

Research Article

Supporting Aged Care Workers to Understand and Respond to the Needs of Trans and Gender Diverse People: An Australian Co-designed Quality Improvement Initiative

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ABSTRACT

Objective: The need for accessible health and support services for older trans and gender people (TGD) Australians is well documented. The aim of this study was to develop and evaluate resources to support aged care workers to meet the needs of TGD clients.

Method: The quality improvement initiative comprised a co-design model with a focus on partnering with consumers, consumer representatives and employees to identify and respond to client needs. A Working Group used a literature review, consultations with key informants to develop resources which were then trialled with employees to evaluate their usefulness and effectiveness.

Results: A 3-page guideline and two diversity stories were

developed. 81% reported the guideline to be very useful; 90% said it was easy to understand. Likewise, 93% said the story was easy to understand and 72% said it was very good at providing knowledge.

Conclusion: The guideline and diversity stories are a potentially useful resource for aged care workers to more effectively understand and respond to the needs of TGD clients. The multi-method and participatory process, which included TGD representatives, not only enhanced the usefulness of the resources, but sent a clear message across the organisation that equity of access was important.

Keywords: LGBTI; Transgender; Aged care; Trans and gender diverse

Impact Statement

Policy impact

Existing aged care workers now have access to in-house, tailored resources to assist them to better understand and respond to the needs of TGD clients/residents. Orientation for new employees will also include these resources which not only supports new employees but sends a message to them that their new workplace values diversity, equity of access and care for all people. Engaging employees and Lesbian, Gay, Bisexual, Trans and Intersex (LGBTI) stakeholders not only resulted in tailored and culturally sensitive training resources, the process and resources also educated senior employees and served to highlight key principles in practice going forward such as: the importance of being welcoming; ensuring administrative flexibility; addressing gender stereotypes; respecting privacy; and advocacy.

Practice impact

The content of the resources is clear and concise and encourages aged care workers to be respectful, professional, to make no assumptions about clients/residents, and above all, to listen. Supporting workers to adopt these principles is directly beneficial to older TGD people will have a flow-on effect for

other diverse age cohorts and will also facilitate increased awareness of the need for quality service provision in TGD health and aged care.

Introduction

The need for accessible health and support services for older TGD Australians is well documented, and reveals the long term impacts of discrimination and stigma [1]. Many older TGD people are reluctant to seek aged care services because of past life events, and fear of being treated with further discrimination [2,3]. With appropriate training and education, and a supportive organisational culture, aged care workers have a critical role to play in achieving equity and justice within health care [4]. Furthermore services that apply a TGD-inclusive rather than a cisgenderist framework (an approach that only addresses, for example, pathologising, misgendering and marginalizing language) in ageing and aged care contexts has greater potential to meet the practical needs of TGD people [2].

Trans and gender diverse is used as an umbrella term for anyone whose gender identity/expression differs from what is typically associated with the sex they were assigned at birth. Historically, TGD people have experienced stigma, discrimination, criminalisation, family rejection and social isolation [5]. The disclosure of trans status may result in loss

(family, friends, employment), feelings of betrayal, confusion, hurt and mistrust [6]. TGD older people experience higher levels of depression and anxiety, and report higher levels of abuse than the mainstream older population as well as older Lesbian, Gay and Bisexual (LGB) people [5]. Furthermore, compared to LGB people, trans older adults have greater difficulty with accessing health care, and are more likely to experience financial barriers, receive inferior care and be denied health care [6]. Poor health care is further exacerbated by a lack of knowledge of this population on the part of the professionals involved [7].

Trans older people may have transitioned recently or several decades ago and this will likely impact the nature of their needs [8]. The decision to transition later in life is not taken lightly, and the impact of lifelong societal expectations and internalisation of these expectations needs to be acknowledged [9]. Transitioning requires rigorous screening processes. Gender reassignment surgery is often not an option for all trans people for many reasons including lack of choice, cost and access to surgical expertise. Other common issues for trans older people are pharmacological management (e.g. interactions between hormone and other pharmacological treatments, underdosing, overdosing, cost of hormone treatment) and fears about end of life care and/or dementia particularly around decision-making [10,11].

