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Perspectives of trans and gender diverse young people accessing primary care and gender-affirming medical services: Findings from Trans Pathways

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**ABSTRACT**

**Background:** Increasing numbers of trans young people are seeking medical services worldwide, but there have been few qualitative investigations of the experiences of trans young people attempting to engage with these services to explore in-depth experiences of clinical interactions.

**Aims:** We aimed to explore the experiences of trans young people accessing primary care and gender-affirming medical services in Australia for reasons related to their gender.

**Methods:** Using data from a large mixed methods cross-sectional study, we explored the personal experiences of trans young people aged 14–25 (N = 859) receiving care within primary care services and gender-affirming medical services. Qualitative data on these service experiences were thematically analyzed.

**Results:** Trans young people in Australia reported experiencing difficulties when accessing medical services, especially in relation to gender-affirming medical intervention, referrals to specialist services, and obtaining clinical support in an affordable and timely manner. We found that trans young people were frequently confronted with negative experiences due to clinicians lacking expertise in providing gender-affirming care. Trans young people also reported many positive experiences, including feeling their gender identity was valued and respected by certain services. Although many practitioners attempted to assist their trans patients, they often did not provide satisfactory care and young people were often left to navigate the health care system unsupported. These interactions were often constrained by long waiting times and service cost.

**Discussion:** In general, clinicians require further training to be able to respectfully interact with trans patients and to adequately assist trans young people to obtain necessary medical care. The danger of providing such non-affirmative care to a trans young person is not only invalidating the young person's identity, but also an elevated risk of ill-health due to later avoidance of health care.

**Introduction**

The number of trans and gender diverse (herein trans)\textsuperscript{1} young people in Australia seeking support from medical service providers has been significantly increasing in recent years (Telfer et al., 2015), reflecting a trend that has been noted internationally (Cohen-Kettenis et al., 2011). Recent estimates indicate that 2.3–2.7% of high-school aged adolescents are trans or gender nonconforming – young people whose gender differs to that presumed to them at birth (Fisher et al., 2019; Rider et al., 2018). Research has shown that trans young people historically have had difficulty accessing health services that are clinically competent in regard to trans health (Acevedo-Polakovich et al., 2013). However, there have been few qualitative investigations from the perspective of trans people on navigating healthcare services.

Within trans healthcare, the consensus is that primary care providers should ascertain the level of support that their trans patient needs, assess any mental health symptoms, plan for the future health desires of the patient, and update medical records with the patient’s name and pronouns (Cliffe et al., 2018). In addition, primary care providers working with trans clients should have expertise in monitoring and administering hormonal interventions for young...
people (Cliffe et al., 2018), and have awareness of appropriate referral pathways (e.g., to endocrinology). There are multiple current accepted standards of care for medical professionals working with trans young people (Coleman et al., 2012; Hembree et al., 2017; Telfer et al., 2018), however medical practitioners commonly do not receive training on trans health (Korpaisarn & Safer, 2018), resulting in trans people experiencing difficulties in accessing medical care that affirms their identity and meets their needs.

Globally, trans people report negative experiences when attempting to access medical services, which in turn contribute to poor mental health (Riggs et al., 2014; Winter et al., 2016). It is known that trans young people experience barriers in accessing medical care that is inclusive of gender diversity (Acevedo-Polakovich et al., 2013), including attending appointments with clinicians who are insufficiently knowledgeable and/or supportive of gender-affirming medical interventions, delays in receiving care due to difficulties in locating a practitioner with experience in trans health, and gatekeeping practices which delay access to gender-affirming medical care. Staff misgendering patients (referring to a person as the incorrect gender, commonly through incorrect pronoun usage) and making discriminatory comments promotes a negative, and sometimes traumatic, health care experience for trans patients (Dolan et al., 2020; Riggs et al., 2014). Feelings of isolation from services are associated with symptoms of depression and anxiety, as well as self-reported self-harming behaviors and suicide attempts in trans young people (Strauss et al., 2020a). A recent Canadian study found that 43.9% of trans people felt their overall health care needs were not met (Giblon & Bauer, 2017). In addition, a recent study in the US reported that trans young people experiencing mental health difficulties were more likely to experience a clinical interaction where they felt they were not respected, and also were more likely to need to educate their care provider on gender diversity (Kattari et al., 2020).

In Australia and New Zealand, trans people have expressed significant concerns over accessing services after either having a negative experience themselves or upon hearing of adverse experiences from others (Pitts et al., 2009), and report difficulties in locating a practitioner who is trans-affirming (Bartholomaeus et al., 2020). In Australia, 42.1% of trans young people have experienced reaching out to a service provider who did not understand, respect or have any prior experience with gender diverse people (Strauss et al., 2017). Trans young people are also less likely than their cisgender peers to access services for health needs, such as regular health checkups (Rider et al., 2018). In addition, emergency care may be avoided even when in crisis because of a lack of provider competency and anticipation of discrimination including fearing for one’s safety, objectification in the emergency department, and negative reactions to disclosure of the individual’s gender history, e.g., misgendering and refusal to use the individual’s name and/or pronouns (Samuels et al., 2018).

