



Transgender and gender diverse people with endometriosis: A perspective on affirming gynaecological care

Sam Jeffrey¹ , Louis Ashton², Tania Ferfolja³ and Mike Armour^{1,4}

Abstract

Transgender and gender diverse people presumed female at birth experience gynaecological conditions, such as chronic pelvic pain at elevated rates, estimated to impact between 51% and 72% of this population, compared to rates of up to 26.6% in cisgender women. The negative impact of these conditions is likely amplified due to limited access to safe and affirming healthcare. Despite this high prevalence rate, there is limited research investigating the prevalence, presentation or management options for trans and gender diverse people with endometriosis. Cisgender women with endometriosis report barriers to accessing care, with lengthy times to diagnosis and limited treatment options available. However, barriers for trans and gender diverse individuals are enhanced by physician bias and lack of education in gender-affirming care. This is reflected in stories of discrimination and denial of basic healthcare. A healthcare environment built on the presumption that gynaecological patients are women, others trans and gender diverse patients, which can result in avoidance of needed medical care. A lack of knowledge of gender-affirming care alongside healthcare provider bias highlights a need for gender-affirming care and bias reduction training in undergraduate healthcare provider curricula. Research to date assessing current curriculum in Australia and Aotearoa (New Zealand) shows limited inclusion of lesbian, gay, bisexual, trans, queer, intersex, asexual and other related identities content as a whole with gender-affirming care being among the least-frequently addressed topics. This review will detail barriers to accessing gender-affirming healthcare specific to gynaecology, interweaving the experiences of a non-binary individual seeking access to gender-affirming endometriosis care.

Plain Language Summary

Transgender and gender diverse people with endometriosis: a perspective on affirming gynaecological care

Transgender and gender diverse people have limited access to safe and affirming healthcare. Barriers to accessing care are particularly prominent for those presumed female at birth attempting to access gynaecological care for conditions, such as endometriosis or chronic pelvic pain (CPP). A key barrier to safe and affirming healthcare for this population is a lack of inclusion of trans and gender diverse health in healthcare provider curriculum. The dearth of healthcare providers knowledgeable in gender-affirming care results in healthcare discrimination and poorer health outcomes for trans and gender diverse people.

¹NICM Health Research Institute, Western Sydney University, Penrith, NSW, Australia

²Patient Author, Melbourne, VIC, Australia

³School of Education, Western Sydney University, Penrith, NSW, Australia

⁴Translational Health Research Institute, Western Sydney University, Penrith, NSW, Australia

Corresponding author:

Sam Jeffrey, NICM Health Research Institute, Western Sydney University, Penrith, NSW 2751, Australia.

Email: 22077344@student.westernsydney.edu.au



Keywords

chronic pelvic pain, education, endometriosis, gender diverse, menstruation, non-binary, transgender

Date received: 30 November 2023; revised: 29 March 2024; accepted: 15 April 2024

Introduction: the healthcare needs of trans and gender diverse people

The terms transgender and gender diverse refer to those whose gender does not align with that presumed at birth. This includes but is not limited to transgender men, transgender women, brotherboys, sistergirls, Takatapui, Tāhine, non-binary, agender people and those with fluid genders.^{1–3} Trans and gender diverse people constitute between 0.5% and 4.8% of the Australian population (accurate statistics are absent due to a lack of inclusion in Australian census data), equating to over 1 million people.⁴ Trans and gender diverse people require access to gender-affirming healthcare to thrive. Although the demand for gender-affirming services is rising, many trans and gender diverse people are left waiting for years to access this often life-saving care or routine medical care.⁵ Gender-affirming care refers to not only gender-affirming hormone therapy (GAHT) or surgeries but also treating trans and gender diverse people with respect, creating a welcoming clinical environment, using their correct pronouns, name and other preferred language and running appropriate health screenings.⁶

Trans and gender diverse people have been identified as a priority population in multiple national strategies by the Australian Government⁷ due to a higher burden of physical and mental health concerns resulting from discrimination, including poor access to gender-affirming healthcare.⁸ Recent surveys of the Australian trans and gender diverse population show three key priorities: affordable and available gender-affirming care; accessible and easy pathways to access gender-affirming care; and, a healthcare sector knowledgeable in gender-affirming care.^{5,9} These priorities are critical; trans and gender diverse people report lower levels of psychological distress, self-harm and suicidality when they experience respectful and competent gender-affirming care.¹⁰ Unfortunately, many trans and gender diverse people report struggling to access gender-affirming care with 60% of trans and gender diverse young people in Australia reporting feeling isolated from healthcare services.¹¹

