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Title: Improving Cervical Screening in Trans and Gender-Diverse People

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Abstract

Objectives: To explore issues related to cervical screening attendance for trans and gender diverse Australians.

Design: A community-based participatory research survey was conducted on health and cancer care. Data were analysed using descriptive statistics and a regression.

Setting and Participants: The survey was conducted online in 2018 and involved 196 trans and gender diverse people with a cervix (76 trans men, 120 gender diverse people).

Main outcome measures: Awareness, healthcare provider recommendation and participation in cervical screening were assessed. Four variables associated with attendance to cervical screening (age, healthcare provider recommendation, like for body, and gender) were included in a regression.

Results: The sample was young; over half (52.6%) were between 20-24. Two thirds (67.4%) of the sample had strong or moderate dislike for their body. Almost half (44.6%) had never had a healthcare provider recommend cervical screening to them. Close to half (48.0%) have never had cervical screening, with only 21.9% reporting that they are regular screeners. Over a quarter (27.5%) of people who have participated in screening have had an abnormal result. The most common reasons for never having attended screening were that it is too emotionally traumatic for them (55.3%) and the inability to find a healthcare provider they are comfortable with (38.3%).

Conclusions: Trans and gender diverse Australians with a cervix are unlikely to be regular participators in the National Cervical Screening Program. If the program is to continue its' successes in reducing cervical cancer rates, it must address underscreening in minority populations. Education for healthcare providers who perform screening is recommended. Self-collection methods are likely to encourage greater participation for this community.

The known: A growing body of international evidence indicates that transgender men and gender diverse people with a cervix are less likely to participate in cervical screening.

The new: Only one in five of the trans and gender diverse respondents in this survey reported regular attendance to cervical screening. Inability to find a healthcare provider they are comfortable with was a significant reason for never having attended screening, whilst healthcare provider recommendation predicted regular attendance.

The implications: Under-screening in this population must be addressed through targeted health promotion, healthcare provider education, and greater availability of self-collection methods.

Introduction

With the recent release of the first *National Cervical Screening Program monitoring report*, the Australian Institute of Health (AIHW) has predicted that Australia will become the first country in the world to eliminate cervical cancer (1). This is due to the ongoing success of the National Cervical Screening Program (NCSP), introduced in 1991, and two important developments – human papillomavirus (HPV) vaccination and renewal of the program which saw HPV testing become the primary method of screening (1). Globally, cervical cancer is the fourth most commonly diagnosed cancer in women and is higher in countries without screening (1). In Australia, this drops to the fourteenth most commonly diagnosed cancer in women, demonstrating the strong effect of screening and vaccination (1).

The most significant risk factor for developing cervical cancer in Australia is being under- or never-screened (2). Research from the AIHW has shown that almost three-quarters of cervical cancers diagnosed from 2002-2012 were in those who either never screened or were lapsed screeners (1). Whilst Australia has much to celebrate in terms of the NCSP, issues exist for a selection of minority populations who are under-screened, such as Aboriginal and Torres Strait Islanders, the socioeconomically disadvantaged, and those living remotely (2).

There is emerging concern regarding the cervical screening rates of the trans and gender diverse (TGD) community (3). Although the Australian Government does not collect data on how many people identify as TGD, international estimates suggest that they comprise 0.1-0.7% of the population (4). The majority of trans men have a cervix, with Australian research reporting a hysterectomy rate of around 14% (5). In Canada and the U.S. it has been documented that trans men and other people with diverse genders have lower participation rates in cervical screening (6, 7). Further, there appear to be higher rates of inadequate (due to testosterone-associated cervical epithelium atrophy) and abnormal tests for trans men and

gender diverse people with a cervix (8, 9). Within Australia, research has found that TGD people avoid healthcare due to insensitive services, inadequate knowledge of providers, access and safe disclosure barriers, and bad experiences (10), although little is known about their cervical cancer screening practices and experiences.