Trans young people in the Netherlands who have been able to access gender-affirming interventions as a child, adolescent or young adult have shown mental health outcomes similar to the general population (de Vries et al., 2014). A recent review (Mahfouda et al., 2017) found that puberty suppression improved psychological health for pubertal trans children with marginal associated risk of poor health outcomes. In addition, a recent US study has demonstrated that access to pubertal suppression when desired is associated with lower odds of suicidal ideation compared to trans people who wanted pubertal suppression but were unable to access it (Turban et al., 2020). For adult populations, it has been reported that hormonal interventions have a positive impact on psychological functioning and quality of life (White Hughto & Reisner, 2016), but there are not yet sufficient data to fully explain the longer term effects of these interventions on mental health and quality of life. Nonetheless, some prospective cohort studies indicate that after hormone initiation, trans adults experience lower levels of anxiety, depression, and other adverse psychological indicators (White Hughto & Reisner, 2016). Recent studies in the US report increased wellbeing, decreased psychopathology and decreased suicidality in trans young people after receiving gender-affirming hormones (Allen et al., 2019; Kuper et al., 2020). This evidence suggests the high rates of poor mental health among trans young people decrease when appropriate medical interventions are made accessible to those who need them.

Gender-affirming surgery/ies have also been shown to improve the mental health and quality of life of trans young people, however there is little exploration of these outcomes in trans young people and a scarcity
of longitudinal research (Mahfouda et al., 2019). Research with trans adults in Australia indicates those who have accessed hormones and surgery/ies are less likely to experience clinically significant depressive symptoms (Hyde et al., 2014), and gender-affirming surgery is important to improving trans individuals’ quality of life (El-Hadi et al., 2018; Passos et al., 2019). Despite the benefits to mental health and quality of life, access to gender-affirming services is scarce: a recent study in Australia reported that only 39.8% of trans adults rated their access to gender-affirming care as “good/great,” 29.6% as “OK, can access some things” and 22.1% as “non-existent/poor” (Callander et al., 2019). Long-term longitudinal studies and more robust data are needed to determine the effects of gender-affirming medical interventions on mental health in trans people of all ages.

There is currently a significant absence of literature on the experience of accessing Australian medical services for trans young people. It is known that feeling isolated from services is associated with mental health difficulties (including suicide attempts) (Strauss et al., 2020a), but there has been little exploration of the clinical milieu in which trans young people access, or attempt to access, medical services. The aim of this study was to understand the experiences of trans young people attempting to access and navigate primary care and gender-affirming medical services.

Methods

The Trans Pathways survey utilized an online questionnaire developed jointly through community consultation with trans young people and parents of trans young people to assess mental health and experiences of health services among trans young people. The survey was mixed methods (including both closed and open-ended questions) and encompassed topics of mental health, drivers of mental health difficulties, positive factors influencing mental health, and experiences in accessing medical and mental health services. Participants were recruited across Australia, primarily through social media, gender clinics, youth mental health services, support groups, and word of mouth. Qualtrics online survey software was used to construct and host the questionnaire which utilized branch, display and skip logic based on participant responses. Participants received an online participant information form upon clicking the study link which included information on contacting the researchers for additional study details, and consented to the study by proceeding to the questionnaire. Parental consent was waived for this study. All questions were optional, except those used to determine study eligibility (i.e., identifying as trans or gender diverse, age, residing in Australia at the time of the study). The study was approved by the University of Western Australia ethics committee (RA/4/1/7958).

Measures

In this paper we report on findings related to experiences in accessing primary care (primary care physicians/general practitioners) and gender-affirming medical care (included in the survey questionnaire as “medical transitioning services”) specifically in relation to their gender (i.e., not for general health reasons). For gender-affirming medical services, participants were asked whether they had accessed a children’s hospital, pediatrician, adult hospital, private endocrinologist, or private surgeon. For both primary care and gender-affirming medical services, open-ended questions were used to elicit reasons for service access, age at first access attempt, wait-times until first appointment, and frequency of access attempts [asked as follows: “How many GPs did you need to visit until you received the help you were looking for (if you received it)?”]. Participants also rated their satisfaction with each service (once the service was accessed) using a 5-point Likert scale from 1 = very low to 5 = very high satisfaction. In addition, participants were asked if staff at each service type were respectful of their gender identity. Participants were asked to elaborate on their experience with each service in more detail through open text boxes.