Those at the intersections of marginalized identities experience heightened discrimination and poorer access to culturally sensitive healthcare.² For instance, poorer health outcomes are reported for transfeminine people, trans and gender diverse people of colour, disabled and neurodivergent people.¹² Specific to Australia, Aboriginal and Torres Strait Islander trans and gender diverse people struggle to access both culturally sensitive and lesbian, gay, bisexual, trans, queer, intersex, asexual and other related identities

(LGBTQIA+) friendly care.² A lack of access to gender-affirming care in regional areas also disproportionately affects this community.¹³ Likewise, in Aotearoa, Maori and Pasifika people experience higher health risks related to discrimination.¹⁴ Research reflects the importance of a strong sense of belonging to culture, community and family/whanau within Aboriginal, Torres Strait Islander, Māori and Pasifika communities.³ The impacts of colonialism which discouraged the expression of diverse genders and sexualities previously accepted within these communities have huge ramifications for the wellbeing of trans and gender diverse First Nations people.³

Access to gynaecological care

Access to gynaecological care for trans and gender diverse people is hindered by cisnormative assumptions which frame gynaecology as 'women's health'.^{15,16} We see this in the lack of inclusive language, imagery and lack of providers knowledgeable in gender-affirming gynaecological care.^{15,17} When accessing care, trans and gender diverse people report experiencing misgendering, a lack of trauma-informed care, invasive questioning irrelevant to their care, severe pain during gynaecological examination, provider incompetence, gate keeping of medically necessary surgeries and even complete denial of care.^{17–21} These experiences of discrimination have significant ramifications on future attempts to access care, with one gender-queer individual reporting removing their own intrauterine device (IUD) due to fear of returning to their healthcare provider.²¹ Another reported a cancer scare due to their provider being unable to interpret the pap smear results of an individual on testosterone, and another trans and gender diverse individual was diagnosed with a prostate infection despite informing their provider that they did not have a prostate.²¹ People with intersex variations similarly experience healthcare discrimination and poor access to non-pathologizing medical care.²² This is relevant as people with intersex variations have unique gynaecological needs, and up to 40% identify as trans and gender diverse.²³ Intersex individuals make up between 1.7% and 4% of the population, yet there is limited research to date on the gynaecological needs of this group.²²

Chronic pelvic pain and endometriosis in trans and gender diverse people

Trans and gender diverse people commonly experience chronic pelvic pain (CPP), yet have limited access to

gynaecological care. CPP affects between 51% and 72% of trans and gender diverse people presumed female at birth, and while endometriosis is a common cause of CPP, there is limited research investigating the prevalence, symptoms, treatment or experiences of endometriosis in trans and gender diverse people.^{24–27} As stated above, the experiences of intersex people accessing gynaecological care for endometriosis or CPP are also absent from the research literature. Endometriosis is a chronic multi-system disease affecting between 1 in 7–10 women and people presumed female at birth.^{28,29} It is characterized by debilitating pelvic pain, fatigue, menorrhagia, dysmenorrhoea, gastrointestinal distress, dyspareunia and dysuria.^{30,31} This condition can have huge repercussions on the psychological and social wellbeing of the individual and can impact their financial security.^{31,32} These ramifications are compounded in trans and gender diverse populations due to poorer access to gender-affirming healthcare, and higher rates of mental health concerns, and social, housing and employment discrimination.^{11,33,34}

Endometriosis has a lengthy diagnostic delay of 8 years with limited management or effective treatment options available largely attributable to the stigmatization and normalization of pelvic pain and a lack of healthcare providers educated about endometriosis.³⁵ This diagnostic delay is expected to be greater for trans and gender diverse people who experience additional barriers to accessing healthcare and for those at the intersections of marginalized identities, particularly trans and gender diverse people of colour. Endometriosis has historically been defined as an upper-class white women's disease, which still influences care today and can be observed in diagnostic bias.³⁶ Cisgender women historically report feeling dismissed and marginalized by medical professionals when seeking diagnosis and treatment for endometriosis and pelvic pain.³⁷ Therefore, trans and gender diverse people are a marginalized group, within an already marginalized group, making seeking and obtaining an effective diagnosis even more challenging.