Reported barriers to screening for trans men and gender diverse people include; gender dysphoria (discomfort with gendered body organs); history of sexual trauma; pain; bad experiences in healthcare; discomfort disclosing their gender; healthcare providers (HCPs) not broaching the topic, lacking knowledge or refusing care; misconceptions regarding HPV transmission; and lack of social support and financial resources (3, 8, 11-15). Australia's movement to eradicate cervical cancer will only be successful if HCPs increase their outreach to under-screened populations, including TGD people with a cervix.

This paper reports on data from a national study on health and cancer care for TGD Australians. The study was conducted due to a lack of evidence both within an Australian context and internationally that addresses the concerns of TGD people in cancer care. This paper details the methods and results as they relate to cervical screening and offers a discussion of the implications of the findings.

Methods

This study used a community-based participatory research design to conduct an online survey. The community was consulted and involved throughout including during the survey design, recruitment, analysis and reporting, and key informant interviews were conducted to guide research development – and information on themes and sensitive language use were derived from community expert representatives. Further detail of other information from the informant interviews only has been published (Kerr, Fisher and Jones; 2020), and of methods for other cancer types (16).

Participants and Procedure: This sample is a convenience sample recruited through paid online Facebook advertising and TGD community promotion (generating a snowball sample). The study received ethics approval from La Trobe University's Human Research Ethics Committee. The anonymous questionnaire was provided in a secure online format. A total of 854 surveys were saved, one third of which were incomplete surveys. Data cleaning removed 21 responses which were illegitimate (mischievous responders), leaving 537 participants. The total number of survey participants included in current analysis is 196 as these participants had a cervix, were of an eligible age for screening and completed the cervical screening section. Eighteen- and nineteen-year olds have been excluded from analysis given that data collection finished slightly more than one year after the changes to the NCSP that raised the commencement age from 18 to 25. The mean age of participants was 26.71 (SD = 7.22, range 20-53). Of the sample, 38.8% were trans men (n=76) and 61.2% gender diverse (n=120). 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 (including sections on cervical, breast and prostate screening). 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 large-scale TGD research. This paper reports on a selection of the findings that relate to cervical screening, measures and response options can be seen in the results tables.

Analysis: SPSS V25 was used to analyse the data. Descriptive statistics were run for selected key socio-demographics, gender affirmation, access to healthcare, cancer care and cervical screening – frequencies are presented with the number and percentage. Researchers wanted to

know what factors influenced attendance to cervical screening. For this reason, a standard multiple regression was conducted to see if the four measures of age, healthcare provider recommendation, like for body (as a measure of dysphoria), and gender predicted attendance to cervical screening. Further analysis considered how much variance could be explained by these factors, and which of these factors is the best at predicting attendance to cervical screening.

Results

Tables 1-2 detail the characteristics of the sample and answers to cervical screening questions. The sample is overall young, with over half (n=103, 52.6%) being between 20-24, just old enough to potentially have received a cervical cancer screening recommendation prior to changes in guidelines. Half are in the lowest income bracket (AUD\$0-\$18,200) (n=94, 50.5%). Homelessness had been experienced by one third of participants (n=70, 36.5%), and neurodiversity (e.g. autism) was disclosed by 41.5% (n=76). Two thirds of the sample had strong or moderate dislike for their body.

In terms of cervical screening, most people did not correctly answer the cervical cancer screening awareness items, with only 14.8% correctly answering that someone who has not been sexually active does not need to participate and half (51.5%) correctly identifying that the program had recently changed. Two thirds (66.8%) of participants had no or little concern of developing cervical cancer, and 44.6% had never had a HCP recommend cervical screening to them even though all could have potentially received a recommended screening before guideline changes. Almost half (48.0%) have never had cervical screening, with only 21.9% reporting that they are regular screeners. After excluding those aged 23 and younger due to the likelihood they had only been screened once, a quarter had never been screened (26.9%), and just over a third reported they were regular screeners (36.1%). Over a

quarter (27.5%) of people who have participated in screening have had an abnormal result. People who had not attended screening were asked why, with the most common reasons being that it is emotionally traumatic (55.3%) and inability to find a HCP that they are comfortable with (38.3%).

