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Title: Key Informants Discuss Cancer Care Research for Trans and Gender Diverse People

Abstract: *Purpose* The aim was to explore issues in relation to accessing cancer care for the Australian trans and gender diverse community through key informant interviews to inform a study on the topic. *Methods* Semi-structured interviews were conducted with key informants who either had clinical and/or research experience with trans and gender diverse populations or were members of the community who act as advocates (total n=14). Participants had diverse genders, including three trans women, one trans man, three non-binary people, six cis woman and one cis man. Thematic analysis was used to analyse the transcripts. *Results* Four themes were identified in the data; 'More Important Issues'; Experiences of Cancer Care; Barriers to Care; and (Potential) Facilitating Factors. *Conclusion* The findings show the inconsistencies in awareness of cancer in the trans and gender diverse population, both within the community itself and in healthcare. There are issues concerning under-utilization of screening services, healthcare workers lacking knowledge, and an invisibility within organizations and systems. Training and education are needed in health and cancer care, as are partnerships with community organisations, inclusive policies, improved data collection on gender, targeted health promotion, and research.

Introduction: Cancer research and literature frequently contain assumptions about gender and do not collect data on diverse identities; the needs of trans and gender diverse (TGD) individuals are therefore invisible [1]. Gender affirming treatments (hormonal and surgical) may affect how people should be screened for cancer and their risk [2]. There is little research considering the TGD population's cancer incidence and mortality; no overall increased rates have been observed [3,4]. However, emerging evidence suggests higher rates of cancers related to viruses (e.g. HPV and HIV) and tobacco-use [4]. One study has considered the experiences of TGD people with cancer and found unique needs and issues related to patient education and decision-making, for example the lack of information that is relevant to them and their need to expend time and energy finding resources [5].

The Australian healthcare system is one of the most affordable and accessible in the world [6]. Despite this, Australian TGD healthcare research emphasises insensitive services, inadequately trained healthcare workers (HCWs), access and safe disclosure barriers, and frequent bad

Key words: transgender, gender diverse, community-based participatory, key informant, cancer care.

experiences, resulting in healthcare avoidance and poorer health [7,8]. These problems are likely to extend to cancer care, and result in poorer outcomes within oncology.

TGD study guidelines suggest that community-based participatory research (CBPR) approaches benefit the community and improve research validity [9]. CBPR has been highlighted as an ideal way to address cancer disparities [10]. Further, the lack of evidence on cancer and the TGD community mean that there is little guidance on how researchers should proceed, warranting exploratory approaches [11]. Therefore, the authoring research team (tenured health science university academics/ Assoc. Profs and their PhD student, with backgrounds in transgender health studies and oncology) conducted key informant interviews as part of a CBPR study on cancer care for the TGD community. The aims were to uncover the issues related to cancer care for TGD people. This paper provides the methods, results and implications of these interviews.

Methods: The study targeted a cross-section of key stakeholders who had experience working with the TGD community, over the age of 18 and living in Australia. Ethical approval was obtained from La Trobe University's Human Research Ethics Committee. Participants were identified through research publications, gender services networks, a conference and community advocacy groups and approached in person and by email. Verbal and written informed consent were obtained prior to a semi-structured, one-on-one, audio-recorded in-person, phone, or video interview. Participants were asked four questions: 'When you think of the TGD community and cancer, what comes to mind?'; 'Does this seem to be a concern or a prominent issue?'; 'What do you think may stop some TGD people from accessing cancer services?' (cancer services were defined as broadly inclusive – from screening/prevention into survivorship); and 'In terms of getting TGD people involved in cancer care, how do you think this would be best achieved?'. Recruitment continued until data saturation was reached. Interviews were audio-recorded, transcribed and a thematic analysis was performed.

Thematic analyses followed Braun and Clarke's deductive and inductive steps [12]. This was appropriate since the deductive analysis ensured the key informant interviews could answer research questions, and the inductive analysis allowed for exploration of unexpected themes given the

understudied topic. The first phase involved transcription, reading and re-reading, and reflecting on the data. Initial codes were then developed in the second phase. Codes were then grouped into themes, discussed by the team, examined for coherency, strength of support from the data and weighed against other themes for refinement.