Statistical methods

Participant age at the time of service access was stratified into those under 18 years compared to 18 or older. Access rates were also analyzed by gender identity categories (male, female and non-binary) and by gender presumed at birth. IBM SPSS Version 25 was used to calculate descriptive statistics. A general inductive approach was used to analyze and categorize the qualitative data (Thomas, 2006). A general inductive
approach guided by a realist conceptual framework was used to guide the qualitative thematic analysis through understanding themes in the data without testing an a priori hypothesis, and without being restricted to a particular theoretical approach, e.g., grounded theory (Braun & Clarke, 2006). A realist conceptual framework was deemed appropriate due to the aim of the study to describe the experiences of participants from their own viewpoints (Madill et al., 2000). This methodological approach was chosen due to the nature of the survey being exploratory rather than testing a specific hypothesis, and the non-assumptive and open wording of the qualitative survey questions (e.g., “Please tell us about your experience”). The interpretation of the data was informed by Ansara’s cisgenderism theoretical framework (Ansara, 2010; Ansara & Hegarty, 2014; Blumer et al., 2013), specifically around how experiences within clinical interactions impact a trans young person’s identity and validation of self, acknowledging that existing research on trans health reflects a historically ciscentrist health system. The qualitative data underwent detailed review involving reading of the full responses prior to analysis and coding by two researchers (PS and ZW) using NVivo software to determine common themes and to ensure rigor in the qualitative analysis. Two coders were used in the analysis process to ensure that bias in interpreting codes was minimized. The two coders identified and discussed any discrepancies in the coding. The resulting codes were then examined for overarching patterns to draw together the central themes which are presented here (Braun & Clarke, 2006; Clarke & Braun, 2018).

Results

A total of 859 trans young people aged 14–25 responded to the online survey. The majority of participants were non-binary including genderqueer and agender (48.5%, N = 417), followed by male participants (29.7%, N = 255) and female participants (15.0%, N = 129). The overall sample had a mean age of 19.37 (SD = 3.15), with 74.4% of participants presumed female at birth (N = 639) and 25.6% presumed male at birth (N = 220). Participants described their gender identity in an open text box. Additional demographic details on this cohort have been described in detail elsewhere (Strauss et al., 2017, 2020a, 2020b).

Of the total study population, 463 participants (65.2%) had accessed primary care services, 251 (35.4%) had accessed gender-affirming medical services, and 240 (33.8%) had accessed both. Service access rates and characteristics are reported in Table 1. Of these participants, N = 203 provided qualitative data on their experiences in accessing primary care, and N = 95 provided qualitative data on their experiences in accessing gender-affirming medical care. In general, there was a large variation in the experiences of trans young people attending primary care services

<table>
<thead>
<tr>
<th>Table 1. Primary care and medical transition service access details.</th>
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<tbody>
<tr>
<td><strong>Type of service</strong></td>
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<tr>
<td><strong>Access frequency, n (%)</strong></td>
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<tr>
<td><strong>Access frequency for both services combined, n (%)</strong></td>
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<tr>
<td><strong>Age at first access attempt, n (%)</strong></td>
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<tr>
<td>Under 18</td>
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<tr>
<td>18 or older</td>
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<tr>
<td><strong>Access rates by gender presumed at birth, n (%)</strong></td>
</tr>
<tr>
<td>Male: total sample n = 178</td>
</tr>
<tr>
<td>Female: total sample n = 532</td>
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<tr>
<td><strong>Access rates by gender, n (%)</strong></td>
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<tr>
<td>Male</td>
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<tr>
<td>Female</td>
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<tr>
<td>Non-binary</td>
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<tr>
<td><strong>Number of times accessed to get help needed, n (%)</strong></td>
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<tr>
<td>Once</td>
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<tr>
<td>2-4 times</td>
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<tr>
<td>5-9 times</td>
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<tr>
<td>10 months or more</td>
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<tr>
<td>Still waiting or never got an appointment</td>
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<tr>
<td><strong>Length of wait for first appointment, n (%)</strong></td>
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<tr>
<td>1 month or less</td>
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<tr>
<td>2-3 months</td>
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<td>4-6 months</td>
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<tr>
<td>7-9 months</td>
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<tr>
<td>10 months or more</td>
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<tr>
<td>Still waiting, or never got an appointment</td>
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<tr>
<td><strong>Satisfaction with service n (%)</strong></td>
</tr>
<tr>
<td>Very Dissatisfied</td>
</tr>
<tr>
<td>Somewhat Dissatisfied</td>
</tr>
<tr>
<td>Neutral</td>
</tr>
<tr>
<td>Moderately Satisfied</td>
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<tr>
<td>Highly Satisfied</td>
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<tr>
<td><strong>Gender acceptance within service, n (%)</strong></td>
</tr>
<tr>
<td>Respectful or mostly respectful</td>
</tr>
<tr>
<td>Sometimes respectful or mixed response</td>
</tr>
<tr>
<td>Not at all respectful or mostly not respectful</td>
</tr>
<tr>
<td>Did not disclose gender to service</td>
</tr>
</tbody>
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and gender-affirming medical services, ranging from some favorable positive responses to very negative commentary where participants described discriminatory and non-affirming interactions with medical practitioners. We describe the specific experiences of primary care and gender-affirming medical services in detail below.