The Australian aged care system caters for people aged 65 and over (and indigenous Australians aged 50 and over) who can no longer live without support in their own home. Care is provided in people's homes, in the community and in residential aged care facilities (nursing homes) by a wide variety of providers. Ongoing advocacy over the last few decades by key organisations in Australia has culminated in the 2017 Commonwealth Aged Care Diversity Framework (12: p.2) which "seeks to embed diversity in the design and delivery of aged care; and support action to address perceived or actual barriers to consumers accessing safe, equitable and quality aged care, while enabling consumers and carers to be partners in this process". Furthermore, the goals and principles of the 2012-2017 National LGBTI Ageing and Aged Care Strategy (the LGBTI Strategy) remain relevant and useful going forward, with opportunities to improve inclusivity, leverage organisational support and increase training and support to staff [12-14]. There is also a commitment to release a LGBTI Action Plan for Australia in 2018.

XXX (Organisation de-identified) is a large Australian wide and experienced provider of At Home Support services, Retirement Living and Residential Aged Care. Aged care workers in Australia work across all formal services provided for older people, which include health and social care. In 2014 XXX undertook a LGBTI Inclusive Practice Self-Assessment, using standards developed by Gay and Lesbian Health Victoria (GLHV) and Val's Café [15]. This was conducted to assess the extent to which inclusive and equitable services were currently being provided to LGBTI consumers. In total, 50 items of evidence identified areas of good practice, and 19 recommendations for improvement were made. This work emerged out of and sits alongside the XXX Diversity Framework 2017-2025 (XXX) and the Diversity Conceptual Model (XXX) which was developed

in 2016. It also informed the subsequent development of an organisation wide LGBTI action plan for XXX.

With the momentum provided by the national LGBTI Strategy and Aged Care Diversity Framework, there is growing evidence and guidelines to support aged care providers to investigate and improve the cultural safety and inclusivity of their practices for their LGBTI clients [2,16]. However, the specific experiences of TGD people are rarely explored in isolation from the broader LGBTI community.

As part of the organisation's quality improvement processes, it was agreed between XXX and the funding bodies Sidney Myer Fund and GALFA, to implement one of the recommendations from the LGBTI organisation-wide self-assessment-to develop some resources to support aged care workers to understand and respond to the needs of transgender people with a particular focus on continence care and wound management. The objectives of the project were to:

1. Equip aged care workers (e.g. community nursing, allied health and home and residential care employees) with general knowledge about health and wellbeing needs of TGD people, utilising digital diversity stories.
2. Develop an accessible, evidence-based guideline for employees working with TGD people (herein the guideline).

This paper documents the innovative co-design process of developing these resources and the evaluation of their appropriateness, acceptability and usefulness with aged care workers at XXX.

Methods

This project comprised a co-design model with a focus on partnering with consumers, consumer representatives and employees to identify client/resident needs. A co-design approach, whereby all stakeholders were involved in all stages of the project, was used to maximise the accuracy and usefulness of the final products.

Individuals with specific expertise or key roles within TGD community were invited by the Project Manager to join the Working Group. The Group was specifically tasked to provide expert advice and oversee the development and content of the resources and evaluate the final products. The Working Group comprised of specialist diversity and clinical employees from XXX (including the Project Manager and Officer), representatives from Transgender Victoria and Gender Diversity Australia, The Shed (formerly FTM), as well as three people who identified as transgender.

The Working Group split into two smaller groups to draft and develop the resources, one for each resource. Each of these smaller groups conducted two focused discussions which were comprehensively documented with written notes. In between discussion groups, Working Group members revised and refined the content. The findings were presented to the larger Working Group and again refined and edited.

A literature review was conducted to assist the Working Group to identify potential issues for concern, and inform the content development of the two resources and the questionnaires. The literature search was carried out early in the project using CINAHL (a nursing and allied health database). The search strategy comprised a combination of terms pertaining to three concepts: 1) Transgender and Gender diversity; 2) Aged Care/Ageing; and 3) Nursing interventions and conditions. Unpublished (grey) literature on the topic was sought using the same terms in searches of the Australian Government Department of Health and websites of transgender organisations across Australia and internationally. The titles and abstracts of the articles retrieved were scanned by a member of the Working Group, the literature was summarised and presented to the Group and key articles were circulated.