Results: Fourteen participants were interviewed. Six participants had conducted research with TGD people (one of whom also provided clinical care), three provided clinical care to TGD people (as a nurse, general practitioner, and specialised paediatric gender affirmation services), four people acted as community advocates, one person was a cancer social worker who did LGBT-inclusive work in their role, and one person was involved in governmental policy relating to sexual and gender equality. All participants lived in major cities. Participants' genders were three trans women, one trans man, three non-binary people (people who identify their gender as being other than the binary man/woman), six cis woman, and one cis man ('cis' is the term used for people whose gender aligns with their sex assigned at birth). Four themes make up the results; 'More Important Issues'; Experiences of Cancer Care; Barriers to Care; and (Potential) Facilitating Factors.

'More Important Issues': Participants described the TGD community's cancer awareness and whether cancer was a prominent issue. Gendered cancers (e.g. breast) and the cisgendered approach to dealing with these came up consistently. A cis participant commented that:

... because of gender binaries people don't think that a whole range of people can have a whole range of body parts, therefore we need to be screening for different things for everyone rather than presuming 'you look like a woman so you won't have a prostate.'

Participants reported '*silence*' and '*invisibility*' surrounding cancer and TGD people due to the lack of awareness related to gender diversity, cancer being a '*taboo*' subject, and that cancer in this population was considered relatively rare. However, one trans participant thought TGD people would be over-represented in cancer rates due to tobacco use. Hormones and their relation to cancer risk was raised by three participants. These participants expressed uncertainty about the level of risk from hormones, citing the lack of research evidence.

All of the participants saw the issue of cancer and the TGD community as concerning, however, for two participants it did not seem a prominent issue, with many other participants reflecting this in their comments on the lack of discussion on the topic amongst the community and within services. One non-binary participant stated, *'Why is this an issue? Because it's not in my experience something that comes up a lot.'*

Awareness of the topic within the TGD community and HCWs were discussed. Both were seen to have low levels of awareness potentially influencing each other, as one non-binary participant expressed, *'if it's not in the clinician's consciousness, if they're not warning people about it, then it probably wouldn't be an issue that [TGD] people raise.'* Two participants talked about emerging awareness; *'maybe there's some growing awareness... but I think there's still so much misunderstanding and probably more thinking that there's more important issues to resolve first.'* Three participants talked about the inconsistency of awareness throughout the TGD community, and that younger TGD people are less likely to discuss cancer. Generally, participants thought that it was not a top priority for the TGD community compared to other issues such as gender affirmation, socioeconomic factors and societal acceptance.

Experiences of Cancer Care: Participants described experiences of TGD people accessing cancer care. Under-utilisation of services came up consistently, especially screening. Half of the participants identified dysphoria (disidentification and discomfort with gendered body organs) as a major barrier. TGD people may find it distressing to acknowledge or be touched around the chest and genitals. Similarly, there is a reluctance to attend services that are gendered spaces (e.g. gynaecology clinics). Conversely, certain screenings may be affirming, as a trans participant expressed:

Trans women would probably go for an internal ultrasound because it's engaging with their bodies how they identify, and they get to do a woman thing.

The lack of understanding on the part of services, particularly in relation to diverse bodies was also a problem. A trans participant said:

If we're on hormones, our bodies work in a way that is very different... My body now doesn't exactly work in a way that a cis woman's body works, but it definitely no longer works, feels, is a

way for me to inhabit a body in the same way that a man inhabits his body... it is a concern that they're not going to get it right, they're not going to find the right thing.

It was widely reported that TGD people have uncertainty and fear when accessing services, linked to previous and ongoing mistreatment. They do not have confidence that they will receive sensitive and appropriate services. One participant also expressed the belief that HCWs do not have the same level of care for TGD people as for cisgender people.

Three participants raised pain during cervical and breast screening. One participant described how providers may be rough with TGD people during cervical screening, and gave several reasons as to why this may be the case:

Rough procedures from clinicians that were obviously not too happy doing it, not comfortable in themselves, or maybe it was nerves that they're not doing it as nicely, or maybe it's just that reaction I get so many times when I have to go for tests or screening that I have mutilated my body, so everything's just a bit more aggressive.