Standard multiple regression was used to assess whether age, healthcare provider recommendation, like for body (as a measure of dysphoria) and gender (trans man compared to gender diverse) predict attendance to cervical screening. The variance explained by this model was 44.0%, $F(4, 190) = 37.27, p < .001$. All four variables were statistically significant, with older participants more likely to be regular screeners ($beta = .39, p < .001$), followed by those who received a healthcare provider recommendation for screening ($beta = .29, p < .001$), like for body ($beta = .18, p = .002$), and those identifying as gender diverse ($beta = .18, p = .002$).

Table 1 Characteristics of the sample (n=196).

Age		
20-24	103	52.6%
25-34	62	31.6%
35+	31	15.9%
Remoteness classification		
Major city	158	81.0%
Inner regional	28	14.4%
Outer regional	9	4.6%
Individual Income before Tax (AUD)		
\$0-\$18,200	94	50.5%
\$18,201-\$37,000	39	21.0%
\$37,001-\$87,000	43	23.1%
\$87,001-\$180,000	10	5.4%
Experienced Homelessness	70	36.5%
Disclosed an Area of Neurodiversity	76	41.5%
Disclosed a Disability	66	36.3%
Like for own body		
Strongly dislike	57	29.1%
Moderately dislike	75	38.3%
I feel neutral towards my body	27	13.8%
Moderately like	21	12.2%
Strongly like	13	6.6%
Disclosure of gender to healthcare providers		
Never	29	14.9%
Only if I have to	81	41.8%
Sometimes	48	24.7%
Always	18	9.3%
I have no choice as my documentation shows this information	18	9.3%

Table 3 Cancer care, awareness and cervical screening.

Cervical cancer screening awareness items (correct responses)		
It is not necessary to have screening for cervical cancer if someone with a cervix has never been sexually active in any way (<i>true</i>).	29	14.8%
The Australian cervical cancer screening program has recently changed (<i>true</i>).	101	51.5%
Concern for developing cervical cancer		
No concern	41	20.9%
A little concern	90	45.9%
Moderate concern	53	27.0%
Extremely concerned	12	6.1%
Healthcare provider discussed/provided information on cervical cancer	64	32.7%
Healthcare provider recommended cervical screening		
Never	87	44.6%
Once	59	30.3%
Often	49	25.1%
Ever had cervical screening (all)		
Never	94	48.0%
Once/rarely	59	30.1%
Regularly	43	21.9%
Ever had cervical screening (aged 24+, n=108)		
Never	29	26.9%
Once/rarely	40	37.0%
Regularly	39	36.1%
Ever had an abnormal result*	28	27.5%
Reasons for never having attended cervical screening**		
Physical pain	13	13.8%
Have not had sex	29	30.9%
Emotionally traumatic	52	55.3%
Previous bad experiences	10	10.6%
Inability to find healthcare provider that they are comfortable with	36	38.3%

*Percentage based on number of people who reported they had previously had cervical screening (n=102).

**Percentage based on number of people who reported that they had never attended cervical screening (n=94).

Discussion

The results present a snapshot of the issues facing TGD people with a cervix accessing cervical screening, the vast majority of whom report either never- or under-screening. This sample had high rates of being in a low-income bracket, having experienced homelessness, neurodiversity and disability, which is consistent with previous Australian research (10, 17). Such vulnerabilities are likely to contribute to difficulties participating in cervical screening. Further to this, two thirds (67.4%) reported that they either strongly or moderately disliked their body, and only 9.3% always disclosed their gender in healthcare interactions – both of which may contribute to underscreening.