Throughout the process the project manager and officer made regular contact with key informants to verify and ensure the content and quality of both resources and to check they were acceptable from a client perspective. This included a formal presentation to members of a Community Advisory Group.

Three more in-depth consultations were conducted by members of the Working Group specifically to inform the content of the digital stories. Participants were selected on account of their specific expertise or experience to inform the content of the resources. For example, one interviewee was a trans man for the purpose of drafting the female to male transgender digital diversity story. Another interview was conducted between a Senior Clinical Nurse Advisor and client representative to look more specifically at the wound care needs of trans women.

Evaluation Questionnaires

Two 5-item questionnaires designed by the Working Group and informed by the literature were administered by XXX

diversity employees-one related to the guideline and the other related to one of the stories. The questionnaires were distributed to two different, randomly selected, groups of aged care workers during a 6-week period in March and April 2017. All participants were asked if they had ever worked with any TGD clients/residents. Questionnaire items included 6 Likert scales as well as 3 open ended questions: Can you suggest any ways in which we could improve the Guidelines? Based on the Digital Story what do you feel are some of the issues for the client? Can you suggest any ways in which we could improve the Digital Story? Given this evaluation was part of an internal quality improvement process, it was not within the scope of the study to validate the questionnaire, rather the items were designed to best fit for purpose (Table 1).

Guideline

The guideline was circulated to existing and new employees to read and review, with a request to complete a questionnaire. Employees included those from the HIV and Homeless Persons Programs, managers and clinical quality and risk managers, and clinical employees.

Digital Diversity Story

Orientation sessions for new employees were conducted in each of the four Melbourne regions. As part of the orientation, employees were given the diversity conceptual model (DCM) (XXX) and asked to listen to a digital story about a trans client and mark the DCM accordingly. Twenty-nine new employees completed a questionnaire about this story after the session.

Analyses

The Likert items in the questionnaires were analysed by percentage of participants who recorded a response above 8

Table 1: Percentage response to Likert scale items.

Likert Scale Item (1-10)	Response Category*	Response % (n=31)
Have you ever worked with any Transgender or gender diverse Clients?	Yes	45%
	No	42%
	Uncertain	13%
Do you feel the information in the “Guidelines: Working with Transgender and Gender Diverse Clients” is useful?	Very useful	81%
	Quite useful	13%
	Not useful	6%
Do you think the information given to you is easy to understand?	Very easy to understand	90%
	Quite easy to understand	10%
	Not easy to understand	0%
How well do you feel the Guidelines explained where you would be able to get more information and/or help?	Very well	87%
	Quite well	10%
	Not well	3%
Do you think the Digital Story presented to you was easy to understand?	Very easy to understand	93%
	Quite easy to understand	7%
	Not easy to understand	0%
Did the Digital Story provide you with knowledge on how to recognise and respond to the needs of a Transgender client?	Very well	72%
	Quite well	24%
	Not well	4%

(out of 10 on the scale). Open-ended responses were collated for each question and key concepts were summarised. Quotes were used where necessary to illustrate themes.

Resources

Drawing on data provided via in-depth consultations, small working groups and key informants, as well as evidence from the literature, the Working Group developed a 3-page guideline and two digital stories

The evidence-based Guideline for Working with TGD people were designed for use by all XXX employees across all service types, in all Australian jurisdictions and catchments. The purpose of the guideline was to support employees to provide culturally appropriate and safe care to consumers who self-identify as TGD. Prompts were listed under five main topics (identification; respect for individual; partnership; networking; and diversity) to encourage employees to consider some important issues when negotiating, planning and providing services to clients/residents, their careers and families. This guideline is only available for internal use at XXX.

Client/resident diversity stories with a transgender focus were produced, one of which is available as a short (2-3 min) video online (Link removed for de-identification) narrated by and from the perspective of an employee. The stories describe many issues that confront TGD individuals in society, health and in ageing and highlights ways in which the health care professional can assist in resolving issues or ensuring that they do not occur.

