Dis-ease of Access: Health and Cancer Care Survey for Trans and Gender Diverse Australians

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Introduction

Drawing on results from a national survey involving 537 Trans and Gender Diverse (TGD) people, this chapter will focus on the experiences of TGD Australians accessing health and cancer care. The results document some of the diverse demographics of the TGD community in Australia, explore access to health and cancer care within the Australian context, and examine levels of awareness around cancer. The diversity includes many genders, sexualities, and backgrounds, whilst showing that TGD Australians remain a marginalized group that experiences much adversity. The data show that many TGD people have problems accessing healthcare due to experiences of mistreatment and ignorance on the part of providers – currently, access is plagued by dis-ease. Further, it appears that general awareness campaigns for cancer are not reaching this population. The recommendations offer ways forward through partnerships with TGD people themselves.

Social recognition and acceptance of TGD people is increasing in Australia. There has been an accompanying rapid rise in referrals for gender affirming care – some specialist clinics have seen their attendance multiply by ten in five years (2011-2016) (Cheung et al. 2018). Almost all of the specialized gender affirming care is provided by private professionals and there is a lack of funding and services (particularly outside of the major cities) (GLBTI Health and Wellbeing Ministerial Advisory Committee 2014; Telfer, Tollit and Feldman 2015). Research has documented that TGD people in Australia experience high rates of marginalization and discrimination in the general community, with poor mental health and an increase in detrimental health behaviors (e.g., smoking) as a likely consequence (Hyde et al. 2014; Smith et al. 2014). Limited pathways to surgery mean that TGD people often have body parts and organs which cause them significant distress (GLBTI Health and Wellbeing Ministerial Advisory Committee 2014). Such distress can act as an additional barrier to accessing healthcare and cancer screening services. However, the more significant barriers appear to be the mistreatment commonly experienced by this community and the lack of awareness within the healthcare system (Jones et al. 2015; Riggs and Due 2013). Many TGD people have a strong and justified fear of mistreatment and may avoid services as a result. The paucity of research addressing this issue is a further exacerbation, as even gender affirmation specialists may find themselves unable to make evidence-based decisions or enact change due to the lack of data. Additionally, population-based research and registries do not include information on diverse genders. Subsequently, there is a lack of consideration in policies and allocation of resources (Ansara 2016). This chapter will outline a national Australian study of TGD people that explored their experiences of accessing health and cancer care, providing background, methodology, results, discussion, conclusion and recommendations.

Social, Health and Care Experiences of TGD Australians

Australian research has established that TGD people experience a variety of adverse circumstances due to social marginalization and stigmatization. For example, TGD Australians are generally well-educated, yet this is not reflected in their income or employment rates, with significantly lower income and levels of employment than both the general and (cis) gay, lesbian, and bisexual population (Boza and Nicholson-Perry 2014; Jones et al. 2015; Hyde et al. 2014). They are also at a greater risk of homelessness, frequently encounter familial rejection, and are likely to be socially isolated, especially if they live outside of a metropolitan area (Jones et al. 2015; McNair et al. 2017; Riggs, Ansara and Treharne 2015). Up to 87.4% of TGD Australians report having experienced discrimination based on their gender (Couch et al. 2007). Areas of discrimination include social/community, employment, economic and family, and may be in the form of verbal, written, physical, sexual, or exclusory actions (Beyond Blue 2012). A range of lifestyle behaviors that may influence cancer risk have also been found in relatively high rates including: smoking, alcohol abuse, and limiting exercise due to discomfort (intense exercising may be dangerous for people who use chest binders) (Boza and Nicholson-Perry 2014; Hyde et al. 2014; Smith et al. 2014). Higher rates of poor mental health when compared with the general population have been documented, with depression found to be up to four times that of the general population (Hyde et al. 2014). Arguably, the three main factors that determine mental health for TGD Australians are discrimination, access to gender affirming technologies, and social/familial support (Riggs, Ansara and Treharne 2015).