Most participants thought it was unlikely that GPs would be initiating the appropriate screening for TGD people, partly due to misconceptions (e.g. '*you don't need a Pap if you've never had man-sex*'). The gendering of most screening means that doctors may not offer 'female' screening to men or 'male' screening to women.

Less frequently, participants mentioned the difficulties associated with bowel cancer screening. One trans participant discussed the challenges related to colonoscopies:

It's down in that area where you cannot not be noticed that you're trans... So that element, the magnitude of trust that you have to put in someone's hands to go unconscious and wonder if you're coming out the other end okay.

Barriers to Care: A prominent topic for this theme was the experiences of adverse social conditions, including ongoing mistreatment in society broadly but also within healthcare. Specific areas highlighted included low socioeconomic status, under-employment, discrimination, familial rejection, social isolation, and the resulting mental health problems for many in this community. Such things make the trans and gender diverse community particularly vulnerable, and perpetuate a lack of access to appropriate healthcare, both through the barriers created by the social conditions and the distrust of services that individuals have. One trans participant said:

I've seen and experienced that once you introduce pain or illness into being gender diverse and usually lower income, it actually means that they probably get below the threshold where they can even imagine taking on a service, or receiving medical assistance in any capacity at all.

Other barriers mentioned by participants included concerns about privacy and having to 'out' oneself. One trans participant discussed self-negation as a barrier:

You live your life a certain way, you have habits of thoughts and behaviour... if you've lived a significant number of years actually attempting *not* to kill yourself every day, you're much more comfortable with that idea, so you're much more comfortable with self-harm, you're much more ready to say 'oh fuck it, I'm not going, that'll just help me get out of here faster anyway' – there's almost a propensity to not [attend cancer screening].

The most important issues relating to barriers were regarding the provision of care; specifically, interpersonal interactions, organizational elements and health promotional material. Participants indicated that problems in the medical profession were widespread, starting in pre-vocational education. Language use was a major factor affecting doctor-patient relations; HCWs frequently misgendered or referred to TGD people inappropriately. Three participants posited that specialists' communications were poorest. Participants cited lack of training on TGD issues as the root cause of poor care, but prejudiced doctors were also common, and others who felt confronted. Clinicians frequently asked the patient to explain TGD issues. Conversely, some clinicians ask no questions about patients' genders, or only ask people who appear identifiably TGD, therefore many are unaware of patients' needs. Generally, the medical profession was seen as sticking to the '*traditional*' and not engaging with things that were '*difficult*'. Interpersonal issues extended to all HCWs, including ancillary staff. Anyone could be a source of discrimination; receptionists were mentioned by four participants as misgendering or outing TGD people in waiting rooms. For five participants, hospitals offered the most inappropriate, insensitive treatment of TGD people. Hospital size was cited as an issue, as staff attitudes towards TGD individuals may vary widely. TGD people's stressors when accessing healthcare complicate their ability to be informed consumers.

The system was consistently seen as being ill-equipped to provide appropriate care for TGD people, resulting in inequity across services. Participants thought the system was suppressing and denying the issue, preventing TGD people from voicing their concerns. Two cis participants

described the impossible situation that arises when evidence is needed to change systems, yet systems needing change avoid collecting the relevant data (*'you end up in this strange bureaucratic data loophole'*). Another cis participant talked about the broad umbrella of 'LGBTI people', wherein diverse concerns are *'diluted down'*. One non-binary participant speculated that in cancer services, diversity issues may be ignored or forgotten because the seriousness of the disease is prioritised. Six participants mentioned scattered cancer services/initiatives that were TGD-inclusive (e.g. a breast-screening service that offers specific evenings for TGD people to attend mammography); however, this was invariably seen as not enough, particularly because of the size of the cancer care system.

The bureaucratic elements of healthcare came up regularly. The lack of inclusion of TGD people in policies was raised; however, intake forms and databases were more problematic. Eight participants said most systems do not allow for meaningful collection of gender information, and commonly ask for 'next of kin' not 'emergency contact' (potentially distressing for TGD people experiencing familial rejection). TGD people were thus frequently misgendered and misnamed on registration forms, wristbands, discharge paperwork and death certificates.