Medical management of endometriosis does not differ significantly between trans and cis individuals and largely consists of hormonal contraceptives, surgical excision, analgesics, tricyclic antidepressants, antifibrinolytic agents, non-steroidal anti-inflammatories and gonadotropin-releasing hormone analogues.^{35,38,39} Significant numbers of cisgender women with endometriosis access complementary medicine (CM) due to dissatisfaction with pharmaceutical or surgical management reported among 45.4%.^{40,41} Dissatisfaction with medical support among trans and gender diverse people with endometriosis is unclear; however, numbers are likely to be greater due to additional barriers to care. Heteronormative and cisnormative assumptions which underpin gynaecology, including the prioritization of penetrative intercourse and reproductive capacity over pain management, are particularly

harmful to LGBTQIA+ populations and likely increase dissatisfaction with care.¹⁵ This may similarly lead more trans and gender diverse people with endometriosis to access CM. CM in cisgender women with endometriosis has shown success in reducing dysmenorrhoea, shrinking endometriotic lesions and supporting pregnancy, alongside lower rates of adverse effects versus pharmaceutical interventions.^{42,43} Therefore, it is essential that both CM and medical providers are competent in gender-affirming care.

Experiences of endometriosis care as a trans and gender diverse individual in Australia

Australia was the first country in the world to implement a national action plan to help improve the lives of those with endometriosis. The National Action Plan for Endometriosis (NAPE) was released in 2018⁴⁴ to help support new advances in diagnosis and treatment. While there have been improvements as a result of the plan, such as the introduction of specialist pelvic pain clinics,⁴⁵ the Australian government has recognized that marginalized groups, such as trans and gender diverse people, are not currently well represented in the plan, and in mid-2023 released a targeted call to specifically improve this.^{46,47}

The experiences of the author, L.A., accessing gynaecological care for endometriosis in Australia as a non-binary transmasculine person add valuable insights to this topic. They noted limited care available when presenting as a woman, versus absent care specific to non-binary people as they socially and medically transitioned. Non-binary individuals frequently avoid disclosing their gender due to fear of discrimination which results in inadequate care, self-medication and skewed data, disguising the need to adapt healthcare to be inclusive of non-binary genders.⁴⁸ L.A. experienced a lack of providers competent in gender-affirming care, and in some instances, providers refused to adopt their correct pronouns. As a result of these kinds of experiences, trans and gender diverse people are often required to become experts in their own healthcare due to a lack of providers knowledgeable in this field. In L.A.'s experience, the dearth of literature investigating the impact of GAHT on endometriosis symptoms prevented them from making informed decisions about their health. In addition, common misconceptions around the curative role of hormone therapy or hormonal contraceptives resulted in their symptoms being dismissed while accessing GAHT. This is not in line with the limited research literature, with one study showing sustained symptoms in 40% of trans and gender diverse adolescents prescribed both testosterone and progestin.⁴⁹

Trans and gender diverse people additionally experience disproportionate challenges economically which are compounded by a reduced ability to work in those with CPP or endometriosis.^{32,33} L.A.'s experience accessing

gender-affirming care and specialist services for endometriosis management, while facing workplace and social instability during transition, resulted in significant financial and psychological stress. Given the substantial financial burden that endometriosis already exerts on people,^{41,50} the stress this additional burden places on trans and gender diverse people should not be underestimated. Limited trans and gender diverse-specific social support for those with endometriosis compounded this stress; support groups largely cater to cisgender individuals. An inclusive support space can assist individuals in coping with the often disabling experience of CPP and the anxiety and fear which can accompany this. In terms of online support spaces, it is well-known that trans and gender diverse people commonly report discrimination, bullying and abuse in these spaces, with recent research showing an increase in online anti-trans harassment across Australia over the past year.⁵¹ This highlights the importance of considering the social determinants of health when considering the care of trans and gender diverse people with CPP or endometriosis.

Barriers to care: inclusion in healthcare curriculum

A significant barrier to trans and gender diverse people's access to competent gender-affirming care is a lack of inclusion in healthcare provider curriculum.^{52,53} Research to date which has broadly assessed the inclusion of LGBTQIA+ health in medical curriculum across Australia and Aotearoa has reported minimal inclusion of LGBTQIA+ health as a whole, with trans and gender diverse health among the least covered subtopics.^{53–55} The survey of academics showed that the majority (69%) believed the content to be important, yet did not believe it was relevant to their teaching niche.⁵⁵ The vast majority (74%) were unaware of any faculty support from their university around LGBTQIA+ healthcare.⁵⁵ This is a major barrier to inclusion of trans and gender diverse health in curriculum with 15 medical schools across Australia and Aotearoa reporting no faculty support in this area.⁵³ Sanchez et al.⁵³ additionally reported that of 15 medical schools, only 4 included transitioning or gender affirmation in required curriculum. This is reflected in limited knowledge of healthcare providers and students in gender-affirming care. For example, a survey of fifth year medical students at the University of Otago, Aotearoa, showed that fewer than half were able to explain gender affirmation.⁵⁶ This survey additionally identified poor cultural competency within LGBTQIA+ healthcare, with fewer than half of students aware of the term *Takatāpui* (an umbrella term encompassing LGBTQIA+ Māori people which acknowledges the importance of Maori culture in their queer identity).^{56,57} Similarly, needs assessment reports interviewing Aboriginal Community Controlled Organization staff report that there

is limited inclusion of Aboriginal culture within LGBTQIA+ education. Participants reflected that content was 'really Western' and 'it'd be great to have pre-colonial stories' and a 'cultural lens with the other elements'.⁵⁸