Documentation is another issue that may have wide-ranging effects on TGD Australians' lives. The process of changing one's identifying documents may be a vital step in recognition of their gender (Hyde et al. 2014; Jones et al. 2015). In Australia, different identity documents may be under Commonwealth or state/territory legislation, meaning there are varying requirements, some of which have an unreasonably high burden of proof (e.g., the requirement to have had gender affirming surgery to change one's birth certificate) (GLBTI Health and Wellbeing Ministerial Advisory Committee 2014). Many in the TGD community report being unable to change some or all of their documentation as a result (Hyde et al. 2014). Inability to change documentation may expose them to discrimination and lead to poorer health and wellbeing.

Another factor to consider in relation to the diversity and health of TGD Australians is intersectionality, particularly as it relates to the experiences of Aboriginal and Torres Strait Islander People. Indigenous communities in Australia have experienced ongoing trauma and adversity since colonization began in 1788, including loss of life to infectious disease, violence, forced relocation, and breakdowns in family and community due to the government-sanctioned removal of children from their parents (Kerry 2014). Aboriginal and Torres Strait Islander people suffer considerable disadvantage and, as a result, poorer physical and mental health, with a life expectancy ten years less than the general Australian population (Australian Institute of Health and Welfare 2018). Sistergirl and brotherboy are indigenous Australian terms for two distinct gender identifications – although the terms are not equivalent, sistergirl aligns with trans woman, and brotherboy with trans man (Kerry 2014). Sistergirls, brotherboys and other Aboriginal and Torres Strait Islander people who experience some form of gender diversity, may face significant challenges to their health and wellbeing, and marginalization due to cultural difference may further complicate their access to healthcare. Whilst efforts were made throughout this study to encourage participation of Aboriginal and Torres Strait Islander people, unfortunately there was not a sufficient proportion of the sample to run statistical tests for comparison. This reflects the difficulties in recruiting a culturally diverse sample on a limited timeline and budget, as well as the broader context of ongoing marginalization of Aboriginal and Torres Strait Islander people in Australian society.

For those who can safely access it, Australia is fortunate to have a healthcare system that is one of the most affordable and comprehensive in the world (Lowe and Cristofis 2017). A complicated combination of both public and private, the system includes national subsidy schemes for medical procedures (Medicare Benefits Schedule), medications (Pharmaceutical Benefits Scheme), and private health insurance (Australian Government Rebate on Private Health Insurance) (Lowe and Cristofis 2017). For TGD people, access to subsidies may be limited due to these being 'gendered', and the fact that some gender affirming surgeries are either partly or wholly labelled as 'cosmetic' (GLBTI Health and Wellbeing Ministerial Advisory Committee 2014). Additionally, gatekeeping by healthcare professionals, particularly psychiatrists, is a stressful process for many TGD people and is another barrier to accessing gender affirming care (Ho and Mussap 2017). Gatekeeping may relate to hormones and/or surgery and involves the healthcare professional assessing the individual to see if they meet the criteria for the interventions sought with the goal being to obtain a 'letter' of approval so they may proceed with gender affirming care (ibid.). Australia is a sparsely populated country, with most of its population living in two highly urbanized coastal areas that are widely separated (Australian Bureau of Statistics 2012). Access to healthcare services is especially a problem for those who live rurally/remotely, with increased travel, accommodation and financial burdens (GLBTI Health and Wellbeing Ministerial Advisory Committee 2014).

Australian research has found a lack of TGD sensitive services, inadequate knowledge on the part of healthcare professionals, problems with access, and a high frequency of bad experiences which result in avoidance of healthcare and poor mental health (Couch et al. 2007; Hyde et al. 2014; McLean 2011; Riggs and Due 2013; Strauss et al. 2017). The characteristics of bad experiences for TGD Australians include; lack of respect; expressions of hostility, surprise, discomfort, contempt, and disgust; prejudicial attitudes; misgendering language; the patient having to educate the healthcare professional; refusal of services; and feeling pathologized (Ho and Mussap 2016; Jones et al. 2015; McLean 2011; Riggs and Due 2013). Couch et al. (2007) found that many TGD people are not fully expressing themselves in healthcare, and Smith et al. (2014) reported that only 6% of their participants who experienced mistreatment had made a complaint about it. Due to the negative experiences of themselves and others in their community, many TDG people are understandably reluctant to access services or disclose their gender, which results in unmet needs and the potential to miss serious illnesses or care requirements. Cancer care itself may be especially difficult due since public health messaging about common types of cancer, for example breast and prostate, is usually highly gendered (Kerr and Jones 2017).

