most influenced their experience of dysphoria during invasive procedures. The participants were young overall, with 60.6% (n=206) being between the ages 18-24. In terms of genders, 42.6% indicated that they were gender diverse (including non-binary, genderqueer, agender, and a variety of other identifications), 37.6% were trans men and 19.7% were trans women. Around three quarters were assigned female at birth, and the majority were low income earners (\$0-\$37,000, 76.1%). There were no significant differences in age, gender, sex assigned at birth or income between the overall survey participants and those who responded to the question. As Australia does not collect population-level data on diverse genders, it is not possible to compare the characteristics of the survey participants with those of TGD Australians broadly. See Table 1 for all of the sociodemographics of the survey participants.

[Insert Table 1: Sociodemographics of survey participants]

Results

The most important theme to the survey participants in their response to the question on alleviation of dysphoria in healthcare, concerned the context of the experience (72.4%) – including the interpersonal qualities of healthcare workers (35.3%), language and pronouns (32.6%), and practical aspects (31.8%). Factors associated with systems were also important to survey participants (24.4%), especially education and awareness (21.8%), and to a lesser extent creating welcoming and inclusive environments (7.1%), and access to gender affirmation (2.6%). Notably, almost one out of ten survey participants (9.4%) were unsure, and 4.4% said that there was nothing that could be done to help to alleviate dysphoria. Table 2 shows all themes from the survey

participants. The most common themes for survey participants have been directly taken as those which are most important in the framework, with consideration for their exploration in both sets of interviews. In our discussion of these themes below, we therefore emphasise the survey participants reflections, and also make occasional reference to data and specific quotes from both the key informant interviews and in-depth interviews as relevant; where these deepened or best illustrated understandings for concerns raised by the survey participants.

[Insert Table 2: Themes from survey participants]

Theme descriptions

Context of the Experience

Interpersonal Qualities of Healthcare Workers

Over a third of survey participants talked about the various interpersonal qualities of healthcare workers that would help to mitigate feelings of dysphoria. This was described as “*bedside manner*”, composed of good communication, respect, trust, understanding and professionalism. Especially with regards to communication, it is important that patients are well prepared and educated for procedures and what will happen during them. It is expected that a competent practitioner or researcher will ask the right questions (e.g. using sensitive and appropriate language that matches the individual’s experience) and not irrelevant or invasive ones. Participants emphasised the need for the practitioner to communicate safety and engage in active discussion. In terms of performing the procedure, participants stated that they valued confidence, calmness and efficiency.

As long as the doctor is understanding and professional then I feel respected and can cope with any discomfort.

Survey Participant

Understanding and respect shown by the people carrying out the procedures.

Survey Participant

Asking or listening to patients in terms of what language they're comfortable depending on the specificity of their situation. Acknowledging their discomfort and validating it, not alienating them because of it.

Survey Participant

Many participants talked about other characteristics of healthcare providers that influenced the interaction and would help to minimise dysphoria, including: empathy, open-mindedness, humanity, supportiveness, reassurance, sensitivity, gentleness and appropriateness. As one participant said, they would find invasive procedures easier if people were "*less arseholes*". Further, healthcare workers affirming the patient's gender, not treating them differently and not making assumptions were all valued.

...that was just an immediate assumption on his part that I'm a trans woman, so I must hate my penis and want to chop it off, and that's just not the case at all... I've never had dysphoria with my penis.

In-depth Interview Participant No. 5.

It's a definite worry though, the reactions of other people. I'm caught between not wanting to hide who I am, but also not wanting doctors and allied health staff to be completely transfixed by me being trans and not just getting on with whatever I'm actually there for. Look for potential cancers, stop speculating about what my genitals might look like, you know? But it's always something I am aware of and cautious about.

In-depth Interview Participant No. 9.

I'm also hyper-sensitive to the non-verbal cues, you know, the double look, or that nurse when I rolled over and she was expected to see things and they weren't there, and as I say for the most part the medical profession was terrific, and that, in a way, helped me with my confidence... because I'm always waiting for someone to pick me, someone to say, 'you're not a woman,' and that in itself is very tiring, waiting for someone to say that... and as I said much earlier, had I been pre-operative I think it would've been a lot different, a lot harder, there would've been a lot more obstacles.

In-depth Interview Participant No. 10.

Language and Pronouns

Almost a third of survey participants acknowledged that language and pronouns were a significant part of lessening dysphoria, as certain terms can trigger feelings of discomfort. Particularly important was being affirming of the patient's gender, through the use of pronouns, names, and the terms for their body that the individual uses. This also translates to research in the form of asking questions using the right language, providing appropriate options to questions and, where relevant, addressing participants with the correct pronouns. Relating to pronouns, the healthcare worker should ask about these (including in forms), be open to them, not make assumptions and respect them. Participants discussed how being misgendered can be both distressing and embarrassing.