**Primary care services**

The age at initial access to primary care services varied, with 42.5% of young people first accessing the primary care physician under the age of 18 and 57.5% only accessing primary care as an adult. Just over half of the participants only saw one primary care physician to get the help they needed (56.9%), while 33.1% accessed several physicians and 10% saw more than four physicians before finding one that they felt could meet their needs. Staff at primary care services were not always respectful of the young person’s gender identity: 54.8% of participants reported that staff were respectful or mostly respectful while 25% stated staff were sometimes respectful. Over half of participants found the overall experience to be either moderately or highly satisfactory (57.4%) and 19.7% of participants felt somewhat or very dissatisfied with the experience at the service. The main reasons for access were seeking referrals, hormones, general help, support or advice, mental health concerns, transitioning, medication and prescriptions, gender dysphoria and obtaining a mental health care plan. The main themes developed from the qualitative responses on experiences within the service are reported in detail below.

**Self-advocacy in accessing primary care**

Participants needed to self-advocate to obtain the support, medical care and referrals from primary care providers that they sought. This included educating the practitioner on 1) what it means to be trans, and 2) how the practitioner could assist the young person, including with referrals to additional support services (e.g., psychologist, psychiatrist) or specific gender-affirming services (e.g., endocrinology, surgery).

**Complex pathways to accessing gender-affirmative primary care**

Trans young people often had complex pathways to accessing gender-affirmative primary care, where they saw multiple primary care providers before locating a practitioner who could help them.

…the last and final GP I visited for my treatment still treats me and he has been very respectful and generally fantastic to deal with. Most doctors refuse treatment: my first doctor was respectful and refused treatment on the grounds of no experience, the rest were disrespectful and basically refused, one of them was particularly abusive and rude.

Participants conveyed feeling “lucky” to find a primary care provider who was knowledgeable about gender diversity, trans healthcare needs, and with experience working with trans people. Oftentimes participants sought out a practitioner who was recommended by either trans or broadly LGBTIQA + groups, and these practitioners with experience working with trans people provided better medical care and help with transitioning.

My first GP gave me the wrong information and told me no GP could ever provide HRT. She was very rude about my gender identity and I haven’t seen her since. My new GP, who I got onto via a community LGBT group, has been absolutely perfect and educated, providing me with a script for HRT after blood tests and my second appointment with him.

It was difficult to access a knowledgeable, affirming and supportive primary care provider, and the experience of going through multiple providers before finding an appropriate practitioner was not only harrowing to experience, but also delayed participants’ access to gender-affirming medical intervention and general health needs.

Finding a good GP is very difficult and having a bad first experience set me back not only in my transition but in seeking unrelated medical services.

**Feeling valued and affirmed by the primary care provider**

Many of the study participants reported positive experiences with their clinician, feeling respected and that their gender was valued by the clinician.

The fact that she was willing to believe me on my gender identity and respect my medical autonomy was just a godsend and I wouldn’t be anywhere near as healthy and well-adjusted to transitioning without her support.

**Enduring invalidating experiences to receive care**

Young people were frequently in situations where practitioners were not fully affirming, and due to the
practitioner’s ability to be able to help with aspects of the young person’s care, participants endured these experiences.

Misgenders me a fair bit but is helping me over all.

Some participants reported that their primary care physician misunderstood aspects of gender, or had never knowingly interacted with a trans patient before, which resulted in the young person feeling discomfort during interactions with the practitioner.

The [primary care physician] I saw tried really hard to be respectful and understanding but misunderstood a lot of the ways I thought about my body/my gender and generally misunderstood some of the concepts about being trans, and made me uncomfortable a few times by making assumptions about me.

Other participants reflected needing to explain their gender identity to the practitioner, despite the practitioner already having some awareness of gender diversity. Some primary care physicians were reportedly disrespectful of the young person’s gender identity and invalidated the young person’s identity.

Accessing services as a young trans person is harrowing, incredibly stressful, time and money consuming, and constantly brought me to tears with the invalidating and invasive questions that the transphobic/ignorant doctors and counsellors asked me.