In their important role for primary healthcare, General Practitioners (GPs) are often the first point of contact when engaging with health services. GPs provide ongoing support and care, make referrals to more specialized care (and may be seen as 'gatekeepers' for this reason), and coordinate the care of their patients (Strauss et al. 2017). GPs are the most common healthcare professional for people to access in relation to their gender, and an individual's health needs are more likely to be met if they have a good, regular general practitioner (Hyde et al. 2014; Strauss et al. 2017). In 2014, Hyde et. al. found that only half of their TGD participants that had a regular GP met the criteria for a 'good' doctor-patient relationship. TGD people may have varied experiences with GPs due to the heterogeneity of different clinicians' knowledge and attitudes.

In terms of access to healthcare, it has been found that TGD Australians do not feel that they are having their health needs met (Hyde et al. 2014). Both the government and private sectors are seen to be inadequate to meet the needs of this population, under-funded, and not coping with the demand for gender affirmative care which results in long waiting periods for many individuals (ibid.). Ideally, an individual should be able to choose who provides their healthcare, but currently there are insufficient services for this to be the case for most TGD Australians.

The overarching aims of this study were to explore the experiences of TGD people in health and cancer care, including factors that prevent or promote access. Specific research questions include 'is having unmet healthcare needs associated with more barriers to care?' and which factors may predict barriers to care. The next section details methodology, including survey design, recruitment, and administration.

Study Methodology and Design

This study used a community-based participatory research design to conduct an online survey (Adams et al. 2017; Hacker 2017). The community was consulted and involved throughout, including during the survey design, recruitment, analysis and reporting. Additionally, key informant interviews were conducted with TGD community members and professionals that had relevant knowledge to guide development of the research (for further detail see Kerr, Fisher and Jones 2019).

Participants and Procedure:

A convenience sample was recruited through paid online Facebook advertising and TGD community promotion (generating a snowball sample). A total of 854 surveys were saved, one third of which were incomplete surveys. Data cleaning removed 21 responses which were illegitimate (e.g., mischievous responders), leaving 537 participants. Average completion time for the survey was 22 minutes. The mean age of participants was 26.64 (*SD* = 10.93, range 18-79). Participants' genders were 22.7% (n=122) trans women, 33.0% (n=177) trans men and 44.3% (n=238) gender diverse people. For sex assigned at birth, 70.9% (n=381) were assigned female at birth and 26.6% (n=143) assigned male at birth, with 2.4% (n=13) choosing not to disclose. Of the sample, 6.3% (n=26) reported that they were Aboriginal or Torres Strait Islander. More participant socio-demographics are detailed in the results section.

Measures:

The survey covered four areas: socio-demographics, gender affirmation, accessing healthcare, and cancer awareness and care. Questions were forced-choice, containing 'prefer not to answer' options, and there were text boxes at many points to provide qualitative comments. The number of questions asked of each participant varied as some sections were open only to people who had specific body organs (e.g., a cervix). To allow for comparisons with the general Australian population and international TGD communities, measures were taken from the 2016 Australian Census, the Australian Bureau of Statistics Survey of Healthcare, the Cancer Awareness Measure and other TGD research (e.g., experiences of discrimination from the Canadian Trans PULSE study and bad experiences in healthcare from the 2015 U.S. Transgender Survey).

The Kessler 6 (K6) uses six items to assess levels of general psychological distress (Kessler et al. 2002). Feelings of nervousness, hopelessness, restlessness, depression, effort and worthlessness in the past 30 days are rated on a five-point Likert scale from 'none of the time' to 'all of the time' (ibid.). Scores range from 0-24, with a score over 13 being indicative of probable mental illness (ibid.). The K6 is a reliable tool for measuring psychological distress.