Open conversation about preferred pronouns so that the discomfort of being misgendered is at least somewhat alleviated. ask which terms individuals prefer when referring to particular body parts, and how much communication is maintained throughout the procedure.

Survey Participant

Ask the patient if they have preferred replacement names for particular anatomical structures. Refer to the patient with their preferred pronouns and don't compare body parts to the sex (I.e "this is normal for most females").

Survey Participant

Another prominent topic related to language amongst survey participants was the use of non-gendered language. Survey participant's statements surrounding this included the de-gendering of genitals (e.g. avoiding gendered anatomy terms such as breasts), not basing language on genitals, using the phrase "people with a [body part]" as opposed to "men/women", not referring to the patient's birth sex and using generally neutral or agendered language (such as genitals). It was also seen as important that the procedure itself was not gendered (e.g. cervical screening being for women). Another aspect is not comparing body parts to the patient's sex assigned at birth and use of the word normal. Language that is medical, scientific or clinical was acceptable to many. Participants in the key informant interviews addressing this theme specifically talked about sensitivity to the vocabulary used, and using gentle terminology.

So many people told us, in a sense, horror stories... There was the man who went in and explained that he was trans, that he still had a cervix, and he needed a Pap test, and the minute the doctor looked at the case studies and heard that flipped, and instead of calling him 'mister' went back to using female pronouns, and that's just humiliating, and it's got to be intentional, it's not an accident, when you're looking at somebody who is presenting as masculine to suddenly do that.

Key Informant Interview Participant No. 3.

Cultural competency goes a long way... a basic understanding of terms you do and don't use – and I think it's common sense, but it's obviously not. Refer to the person as their preferred pronoun, ask them their name and their preferred pronoun and don't get caught up suddenly going 'oh it's a transgender' – they're a person. But the language you use, if they say their name is 'John', and they want to be referred to as 'they', that's the language you use, and then being aware of the language that they use for referring to parts of their body.

Key Informant Interview Participant No. 6.

Practical Aspects

For almost a third of survey participants, practical aspects of the context of the procedure identified as impactful around dysphoria included patient control, privacy and a diverse range of other suggestions. Of high importance was person-centred care in which the patient's individual needs are supported and respected and enhanced control given to the patient. This included comments about guiding one's own care; the ability to say stop or that they need a break ; informed consent; being offered options; the ability to choose a doctor of the same gender or who is TGD knowledgeable; and tailoring procedures to the individual. Such practical concerns extend to research and are important considerations in ethics applications. All of these depend on ongoing open dialogue between healthcare worker/researcher and patient/participant and connecting with the community to build trust. Participants emphasised that as it is individual it varies and reinforced the necessity for empathy.

Letting the patient guide their own care, allowing them to feel comfortable to say stop if they need to, or to ask the dr to stand by the side of the bed etc.

Survey Participant

Talk to the patient? It's all individual. And also make sure they trust the doctor/nurse or get someone they trust so the patient is comfortable.

Survey Participant

Privacy and discretion were also prominent topics in these survey participants' perspectives. Comments related to this included having a cover over any sensitive area so that the patient is unable to see, immediate covering up over the area, no mirrors and having the least amount of people involved possible. Other practical aspects that participants mentioned were the provision of tissues, the ability to wear comfortable clothes, warmer hands, careful and precise touching, having a support person present, sensory distractions, sedation, the availability of self-examination, and providing support numbers.

Allow people to wear clothes they feel comfortable in, respect people's choices to have or not have a third party present during physical examinations.

Survey Participant

Systems

Education and awareness

Over one fifth of survey participants mentioned that education and awareness was necessary, which was mostly in relation to healthcare workers but also related to the TGD community and administrative staff. There were a wide variety of ways in which to educate people mentioned, including: posters; pamphlets; training/workshops; courses; education at university; continuing professional development programs; resources; and broadly connecting with the community. The main topics to be educated and aware on were: general TGD issues (including specific healthcare issues such as hormones); dysphoria and the associated discomfort; language; general sensitivity; and

addressing misconceptions. Both survey and key informant participants also mentioned the need for more research and further specialisation.

Education is critical. I've had many exams and it's being treated differently that's frustrating, even if that is in the form of someone trying to do the right thing. As an example, I've had a doctor apologize about 6 times for giving me an exam - although they apologized because they recognised that I might be uncomfortable...just get on and do the darn thing. Explain what your doing, use common but medical language and don't treat me differently.