**Feeling isolated from services that would help**

Young people experienced difficulties in accessing services that would address their needs, and this led to feeling hopeless around whether they ever would be able to locate the support needed.

I felt like I would never find the help I needed and became even more depressed than I was. I was angry that nobody knew where to point me, and that I had to go around in circles so much just to access a basic and simple service.

Related to finding a primary care provider who could directly assist the young person, seeking referrals was another issue described by participants, as young people reported their clinician was unable to appropriately refer them onto other services.

They gave me the referral, but I actually had to tell them what to write on the form because they had no clue what to call my gender identity medically. I didn’t insist on any pronouns or my name, and they didn’t ask. I felt unsafe asking for that.

In the context of primary care, the practitioner was seen as a gatekeeper, acting as a barrier to hormonal medications, surgeries or other services that they needed, and some participants reflected that this hindrance had an effect on their mental health.

I was forced to wait for medication I knew I needed… I hurt myself multiple times that year trying to cope with the hurt and the frustration.

**Primary care providers lacked knowledge of gender diversity**

Overall, responses from participants reflected experiences with primary care services during which it was evident that the practitioner lacked knowledge of gender diversity. Many participants reported that they felt they had to educate their primary care physician on gender diversity, their own needs and help the practitioner know how to help them.

Some [primary care physicians] are good, some are awful. It takes time to find a [primary care physician] who is respectful and knowledgeable around trans issues. It is often a matter of educating them, which is tiresome and also has a negative impact on one’s healthcare.

Further to this, some primary care physicians displayed a lack of knowledge about gender diversity, but young people reflected that the practitioner tried to help them as best they could.

I have a lot of respect for my current [primary care physician], and he has always treated me with a lot of respect (despite not being 100% knowledgeable, he is always open to learning new things).

Other practitioners sought out information on gender diversity to upskill themselves to help the young person.

Doctor had little knowledge of trans issues/health but was willing to research it and was of great help in the end.

**They helped me get where I needed to be**

Despite many negative interactions and hurdles (including the young person advocating for themselves and their needs), young people reflected that the primary care provider helped them “get where they needed to be.” For many participants that meant commencing gender-affirming medical intervention.

I found a GP who was also specialized in trans related health care, after the first appointment I was set on a straightforward path towards medical transition.
An additional positive experience with some primary care providers were regarding the practitioner’s experience with, and knowledge of, mental health, so that the care went beyond medical needs.

The first GP I went to for my psych referral letter didn’t know that much about trans issues but they were still understanding as they had dabbled in mental health.

**Gender-affirming medical services**

Most participants were aged 18 or older (75.4%) when they accessed gender-affirming medical services. The specific services most likely to be used were a private endocrinologist (57.3%) or a private surgeon (35.2%). The majority of young people (89%) reported that the staff at gender-affirming medical services were respectful or mostly respectful, and 66.9% of participants found their experience with the care received to be highly or moderately satisfactory. Of note, 14.5% participants reported they were still waiting for an appointment.

Participants primarily accessed gender-affirming medical services for access to hormones, surgery, unspecified transition needs, information on transitioning, and gender dysphoria.

**Practitioners were experienced and knowledgeable about gender diversity**

Many participants were satisfied with their experience of accessing gender-affirming medical services due to the service staff (reception as well as clinical) being knowledgeable about trans health.

Saw [clinician] for top surgery. Him and his practice manager were perfect with handling my surgery and gender identity.

Positive experiences included young people feeling that their gender identity was respected and understood by the service.

My surgeon was so good. Not at all fussed about the gender identity side of things, he only cared about making me the best chest I could have.

**The practitioner assisted beyond what was expected**

A common aspect in accounts of experiences of accessing gender-affirming medical services was that the practitioner was helpful to the young person in a manner that was supportive of their gender, and assisted with the young person’s care beyond what was expected.

He was very kind and understanding. Did all he could to make everything easier and faster for me to transition, including personally organizing a psychiatrist appointment for months earlier than their next availability. He provided me with all the information I needed and even referred me to a top surgeon.

Practitioners who devoted sufficient time with the young person to discuss their medical care were also viewed favorably.

He was a lovely endo, understanding, listened and talked and assured me of things I doubted and feared. He was great, and bulk billed, and respectful of my identity.

**Frustrations due to barriers in accessing services**

Despite positive experiences reported, participants also felt that services providing gender-affirming medical care were disorganized, with referrals lost between services and miscommunication occurring between clinicians involved in the young person’s care. Many respondents conveyed frustration at significant waiting times to be seen by the appropriate clinician, due to many lacking expertise in trans health.

There are so few endocrinologists with the wish or expertise around treating trans people. It makes waiting lists longer and patient care sub-standard in many cases.