Barriers to care were measured using seven out of ten items from the 'Barriers to Help Seeking' section of the Cancer Awareness Measure (Stubbings et al. 2009). Added to these seven items were two items developed by the team that are specific to TGD Australians ('fear of mistreatment' and 'unable to find a doctor I am comfortable with'). The question was 'do any of the following things stop you from going to the doctor?', with potential answers being 'no', 'sometimes' and 'often'. A Barriers to Care Score was created summing the nine items, with scores ranging from 0-18. The Barriers to Care Score is a key measure for analyses in this chapter.

Analysis:

SPSS V25 was used to analyze the data. Descriptive statistics were run for selected key socio-demographics, gender affirmation, access to healthcare, and cancer care and awareness. Researchers then wanted to answer the question 'is having unmet healthcare needs associated with more barriers to care?' A t-test was run to compare the Barriers to Care Score between the two groups of those who reported having an unmet healthcare need and those who did not. Additionally, researchers wanted to know what factors influenced Barriers to Care Scores. For this reason, a standard multiple regression was conducted to see if the five measures of age, sex assigned at birth, income, K6 score, and number of bad experiences in healthcare predicted Barriers to Care Scores, how much variance could be explained by these factors, and which of these factors is the best at predicting barriers to care.

Results: Sociodemographic, Barriers to Care and Healthcare Experiences

Tables 1-5 display descriptive results for socio-demographic characteristics, health, psychological distress, gender affirmation, barriers to care, experiences of participants accessing healthcare, and cancer care and awareness. The majority of participants were trans men or non-binary, under the age of 25, single, had very low income, and identified as pansexual and/or bisexual. Most participants rated their health as either fair or good, reported high levels of psychological distress, experienced multiple forms of discrimination, had not been able to change all of their identifying documents, and attended a doctor for gender affirmation in the last 12 months. The mean for the K6 score was 12.53. The most common barriers to care were too many other things to worry about, inability to find a doctor they are comfortable with, being too busy, and fear of mistreatment. The mean for the Barriers to Care Score was 6.62. In terms of healthcare experiences, most participants reported that they had an unmet healthcare need (mostly due to cost and fear of mistreatment), were very uncomfortable discussing their needs with a healthcare provider that they do not know, only disclosed their gender to a healthcare provider if they had to and have had to teach a Healthcare Worker (HCW) about TGD people to get appropriate care. Cancer awareness was generally low to moderate, with the majority of participants reporting that a HCW had not discussed cancer topics with them.

Tests of the Research Questions

An independent-samples t-test was conducted to compare the Barriers to Care Score for those who reported ever having an unmet healthcare need (58.8%, n=300) and those who did not (41.2%, n=210). Participants who ever had an unmet healthcare need reported significantly more barriers to care (Mean = 7.69) than those who indicated they did not have an unmet healthcare need (Mean = 4.98).

Standard multiple regression was used to assess whether age, sex assigned at birth, income (dichotomous, ≤$37,000 and $37,001+), K6 score, and bad experiences in healthcare predict the Barriers to Care Score. The variance explained by this model was 32.7%, meaning that almost a third of Barriers to Care are explained by these five factors. Four variables were statistically significant, with the K6 score being of highest significance, followed by bad experiences in healthcare, age, and sex assigned at birth. Income was not statistically significant. Higher Barriers to Care Scores were predicted by higher psychological distress, more bad experiences in healthcare, being younger, and assigned female at birth.

Table 1: Sociodemographic Characteristics of the Sample.