A key factor in the negative healthcare encounters reported by trans and gender diverse individuals is provider bias. Inclusion of trans and gender diverse health in curriculum can legitimize gender-affirming care as a routine part of conventional medicine and may have a 'pre-bunking' effect, reducing healthcare providers susceptibility to disinformation.^{59,60} However, healthcare bias is not necessarily reduced simply by introducing gender-affirming care to medical curriculum. Research in the United States suggests that competency in trans and gender diverse healthcare shares a greater correlation with transphobia versus hours of formal or informal education.⁶¹ Therefore, transphobia and medical bias must be addressed through curriculum to improve healthcare experiences and outcomes for trans and gender diverse people.^{61,62} Care should be taken to avoid binary constructions of sex and gender, the conflation of sex and gender, and the use of pathologizing and stigmatizing language in trans and gender diverse healthcare. An overemphasis on biomedical framing dismisses important sociocultural factors in the construction of sex and gender, and contributes to the stigmatization and pathologizing of trans and gender diverse medical care.⁶³ A structural competency approach which recognizes the societal influences on health outcomes may be a useful tool to reduce bias towards marginalized populations and draws attention to those at the intersections of marginalized identities.^{62,64} Instead of simply describing the existence of health inequities, a structural competency approach discusses the historical and current structural factors which contribute to these inequities.⁶⁵ For example, a curriculum which acknowledges barriers to care, including barriers within the learning institution, profession, wider environment and the history of trans and gender diverse healthcare,^{13,66,67} can teach students how to recognize and respond to illness as a downstream effect of social, political and economic structures.⁶⁵ A structural competency approach has the opportunity to address the intersections of trans and gender diverse First Nations identities by recognizing the ways modern policies, laws and social contexts which criminalize or regulate gender identity and sexual orientation stem from colonial legacies.⁶⁸

It is imperative that trans and gender diverse healthcare is included across medical and CM curriculum to improve healthcare outcomes for this population. Inclusion in curriculum should address factors, such as bias, cultural competency, faculty education, use of non-stigmatizing language, clinical experience with trans and gender diverse patients and inclusion in assessments, case studies and exams.⁶³ Trans and gender diverse health should be included throughout healthcare niches versus segregated

in the curriculum and education on the basics of gender-affirming care made mandatory versus elective content.^{69,70} In the niche of gynaecology, curriculum should use gender inclusive imagery and language (i.e. language which is self-determined by trans and gender diverse individuals), gender neutral language (i.e. people with endometriosis) or additive language (i.e. women and trans and gender diverse people with endometriosis).⁶³ In line with this, informal reference of gynaecology/reproductive medicine as ‘women’s health’ should be avoided and replaced with gender neutral language (gynaecology) or additive language (women’s and trans and gender diverse health). Inclusion of trans and gender diverse people in the development of curriculum is essential to ensure that content meets the needs of this diverse population and does not perpetuate existing medical bias. Importantly, cultural competency for First Nations trans and gender diverse people should be designed in consultation with First Nations trans and gender diverse people (Brotherboys and Sistersgirls, Māori and Pacifica trans and gender diverse, and Takatāpui representatives).

Conclusion

Trans and gender diverse people with endometriosis or CPP currently have limited access to affirming medical care which results in poorer health outcomes.²⁷ Experiences of the author, L.A., highlight the importance of gender-affirming care in gynaecology and the broader social and economic factors which influence healthcare outcomes for this population. A key barrier to care identified is the lack of inclusion of trans and gender diverse health in healthcare curriculum. Further evaluation of current curriculum is required to inform future curriculum change, with no known assessment of CM curriculum to date. Curriculum exploring the health needs of trans and gender diverse people in a non-pathologizing and stigmatizing manner could dramatically improve access to gynaecological care and healthcare outcomes for this population.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Author contribution(s)

Sam Jeffrey: Conceptualization; Writing – original draft; Writing – review & editing.

Louis Ashton: Conceptualization; Writing – original draft; Writing – review & editing.

Tania Ferfolja: Writing – review & editing.

Mike Armour: Conceptualization; Writing – review & editing.

Acknowledgements

Not applicable.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Competing interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Availability of data and materials

Not applicable.

ORCID iD

Sam Jeffrey  <https://orcid.org/0000-0002-2707-331X>

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