The lengthy wait times led to frustrations around not knowing when an appointment would be scheduled, and in turn delays with the young person commencing gender-affirming medical intervention.

The waiting list is out of their control, but I was kept in the dark about it and had no clue when I was going to see anyone.

The wait times experienced were not only in regard to being referred to a service for the first time, but also once in the service participants conveyed that there were lengthy times between appointments, also postponing gender-affirming medical intervention.

When I first arrived with blood test and recommendation, was told everything looked good but just to be safe to get another blood test and come back in 2 months. 2 months is a long time, ended up going on a 4-day drinking bender.

Another issue with gender-affirming care expressed was the financial cost to access services
(e.g., appointment and travel costs), as well as the costs of surgery.

Surgery iscrippingly expensive and it makes me feel dysphoric because it feels like something that is so far off.

Other participants were disappointed with the gender-affirming medical services that exist in Australia and noted that the services that do exist are often not meeting the needs of trans young people, with some participants traveling interstate to receive care.

I had to travel interstate to receive surgery, and it took five years to save the money. Receiving these treatments was necessary for my survival and has made me very happy, much healthier and my life has been easier. But getting access to these services was very difficult, expensive and I had to wait a long time and have many bad experiences.

**Practitioners lacking knowledge and understanding**

Not all participants were happy with the care they received, and did not feel confident in the knowledge that the practitioner had.

I got hormones started, but was glad that I would never have to see that endocrinologist ever again. I didn't feel that he had understanding about what trans lives are like, or my values, or why I would seek treatment. Maybe he did, but he didn't give me that feeling.

Similar to some experiences with primary care providers, young people explained to their treating clinician aspects of trans health.

The endocrinologist had very little trans* experience and had to be told several basic things about transition and what it achieves.

This extended to some services not being inclusive of non-binary identities, and participants not feeling welcome at the service.

**Discussion**

Our findings have shown that trans young people in Australia report a mix of positive and negative clinical interactions with primary care physicians and gender-affirming medical services. The data presented are novel given the large sample size of participants in the study and the limited Australian-based literature examining the experiences of trans young people accessing medical care in relation to gender. In addition, this study focused on the experiences of trans young people accessing medical care specifically in relation to gender from the general medical workforce, not solely practitioners specializing in trans health. The main themes reported reflect that the Australian health system is insufficiently prepared to care for trans young people in a truly inclusive manner, and that trans health is seen as a specialist topic of medical knowledge rather than a fundamental aspect of care. Issues that were identified included participants seeing health providers who were prepared to be friendly toward the trans person with some aspects (e.g., using the correct pronouns) but were incapable of assisting the young person in a timely fashion to access gender-affirming medical intervention (e.g., delays due to not knowing where to refer the young person). Positive interactions with clinicians experienced in trans health were marred by long waiting lists to see such trans-friendly practitioners, expensive appointment costs and often-times the need to travel to see the provider.

Primary care physicians (general practitioners) were often the first point of contact for trans young people and their families, but many participants in our study did not feel general practitioners were adequately knowledgeable of trans health. This inadequate provision of care is likely to have an impact on the wellbeing and mental health of the young person and make them feel invalidated. Participants reflected a tolerance of practitioners who displayed a lack of knowledge in gender diversity (e.g., feeling the practitioner did not understand their gender, but viewing the appointment as a positive experience due to obtaining a referral), but this could be due to the tumultuous journeys young people found themselves on in locating a primary care provider – almost half of the participants saw multiple primary care providers before finding one who could help them. Further to this, considering the barriers to gender-affirming medical interventions, young people may have felt they did not have any other options than withstanding sub-optimal care in order to access the care they sought.

Another finding was that some participants who expressed contentment with their primary care provider commonly also reflected that they were “lucky” to be receiving such care, reflecting a health system in which the norm is for a medical practitioner to lack knowledge of gender diversity. Positive experiences with practitioners were due to the clinician not only being knowledgeable of trans health – but also respecting the young person’s identity and expressing
care for the young person’s wishes in terms of gender-affirming medical intervention. Respecting a patient’s gender identity should be the minimum requirement within a healthcare setting, and professional bodies should ensure that medical practitioners are trained in gender diversity (Strauss, Winter et al., 2020). Such trainings should encourage all staff involved in delivering healthcare to reflect on their own beliefs about gender diversity, including any cisgenderism in their own practice. Environments that are truly inclusive and affirmative of trans people should be standard across Australia.

Moreover, 34.8% of the study population had not accessed a primary care physician in relation to their gender, possibly indicating not knowing a trans-friendly provider, a lack of interest, a lack of family support, not being ready for medical affirmation, or a number of other reasons. Not having contact with a primary care physician is especially pertinent to consider as discomfort or anxiety felt by young people in accessing primary care for gender-related reasons could lead to avoidance of health care for a variety of other needs in the future (Aitken, 2017). In addition, these barriers to care prevent trans young people accessing gender-affirming medical care when they need and desire it, which has a negative impact on their mental health and well-being and prevents trans young people from having autonomy over their bodies.