Gender		
Woman	31	5.8%
Man	26	4.8%
Trans woman	90	16.8%
Trans man	146	27.2%
Genderqueer	32	6.0%
Non-binary	142	26.4%
Gender-fluid	29	5.4%
Agender	11	2.0%
Something else	30	5.6%
Age		
18-24	326	60.7%
25-34	110	20.5%
35-44	59	11.0%
45+	42	7.8%
Relationship Status		
Single and not dating	210	39.7%
Single and dating	61	11.5%
Partnered, not living together	209	20.6%
Partnered, living together	131	24.8%
Polyamorous/open relationship	18	3.4%
Individual Income before Tax (AUD)		
\$0-\$18,200	282	57.6%
\$18,201-\$37,000	89	18.2%
\$37,001-\$87,000	91	18.6%
\$87,001-\$180,000	28	5.7%
Sexuality (multiple response answer)		
Heterosexual	40	9.4%
Gay	61	14.4%
Bisexual	129	30.4%
Lesbian	61	14.4%

Pansexual	150	35.4%
Queer	44	10.4%
Asexual	89	21.0%
Experienced Homelessness	130	31.3%
Disclosed an Area of Neurodiversity	152	38.0%
Disclosed a Disability	103	25.8%
Engagement with the TGD Community		
Never, rarely or yearly	144	34.4%
Monthly	56	13.4%
Daily or weekly	219	52.3%

Table 2: Health, Psychological Distress and Gender Affirmation

Self-reported Health		
Poor	68	12.7%
Fair	176	32.8%
Good	178	33.2%
Very good	96	17.9%
Excellent	18	3.4%
K6 Dichotomous		
High levels of psychological distress	280	52.2%
Low levels of psychological distress	256	47.8%
Experiences of Discrimination		
Silent harassment	455	84.7%
Verbal harassment	382	71.1%
Physical intimidation and threats	199	37.1%
Physical violence	105	19.6%
Sexual harassment	232	43.2%
Sexual Assault	155	28.9%
None of the above	47	8.8%
Changing Identity Documents		

Do not want to	72	13.7%
Have not but plan to in future	196	37.4%
Unable to	82	15.6%
Able to change some	120	22.9%
Changed all documentation	54	10.3%
Hormone Use		
Never taken hormones	247	46.7%
Previously on hormones	18	3.4%
Currently on hormones	244	46.1%
On hormones for medical reasons	20	3.8%
Had Surgery	115	21.9%
Seen a Doctor for Gender Affirmation in the Last 12 Months	303	56.6%
Inability to Access Gender Affirming Care (last 12 months)*	181	43.2%

*Excludes those not desiring access to gender affirming care.

Table 3: Barriers to Care.

	No		**Sometimes**		**Often**
	n	**%**	**n**	**%**	**n**
Fear of mistreatment	219	41.2%	235	44.3%	77
Unable to find doctor I'm comfortable with	165	31.1%	220	41.5%	145
I find my doctor difficult to talk to	245	46.0%	204	38.3%	84
Difficult to make an appointment	239	45.2%	176	33.3%	114
I am too busy	215	40.4%	203	38.2%	114
I do not have money to see the doctor	263	49.3%	166	31.1%	104
Too many other things to worry about	156	29.3%	240	45.1%	136
Difficult to arrange transport to the doctor	329	61.6%	135	25.3%	70
Worrying about what the doctor might find	296	55.3%	161	30.1%	78

Table 4: Healthcare Experiences.

Unmet Healthcare Need (ever)	300	58.8%
Unmet Healthcare Need (last 12 months)	242	47.5%
Reasons for Unmet Healthcare Needs*		
Financial cost	138	46.0%
Fear of disrespect/mistreatment	133	44.3%
Could not get an appointment	105	35.0%
No nearby services	46	15.3%
Refused services due to being TGD	24	8.0%
Comfort Discussing Needs with a Healthcare Provider They Do Not Know		
Very uncomfortable	237	44.5%
Uncomfortable	196	36.8%
Comfortable	87	16.4%
Very Comfortable	12	2.3%
Information Needs Related to Care**		
Have not received enough information	137	36.8%
Have received enough information	235	63.2%
Did Not Have a Healthcare Provider with a Good Understanding of Their Needs, Preferences (last 12 months)***	129	26.9%
Multiple Attempts to Access Appropriate Healthcare (last 12 months)		
Sometimes	225	44.6%
Often	73	14.5%
Worsening Health due to the Length of Time Taken to get Appropriate Care		
Sometimes	166	32.7%
Often	62	12.2%
Needed Emergency Care but Avoided Attending the Emergency Department because they were Trans or Gender Diverse	144	41.3%
Disclosing Gender to Healthcare Workers		
Never	65	12.2%
Only if I have to	225	42.4%
Sometimes	110	20.7%
Always	66	12.4%