Cervical screening awareness appears to be limited in the TGD community; half of our participants were unaware that the NCSP had changed. This is perhaps unsurprising given that only 32.7% of our sample indicated that a HCP had discussed cervical cancer with them, and 44.6% had never had a HCP recommend screening to them. Alarming, 48.0% of participants reported that they had never had a cervical screening, with only 21.9% indicating that they consider themselves to be regular screeners. This is compared to national data in 2018 that estimated 54% of the eligible population participated in screening (1). Given the reduced frequency with which people with a cervix are now recommended to screen, this may be more appealing to TGD people with a cervix, increasing their participation.

Recently, there have been two LGBTIQ-targeted campaigns formed from partnerships between Thorne Harbour Health (formerly the Victorian AIDS Council) and the Cancer Council Victorian (*Public Cervix Announcement* – cervicalscreening.org.au/LGBTIQ), and between the AIDS Council of NSW and the Cancer Institute NSW (*The Inner Circle* – theinnercircle.org.au). Such partnerships could be useful in outreach campaigns of awareness raising and service provision to the populations in most need as seen in this study.

Additionally, the NCSP has begun to use inclusive language, specifically stating that anyone

with a cervix may be eligible for screening, including people who identify as transgender. Inclusive health promotion is valuable and should be expanded at the national and state and territory levels.

An important finding is that one quarter (27.5%) of our participants reported receiving an abnormal test result. Limited research has linked this to changes associated with exogenous testosterone use (9), with a significant lack of research on HPV prevalence in TGD people with a cervix. An Italian study found a high rate of detectable HPV DNA, however, the study was limited by a small sample and called for more research into this (18). Both patients and providers may hold misconceptions regarding the sexual behaviour and HPV-infection risk of TGD people with a cervix, who engage in a variety of sexual practices that may place them at risk of HPV acquisition (19, 20).

Results from the regression show that people are less likely to screen if they are younger, their HCP does not recommend it, and they dislike their body. Trans men were less likely to screen when compared with gender diverse people with a cervix. Further to this, the most common reasons that participants gave for never screening were that they find it emotionally traumatic and they have been unable to find a HCP they are comfortable with. There is significant scope for HCPs to be engaging their TGD patients with a cervix to participate in screening, and international research confirms the importance of this as a facilitating factor (21). Informative guidelines exist to aid this; emphasising communication, patient control and methods to minimise distress (3). TGD people with a cervix will have varying preferences regarding the procedure, the HCP therefore must have a good understanding of the individual patient's needs (3). Sensitive language use is important, including that the HCP ensures they use the correct name and pronouns as described by the patient (names that appear within a health system may be the TGD person's name given at birth) (3). Another aspect of language is using gender-neutral words as much as possible (e.g.

instead of vagina using ‘genital opening’ or ‘frontal pelvic opening’) (3). Atrophy of the vaginal epithelium may occur if the patient is taking testosterone, causing pain during speculum insertion - clinicians may use a smaller speculum to prevent discomfort (3).

The inclusion of a self-collection method in the NCSP may provide a less distressing option for cervical cancer screening in TGD individuals. Australian research has found self-collection to be effective at increasing participation (2). Several studies have been conducted in the U.S. on the preferences of trans-masculine individuals with regards to this. Together, this research found that between 57.1% and 90.3% of trans-masculine people would prefer self-collection to provider-collection (22, 23). The reasons for this included; previous experiences of discrimination; the less invasive nature of the procedure; lower levels of gender discordance; and a greater sense of agency (22, 23). Importantly, the studies also highlighted that there were a variety of preferences for participants, thus in order to improve attendance, TGD individuals should have a choice with regards to which cervical cancer screening method they wish to have. Research with under-screened populations has demonstrated that self-collection has high acceptability and will encourage greater participation in cervical screening (24).

Strengths and Limitations

This study had several strengths and limitations. It is strengthened by the large, national sample of a minority population which was engaged throughout the study in meaningful ways to ensure appropriateness. It is limited by the wholly online nature of the survey, which recruited a sample of convenience that is thus not representative. Additionally, participants self-selected to participate, meaning that the study may contain a higher proportion of people who have had bad experiences. Further, that participants self-reported screening frequency may have skewed results.

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