The study participants reported facing multiple barriers in their search for appropriate primary care and gender-affirming medical services. This included seeing multiple practitioners (often in directly offensive and invalidating environments) before locating a service provider who was able to help them. In addition, trans young people are confronted by long waiting periods for appointments with specialists in trans health, all of which are in high demand. Previous research has also noted that trans people in Australia have problems when accessing care because of geographical inaccessibility and sparse distribution of services (Hyde et al., 2014). A substantial percentage of the Trans Pathways cohort (11.5%) had sought gender-affirming medical care interstate because of the unavailability of practitioners (Strauss et al., 2017). The cost of accessing specialist services such as private surgeons and endocrinologists in Australia is also prohibitively high for a majority of young people, many of whom do not have parental support (Strauss et al., 2020a). Issues surrounding the cost of gender-affirming medical care could be alleviated for many trans people if the coverage for care was included in more private health care plans, and/or covered by Medicare in Australia.

Many of the participants in our study were already adults when first accessing services for a reason related to their gender identity. Possible reasons for this include: 1) some young people may not want gender-affirming medical services until that age; 2) their parents may not have been supportive (or may not have yet been aware) of their child’s gender; 3) some young people may not have yet fully developed or embraced their gender identity until an older age; or 4) there are institutional/systemic reasons inhibiting access and barriers to access including a lack of gender-affirming services in the young person’s geographical area and service cost. We speculate that systemic issues are especially relevant given the shortage of services catering to the needs of trans people in Australia, as well as research spotlighting access barriers in this area (Bartholomaeus et al., 2020; Hyde et al., 2014; Smith et al., 2014).

We note that our sample might include young people who were unable to access puberty suppression, as trans young people in Australia until 2017 needed court approval to initiate puberty blocking hormones (Telfer et al., 2018). Puberty suppression prevents the development of bodily characteristics that develop alongside puberty such as facial hair, broad shoulders, hips widening, and voice deepening. Absence of access to puberty suppression can have long-term implications in terms of later medical intervention to remove or alter these bodily characteristics, some of which are difficult or impossible to alter (e.g., wide hips). Further to this, the ability to access gender-affirming medical care at crucial developmental timepoints can have social repercussions due to not developing alongside peers. Emotionally, being able to access puberty suppression (and other gender-affirming medical intervention) allows individuals to feel affirmed and validated in their gender identity which in turn also benefits their psychological wellbeing.

There was a discrepancy in satisfaction and respect received within gender-affirming medical services where participants largely felt that their gender was respected within the service, but rankings on satisfaction widely varied. This could be due to a variety of factors including delays in obtaining medical
intervention (e.g., the medical practitioner may see a patient for a consult but may not be willing to provide access to hormones or surgery/ies as quickly as desired by the young person), the high cost associated with gender-affirming medical interventions, geographical barriers to accessing services in an ongoing manner, or a number of other factors. The access to such services vary based on the individual’s level of parental support (especially for those who were minors at the time of considering affirming their gender medically), geographical accessibility of services, and financial means to pay for service costs. How participants understood satisfaction within a clinical interaction may vary based on these factors, especially considering that the young person may or may not be accustomed to having their gender validated by others (e.g., by peers and family), so the threshold for what was satisfactory care for such an individual may differ. In addition, considering the high prevalence of non-binary participants in this sample (48.6%), another possibility could be that young people felt dissatisfied with their experience with the service due to the clinician lacking knowledge specifically around gender-affirming medical intervention options for non-binary young people. Non-binary individuals may have different needs in terms of medical care and medical pathways should be flexible to incorporate these needs (e.g., not requiring an individual to be on hormones before undergoing surgery) (Vincent, 2019).

A number of participants noted that their primary care physicians and specialists recognized their own knowledge limits, and that over time these doctors sought information and developed their expertise in trans health care. Ideally clinicians should already have at minimum an understanding of gender diversity, rather than relying on their patients to prompt or provide their education (Aitken, 2017; Strauss, Winter et al., 2020). Practitioners working with trans young people should be aware of the gender-affirming medical needs that a trans young person may present with and adhere to current guidelines for gender-affirming medical care (Coleman et al., 2012; Hembree et al., 2017; Telfer et al., 2018). If the practitioner feels they do not have the expertise to prescribe hormones, for example, there should be systemic structures in place that enable a practitioner to know where to refer the young person so that they can receive the desired gender-affirming medical care. The onus for understanding the specific needs of a trans young person should not be placed on that trans young person – the medical practitioner should instead be the source of knowledge in such a clinical interaction.