I do not have a choice (documentation shows this)	65	12.2%
Never had a HCW know they were TGD and treat them with respect	133	26.5%
Had to teach HCW about TGD people so they could get appropriate care	279	55.6%
HCW refused to give them gender affirming care	115	23.0%
HCW refused to give them general healthcare	106	20.7%
HCW asked them unnecessary/invasive questions related to being TGD not related to the reason for their visit	194	37.7%
HCW has used harsh or abusive language when treating them	80	15.4%
HCW was physically rough or abusive when treating them	30	5.7%
Experienced verbal harassment in a healthcare setting	74	14.2%
Have been physically attacked in a healthcare setting	12	2.3%
Experienced unwanted sexual contact in a healthcare setting	30	5.7%

*Percentages based on those who reported having an unmet healthcare need.
**Excludes those who had no information needs.
***Excludes those who had no healthcare needs.

Table 5: Cancer Care and Awareness

How soon would you see a HCW if you had a cancer symptom		
I would not make an appointment	41	9.8%
Within a year	31	7.4%
Within a few months	86	20.6%
Within a month	76	18.2%
Within a week	46	11.0%
As soon as possible	138	33.0%
HCW has not discussed cancer topics with them	260	60.5%
HCW recommendation of cervical screening*		

Never	155	56.8%
Once	69	25.3%
Often	49	17.9%
Accessed cervical screening*		
Never	163	58.7%
Once or rarely		
Regularly	43	15.8%
Cancer Awareness Items (frequencies for correct responses)		
Hormones can affect everyone's cancer risk (*true*).	191	44.6%
The risk of getting cancer does not increase with age (*false*).	324	75.5%
It is not necessary to have screening for cervical cancer if someone with a cervix has never been sexually active in any way (*true*).	42	9.8%
The Australian cervical cancer screening program has recently changed (*true*).	143	33.4%
People who are assigned male at birth cannot develop breast cancer (*false*).	392	91.8%
People do not have any risk of developing breast cancer if they have had a mastectomy (*false*).	263	61.7%
People with breasts/chest tissue between the ages of 50 and 74 should have a mammogram once every two years (*true*).	314	73.4%
Australia has a nation-wide breast cancer screening program (*true*).	286	66.8%
Australia has a nation-wide prostate cancer screening program (*false*).	19	4.4%
Australia has a nation-wide bowel screening program (*true*).	220	51.4%

*Note: Excludes people who do not have a cervix.

Discussion

This chapter has presented a snapshot of TGD Australians accessing health and cancer care, including analyses around barriers to care. The data builds on findings from previous Australian research, whilst shedding further light on the issues facing TGD people accessing care. As the study shows, Australia has a diverse TGD community, who have various genders (many of which are outside of the binary), many sexual identities, and different backgrounds. The sample was overall young, and many are engaging frequently with others in the TGD population, indicating a strong and evolving community who potentially feel safer to be visible. These are aspects of our participants' experiences that are heartening and offer much hope for empowerment into the future. On the other hand, social stigma and marginalization clearly remain a significant and pressing issue. Of note, and consistent with previous research, our participants had low incomes, high rates of having experienced homelessness, and multiple experiences of discrimination and assault (Hyde et al. 2014). The follow-on from this is high levels of psychological distress and poorer health when compared with the general Australian population. Over half (52.2%) of the sample fell into the range of 'probable serious mental illness' using the Kessler 6, whereas Australian data using the Kessler 10 shows that 11.7% of the general Australian population fall into this category (Australian Bureau of Statistics 2015). Very few people (3.4%) in our sample reported 'excellent' health – this is much lower than the general Australian population, of which 20% have been found to rate they health as excellent (ibid.).