Survey Participant

Doctors, specifically GPs need to learn more about trans health, a lot of doctors have misconception and misinformation about how trans medicine works.

Survey Participant

Teach doctors that it's a serious issue, make them understand that some people need patience and/or coaching to help them through certain procedures that may trigger dysphoria.

Survey Participant

I think a basic level of training in gender issues would have helpful for all medical professionals. Those that I have encountered seem to be completely inexperienced or highly experienced with no inbetween.

Survey Participant

I don't think it's addressed adequately in pre-service training, and I don't think it's addressed very well in any kind of in-service training or ongoing medical training... and I think there's a huge amount of prejudice and misunderstanding.

Key Informant Interview Participant No. 1.

Under a tenth of survey participants mentioned other aspects of the service's system that could be addressed to create a welcome and inclusive environment. These included collecting individual's preferences in forms and/or databases; de-gendering services; and having an online list of TGD-friendly practitioners. Both survey and key informant interview participants especially wanted spaces that felt *safe*.

GP and medical centres sign up on a website as trans friendly
Survey participant

On patient information forms have a box for biological sex and one for gender identity. Have the option for people to write down their identity, pronouns, and preferred name.

Survey participant

To avoid unnecessarily gender exclusive language in the administration of health care facilities (for example signage or mail referring to patients as ladies only, for mammogram, or pap test)

Survey participant

I would like to be able to get reproductive checks without going to a clinic for women

Survey participant

The images and symbols, whether that's a rainbow on the window, and all that stuff is important. People like myself, you know, professional people who aren't rushed may actually Google and look at the service, so you want inclusive things on web pages, before they access.

Key Informant Interview Participant No. 4.

Obviously, the gendered nature of many cancer screening services [is a barrier], BreastScreen, and Pap smears, and prostate checks and stuff like that, they're obviously very gendered in the health promotion side of things and around that prevention area.

Key Informant Interview Participant No. 8.

Access to Gender Affirmation

It is important to note that only nine survey participants (2.6%) responded with a comment relating to gender affirmation procedures, which indicates that although having gender affirming surgery is significant for many people who are TGD, it is not at the forefront of their mind when thinking about the immediate situation of having an invasive procedure which may produce feelings of dysphoria. Comments that participants made relating to gender affirmation included: that if they had access to surgery they would not have any dysphoria; the need for better funding and decreased waiting times; and that people who have had surgery do not find the question relevant. One participant stated, “*I’ll die before I get anything checked,*” and that they wanted “*everything ripped out or off.*” The impact of gender affirmation was reflected across both survey participant and indepth interview participant comments:

I would as a transgender person have far less dysphoria if I had access to medical procedures that would help eliminate this dysphoria, I can't afford and won't be able to for a long time SRS [sex reassignment surgery] or any other that would allow me to feel comfortable in any space.

Survey Participant

I've had SRS, so not sure what you mean by this question.

Survey Participant

I felt bad about my body pre-surgery, gender surgery, once I had gender surgery dysphoria just flew out into the sunset, I was happy with my body after that.

In-depth Interview Participant No. 10.

Other comments

Other comments which survey participants made included relating a personal experience and the irrelevance of the question to them personally (either because they do not experience dysphoria or have had surgery that alleviated it). Importantly, 4.4% of survey participants believed that there was nothing that would be effective in minimising dysphoria.

Discussion

The framework developed in this manuscript (see Figure 1) and described below can be used by researchers in various fields (e.g. sociology, gender studies, public health, education) to design study protocols, services providers to assess their organisation (e.g. healthcare, schools, correctional facilities), and professionals in everyday practice (e.g. healthcare workers, teachers, social workers). Briefly, the framework constructs moving from right to left, proximal to distal, illustrate a layering of our findings and how they might interact and lead to alleviating dysphoria. The more proximal constructs, those closest to the actual experience, centres on the context of the experience – how the professional interacts with the TGD person, the language used, and sensitively managing the practical aspects during the interaction. These factors can be bolstered (or hindered) by characteristics of the service's systems – especially through education and training, environments and system-level influences on access to gender affirmation (e.g., coverage by health insurance, ability to legally change documents).