Importantly, our findings suggest opportunities for addressing the suboptimal care reported by trans young people in Australia. While our results emphasize the need for individualized gender-affirming care based on the different desires of participants from what they were seeking from a clinical appointment (e.g., referrals for gender-affirming intervention versus information about gender diversity), they also highlight common issues faced by trans young people in medical settings. Some simple steps for services to follow to become more “trans-friendly” include: using gender-affirming names and pronouns (even if they are not reflected on legal documents) (Dolan et al., 2020); providing opportunities for young people to indicate their gender on intake forms, alongside gender presumed at birth (Vance & Mesheriakova, 2017), ensuring the service is aware of inclusive care for their trans patients. There are a number of widely used standards of care for trans people, to which clinicians can refer (e.g., Coleman et al., 2012; Telfer et al., 2018) which stress the importance of gender-affirming approaches in healthcare. It is evident from our findings that many medical practitioners are not practicing the affirmative care outlined in such guidelines, which could be because they are not aware of the guidelines, or lack the training in how to apply the standards of care. Medical practitioners have demonstrated interest and significant increases in knowledge of trans health after undertaking training in trans health (Vance et al., 2017), thus professional and educational institutions should see the value in requiring trans health as a component of standard curricula.

In view of the increasing number of trans young people approaching services, it is particularly important that more practicing clinicians are upskilled in trans health, and that initial medical training should incorporate trans health care modules that are inclusive of the diversity that exists within trans populations. Trans populations in Australia should be able to access medically necessary care, and clinicians should be trained to meet this need so that there are more options for care providers, thereby reducing waiting lists and travel requirements.
Study limitations

The current study was cross-sectional in design, thus, more longitudinal research is required focused on the experiences of trans people accessing the health system, the quality of care received and long-term health outcomes. In addition, this sample had more participants presumed female at birth than male, and it is unknown whether this is representative of the broader trans population. As the qualitative responses reported here were recorded through an online anonymous survey, we were unable to ask for elaboration or ask follow-up questions. Less than half of participants who indicated accessing primary care services and/or gender-affirming medical services provided qualitative elaboration on their experiences in accessing the care. Future research is needed in this area with in-depth qualitative interviews with participants of diverse backgrounds across Australia to understand the variety of experiences that trans individuals experience in accessing medical care. The participants in this survey needed to have access to a device to access the online survey, be at least minimally engaged with some support or health service due to the recruitment methods used, and also needed to be willing to tell their story through an online survey and feel safe in doing so. Future research should explore how a broader sample of trans people may be reached and encouraged to participate in research, e.g., using paper-based surveys in complement to online surveys to not restrict access to those without means to access an online survey in a safe place (though an online survey may be considered safer in some contexts than a paper-based questionnaire). Such future research should be led by trans researchers and/or in equal partnership with trans individuals.

Another limitation is that the respondents who accessed primary care and/or gender-affirming medical services would have had the financial means to do so, and for the younger participants some level of parent or guardian support. In addition, participants were asked to reflect on their experiences while receiving care, so the study does not comprehensively report on the experiences of individuals who were unable to locate a practitioner. The questions around service access specified that the young person was accessing the service in relation to their gender, and thus the results presented here are not inclusive of the experiences of accessing medical care for general health needs.

There was a large proportion of non-binary participants in this study, and it is unknown whether this is representative of the population of trans individuals in Australia. Research in Canada reported a similar number on non-binary respondents to a national survey where 41% identified as non-binary (Clark et al., 2018). We asked about gender using an open-text box, allowing for participants to describe their gender in their own words, which may have elicited a larger response of non-binary individuals than in studies where gender is asked about through preempted responses, or in binary clinical samples. Future research should consider asking about gender identity in an open-text box to allow for all identities and encourage young people to feel able to describe their gender in their own words, as has been suggested by other researchers, notably Ansara and Hegarty (2014).

Conclusion

Our findings indicated that although some service providers delivered high quality and trans affirmative care to their trans patients, there were areas for improvement across medical services overall. Oftentimes young people were exposed to clinical interactions which invalidated their gender identity, including practitioners who were directly unsupportive of the young person’s trans identity. This is harmful and invalidating of trans identities and experiences. One additional risk of not providing gender-affirming care is that trans young people who have adverse clinical interactions may avoid contact with health care providers in the future, to the detriment of their future health and wellbeing. We therefore recommend that training in gender diversity and related healthcare needs should be recognized as a core element in all health profession curricula and clinical professional development.

Note

1. We use the term trans here to be inclusive of all genders differing from an individual’s presumed gender at birth, subsuming a range of identities, including “transgender,” “gender diverse” and “gender minority.”

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References