Neurodiversity was reported by well over a third of the sample, with other research supporting a relatively high rate of neurodiversity for TGD people (Strauss et al. 2017). This is significant for healthcare providers to note, as navigating healthcare may be difficult for people who are neurodiverse, with many healthcare professionals lacking knowledge and awareness of appropriate care (Lehmann and Leavey 2017). Further to this, experiences of physical and sexual assault are not uncommon, meaning that TGD people are more likely to have trauma histories. In addition to care that is inclusive for people who are neurodiverse, trauma-informed care is an important step in making services sensitive to TGD people's needs. This involves sensitive screening for a trauma history, developing trusting relationships, minimizing distress, and maximizing autonomy (Reeves 2015). Extending this person-centered care also means addressing an individual's body discomfort, and healthcare providers having an awareness of how and when to ask the right questions about sex organs (*without* being unnecessarily invasive), which is especially important given that most TGD people do not always disclose their gender to healthcare workers.

Given that in Australia the legislation related to various identifying documents may be under state/territory or federal government administration, and the requirements therefore are not consistent, it is unsurprising that the data shows difficulty changing documentation. There is diversity in how TGD people choose to medically affirm their gender, with many choosing to use hormones, however, rates of surgery appear to be relatively low. Partly this is likely because of the young age of our cohort as people are more likely to have surgery the older, they are due to financial circumstances, but in addition to this surgery in Australia is limited and difficult to access (GLBTI Health and Wellbeing Ministerial Advisory Committee 2014). Many (43.2%) of our participants reported that there was a time in the last year they wanted to access gender affirmation but were unable to. This provides further evidence that there are not enough services to meet current demands.

Almost half of our participants said that there was a time they needed healthcare in the past year but did not receive it, which is twice that seen in the general Australian population (Australian Bureau of Statistics 2017). That many say that this is because of cost shows there is still a financial burden associated with accessing healthcare, despite coverage for many aspects of this in Australia. This financial cost could relate to getting time off work and travel and may also be associated with the fact that many gender affirmation specialists are within the private health system. Significantly, 44.3% said they had an unmet healthcare need because they were afraid, they would be disrespected or mistreated, which fits with the high rate of bad experiences in healthcare. Unsurprisingly, few people are comfortable discussing their needs with healthcare workers that they do not know. Over a quarter of participants reported not receiving enough information about their care in the last year, which is more than three times that found in the general Australian population (ibid.). Additionally, just under a quarter said that they did not have a healthcare provider with a good understanding of their needs – considerably higher than the 9% found in the general Australian population (ibid.). The survey results consistently demonstrate that healthcare services and workers are not equitable for TGD people.

There were a range of bad experiences reported by our participants. Over a quarter had never had a healthcare provider know they were TGD and treat them with respect. Over half have had to educate their healthcare provider, almost a quarter have been refused gender affirming care, one fifth have been refused general healthcare, and over a third have had a healthcare provider ask unnecessary questions about their gender unrelated to their visit. In this context, there is complete legitimacy to TGD people's fears of mistreatment. This also reflects the lack of knowledge on the part of healthcare workers and indicates a need for further training.

The analyses around barriers to care show that there are numerous things preventing TGD people from accessing care. For seven out of nine of these barriers, over half of participants reported that these items either 'sometimes' or ‘often’ stopped them from going to the doctor. The items with the most people indicating they ‘sometimes’ or ‘often’ stopped them from going to the doctor were as follows: ‘too many other things to worry about’ (70.7%); ‘unable to find a doctor I am comfortable with’ (68.9%); ‘I am too busy’ (59.6%); ‘fear of mistreatment’ (58.8%); ‘difficult to make an appointment’ (54.8%); ‘I find my doctor difficult to talk to’ (54.0%); and ‘I do not have money to see the doctor’ (50.7%). TGD people have multiple stressors in their lives, including low income and experiences of discrimination, and it is therefore unlikely that making an appointment to see the doctor takes priority. Additionally, their bad experiences as detailed above are affecting their access because they are fearful of what they will encounter in a healthcare setting. Having more barriers to care is associated with unmet healthcare needs, as shown in the T-test.