[Insert Figure 1: Alleviating Dysphoria Framework]

Of highest importance in any immediate situation which may trigger dysphoria are the more proximal influencing factors – especially the interpersonal qualities of the professional involved, language used and practical aspects. This is perhaps unsurprising given that definitions of gender dysphoria (see introduction) include the discomfort that an individual feels related to other people’s perceptions – dysphoria may thus be a highly social, intersubjective experience induced by interacting with others. Research from other fields supports these findings. In a study on the school experiences of Australian TGD students, poor outcomes (e.g. school dropout) were associated with not receiving teacher support and teachers inappropriately identifying TGD students (that is, the interpersonal qualities of professionals and language use)²². Further to this, uniforms also affected the students’ experiences of school (i.e. a practical aspect)²². Research on trans women detained in male correctional facilities has also highlighted the issues faced within this setting – interactions that are far from empathic and inappropriate use of language^{23,24}. Using the framework, services have the opportunity to identify such gaps and move to address them, and researchers to design studies which are sensitive to feelings of dysphoria and may investigate individual experiences. Of particular significance for factors that fall under the ‘context of the experience’ is that they are apparently most important for alleviating dysphoria and are relatively low-level aspects which are easy for any professional working in a field to alter at an individual level.

In terms of the overarching theme of ‘systems’, the most important characteristic appears to be the implementation of training and education. As depicted in the diagram, education and awareness is important because it may have significant flow-on effects which improve the interpersonal qualities of HCWs relating to TGD people, HCW use of language, how they approach practical aspects in immediate situations and help to

create welcoming and inclusive environments. There have been numerous studies on TGD health and wellbeing across many areas that highlight the need for education and training within services to improve their experiences ^{25,26}. Although this has been found to be contentious in particular areas (e.g. for schools see Law ²⁷ and for the police force see Miles-Johnson ²⁸), it has also been found to be acceptable and feasible in many other areas, including the military and within prisons ^{29,30}. Particularly important for education and training is the involvement and input of the TGD community, and covering a range of relevant topics (which may differ based on the organisation, hence the need for TGD community involvement).

Creating welcoming and inclusive environments has been addressed in several informative guidelines e.g. National LGBT Health Education Center ¹⁹, although not specifically related to alleviating dysphoria. Our participants highlighted the need for the de-gendering of services. Services may differ in the ways and level of gender segregation from issues with toilets to entire facilities that are structured based on gender (e.g. prisons for men, prisons for women). As our participants mentioned, sometimes creating a welcoming and inclusive environment may be a simple change of displaying information/posters that demonstrate inclusivity and safety. This, of course, must be backed by adequate training of staff.

It is significant to highlight that whilst much literature on gender dysphoria focuses on the role of medical gender affirmation in alleviating dysphoric distress, it was not as important as the context of the experience – especially things that relate to the HCW (interpersonal qualities, use of language). This suggests that although the body is obviously a major part of experiences of gender dysphoria, concerns regarding social relations are of higher concern. Various environments beyond healthcare may be involved in or have capacity to be of aid in the area of gender affirming medical care

(e.g. schools may have a nurse or counsellor who can be of assistance at facilitating this, correctional facilities have healthcare on site). Assessing this area is important, as it is possible for some TGD people that gender dysphoria can be totally alleviated through gender affirming medical care.

Finally, ‘systems’ broadly relates to high-level organisational structures. Through the creation of policies and programs for change, a variety of systems can have a trickle-down effect on an individual’s experience of dysphoria. For example, appropriate legal recognition of gender by state and territory governments can influence the context of experiences and changes to healthcare can improve access to gender affirmation medical care.

The participants in this study had clear ideas on how dysphoria could be alleviated for them. These themes have been converted to a series of questions in the framework. For example, such important points made by the participants as building rapport and trust through the ways that dialogue is established and maintained became the question ‘are services providers and professionals building rapport and trust with transgender and gender diverse service users through open and active dialogue?’ Follow up questions for each main question investigate the issue further (see Table 3).

[Insert Table 3: The cross-service gender dysphoria alleviation research framework]

This article has supplied a practical model of questions to be used in overcoming heteronormativity and cisnormativity in services (see Table 3); however, prejudices cannot be changed with such information alone. Such a model would be most successfully implemented in practice on a large scale if it were reflected and applied in higher education and industry training programs; and if legislation better underscored a

requirement of non-discrimination policies for all services and professionals (without exemptions on religious grounds).

The study showed the importance of the inclusion of TGD people in the development of research frameworks on gender dysphoria alleviation. The framework developed in this manuscript can be used across many areas – within research, service provision and at the individual practitioner level. The two important areas of consideration are the context of the experience and characteristics of systems. The framework can facilitate an efficient assessment of a service's current practices that identifies important areas in need of change, inform a practitioner's daily practice and be used by researchers for appropriate design of studies and further investigation of experiences of dysphoria within services.

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Declaration of Interest Statement

The authors have nothing to disclose.

Data Availability Statement

Research data are not shared.

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