Finally, four participants said cancer organisations' health promotional material privileged heterosexual, cisgendered perspectives; one trans participant emotively described:

I have sat in that hospital for hours in grief with him on life support... I can tell you I've read every page of every specialist brochure for cancer, just seeing if there was one line somewhere that said they knew I was there and there wasn't, not in one of them.

(Potential) Facilitating Factors: Moving forward, participants called for cultural change through training and education across services, and inclusive policies and procedures. Participants thought that the collection of patient's data also needed to be improved so that it accurately represents individuals. Misconceptions and prejudices need to be addressed with enhanced understanding of diverse genders and bodies. Partnerships with TGD advocacy organisations are also highly valuable, both to aid training and to promote services' 'trained' status. Four TGD participants explained that unless a service's training is promoted, TGD people have no way of knowing it occurred.

Community referral was commonly discussed, with seven participants stressing the importance of trans and gender diverse people connecting to share welcoming and inclusive services.

HCWs needed to increase sensitivity, appreciation of privacy, respect, trustworthiness, empathy, and knowledge. Three participants wanted individual-centred care. A further three participants called for TGD people to be providing services, and two thought that it would be helpful to have liaison officers. Participants stated that more research was needed to provide evidence to back up clinical decisions.

Two participants argued health promotion should be less gendered, including representations of diverse genders. One non-binary participant emphasised the need for TGD-specific health promotional material. Three participants discussed empowerment approaches, and one stated that the approach needed to change from the paternalistic, traditional medical establishment telling people what to do, to being more focused on change within services to meet the needs of all individuals.

Discussion: Overall informant interviews suggest low levels of awareness on cancer and the TGD population; for both HCWs and the TGD community. The TGD community broadly do not have physical health as a high priority because they have to dedicate their time and energy to other important things that affect their wellbeing, specifically gender affirmation, appropriate recognition, safe housing and income.

The position of TGD people in healthcare has been described as invisible [13]. This erasure exists at both informational and institutional levels; often TGD people are left to remedy the situation themselves (e.g. by educating HCWs). Erasure and invisibility also affect funding and resource allocation, and thus service accessibility [14]. Healthcare policies and practices emphasise the importance of cultural competency, yet this is rarely extended to TGD communities [15]. The findings here support the need for enhanced visibility to raise awareness, and improved data collection methods so an evidence base may be formed.

Extremely little is known about TGD people's cancer care experiences. Informants predict an under-utilisation of screening, aligning with research on cervical screening for TGD people [16].

TGD individual-level barriers to accessing services have been found elsewhere, for example the fear that they will not be receive appropriate care due to previous mistreatment, concerns about confidentiality, and dysphoria [7,8]. However, the barrier of gendered spaces is relatively unique to some areas of cancer care. Canadian research has explored how cancer surgery may be experienced as gender affirming by TGD people who were assigned female at birth, however, there is no psychosocial research exploring whether ‘traditional female healthcare’ may be affirming for trans women [5]. More research is necessary to understand the diverse needs of TGD people with cancer.

In this study, participants identified the main barriers to accessing care as issues associated with interactions with HCWs and organizations and systems that do not support or recognise TGD individuals’ needs. HCWs were seen as lacking awareness through to being prejudiced, with significant problems in their use of language, supported by Australian health research [7]. International research has found that there is a lack of training on TGD issues for medical practitioners [17]. This research supports the need for increased education.

Australian research has offered recommendations on how to improve access to care: peer involvement, community consultation, training, intake forms with appropriate questions, enhanced availability of specialised services, and patient-led approaches [7,8]. This research adds to these findings that communication with the community is necessary to let them know whether services are inclusive, and that provisions of TGD liaison officers and TGD health promotional material could also improve access. Given the Australian context, findings may not be transferable to nations where TGD people lack discrimination protections.

Conclusion: The study reported on here builds on previous TGD Australian health research to highlight specific issues related to cancer care. Currently, awareness levels are low both in the TGD community and health and cancer care. HCWs and organizations appear unequipped to sensitively and appropriately meet the population’s needs. Training and education, partnerships with TGD community organizations, inclusive policies, improved data collection on gender, health promotion targeting TGD people, and further research are necessary. Population-based research and registries

should collect data on diverse genders, in order to provide useful frequencies around the epidemiology of TGD people diagnosed with cancer.

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