Approximately one out of six participants reported that they either would not make an appointment or would delay this up to a year if they had a symptom that they thought was a sign of cancer. That the problems accessing healthcare result in a such a serious outcome shows how fearful TGD people are of healthcare environments. Delaying seeking medical attention this long for a cancer symptom is likely to result in higher morbidity and mortality for this community. Other issues in relation to cancer care are that healthcare providers are not discussing the topic with TGD people, and as shown by the generally low awareness levels (table 4), general cancer awareness campaigns do not reach TGD people. There is a need for more focused attention in this area; the TGD population should be a priority group for cancer organizations and specific awareness campaigns should be designed for them. Likewise, mainstream cancer awareness campaigns should stop relying on gendered messaging that actively excludes TGD people.

For participants who have a cervix, the results show that healthcare providers are not recommending cervical screening to them – over half said this had never happened, and a further quarter said this had happened only once. Partly this can be attributed to the young age of the sample (in Australia guidelines state for cervical screening to begin at age 21). However, it is also likely that healthcare providers are making assumptions based on TGD people’s appearances, that they are not asking the right questions, and that TGD people are hesitant to disclose information about their bodies. A small percentage of TGD people with a cervix reported being regular screeners, but over half reported that they had never had cervical screening. Cervical cancer is an extremely preventable disease with screening, and moreover, the biggest risk factor for developing it is not attending screening (Johnson et al. 2016). Healthcare providers and cancer screening awareness campaigns need to be actively including TGD people with a cervix, ensuring that they know that this screening is relevant and important for them.

The findings from the standard multiple regression indicate that, taken together, higher levels of psychological distress, bad experiences in healthcare, younger age and being assigned female at birth significantly predict barriers to care. Research that has examined TGD people delaying care because of fear of mistreatment has found that this results in poorer mental health (Seelman et al. 2017). It is unsurprising that having bad experiences within healthcare is a significant predictor for increased barriers to care, as TGD Australians' expectations are likely to be based on their own and others' everyday lived experience. The results may indicate a trend that as TGD people grow older, they have had more time to find a sensitive healthcare provider, thus they have fewer barriers. People who were assigned female at birth may find the prospect of accessing care difficult since those certain procedures (e.g., cervical screening) may be especially invasive and uncomfortable for them. Income was not a significant predictor for barriers to care, which may reflect the fact that Australia's health system is largely affordable. Overall, the data demonstrate clearly that accessing health and cancer care as a TGD person can be very difficult.

Conclusion & Recommendations

The TGD community in Australia is diverse, evolving and strong. However, there is ongoing social marginalization, stigma and experiences of violence, and much work to be done to improve the situation. This survey found numerous, wide-ranging examples of problems related to accessing health and cancer care. There is a critical need for widespread training and education of people working within the healthcare system, and patient-centered care that is appropriate for people with neurodiversity and trauma histories. Enhanced coverage and accessibility are needed for gender affirmation services, which are currently insufficient to meet demand. The recommendations are as follows:

1. The data strongly support a person-centered approach to health and cancer care for TGD individuals, which considers gender, bodies, neurodi-

versity and trauma histories. Healthcare workers need to be initiating the relevant conversations in a sensitive manner and tailoring their care appropriately.
2. There is a need for widespread training and education, including in prevocational courses for medicine, nursing, and allied health.
3. Health and cancer policies should make TGD people a priority population.
4. Changes need to be made regarding the ways in which population-based research and registries collect gender/sex information.
5. Gender affirmation services need increased funding to ensure accessibility.
6. There is a need for general cancer awareness campaigns to be more inclusive of TGD people and also a need for specific TGD campaigns.
7. Health and cancer care need to make partnerships with the TGD community to develop guidelines and interventions to improve care.

Health and cancer care must make the TGD population a priority group, and population-based data collection needs to change in order to get a better picture on what is happening for this community. The dis-ease of access is in need of comprehensive treatment.

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