Results

Of new and existing employees who responded to a questionnaire, 33% and 86% respectively (45% average) reported to have worked with TGD clients/residents in the past. The majority of participants rated the guideline and digital diversity story positively (Table 1).

Of 6 new and 24 existing employees who reviewed the guideline, 81% reported it to be very useful, and 90% said the information was easy to understand. Of all respondents, 79% felt the guideline explained very well where they would be able to get more information and/ or help. Some of the suggestions to improve the guideline included: providing more focus on “non-traditional relationships and relationship arrangements”, building trust between clients/residents and employees, identifying issues around stigma and discrimination, and more information relevant to specific needs of trans men and trans women. A number of employees said how important it was to ask clients/residents about their gender, with a new employee suggesting that it would be useful to include information about “Ways to ask clients how to self-identify their gender” and “How to start the conversation”.

Of 29 employees who reviewed the digital story, 93% said that it was easy to understand, 72% said it was very good at providing knowledge about how to understand and respond to the needs of TGD clients/residents. Participants reported back

that the digital story highlighted for them: the importance of correct documentation of gender; and fear of discrimination, stigma, illness and mental health issues being important to consider when working with TGD clients/residents. Several respondents suggested the digital story be told by TGD clients/residents themselves (as opposed to from the perspective of employees) - “It would be good to have a direct narrative from a client on their experience” and to “definitively identify the care needs/issues from both the client perspective and the nurse perspective”.

Discussion

This multi-method, quality improvement process resulted in the development of resources which were rated highly by employees and ultimately the people who would be using them. Consultations with TGD people, research evidence, and the expertise of the service providers (who understand that their workers are time poor and value concise, user-friendly information) combined to provide high quality tailored resources. Respondents made suggestions for improvements which will be incorporated into ongoing orientation training programs and materials as appropriate going forward. Despite suggestions for more detailed information in the guideline, it is perhaps more important to keep it brief and have targeted information that is the most relevant to providing safe and inclusive care. These resources complement the Department of Health’s suite of LGBTI ageing and aged care resources available online - <https://agedcare.health.gov.au/support-services/my-aged-care/lgbti-ageing-and-aged-care-resources>.

The multi-method and participatory process which comprised a range of people from diverse backgrounds is likely to have enhanced the usefulness of the resources. Most importantly, using a co-design approach ensured that the resources were developed and informed by the wisdom and experiences of TGD people themselves and at the same time advocated for transgender individuals and assisted to remove barriers to healthcare [17,18]. Engaging older TGD people in this planning and review process not only assisted in empowering older TGD consumers but maximized the likelihood that cultural safety was achieved [2].

The composition of the Working Group was crucial. While the initial recruitment into the Working Group was more focussed on the health and ageing issues of trans women, the project team actively recruited a trans man into the Working Group which corrected the imbalance in the Working Group and ensured that the perspectives of trans men were included in the final resources available to employees. Having trans men and trans women perspectives was also confirmed in the literature reviewed.

The experiences of TGD older people have rarely been the focus of examination within aged care settings and in isolation from the broader LGBTI community. The findings highlighted that the needs of older trans men and trans women are quite distinct and may benefit from being considered separately. For example, specific issues relating to wound management post transitioning surgery emerged, indicating a need for wound care education.

Often trans people will not identify as trans, but rather the gender they align with i.e. a man or a woman [5]. This may make it challenging for aged care providers. The importance of acknowledging and understanding carer and non-traditional relationships in the lives of transgender clients/residents was also highlighted in the consultations.

A review of the National LGBTI strategy identified current attitudes and values of staff and management, a lack of resources and a need for training and networking as key challenges going forward [14]. In addition, significant barriers included a lack of management support, resistant staff and pre-existing prejudicial values. This project illustrated how these barriers and challenges can be addressed head on, utilising a co-design approach which focused on training and education of new employees. Furthermore, the resources developed are now available for use by all new and existing XXX employees. Due to the merger between XXX, the resources are available to a much larger population of employees across Australia, which has the potential to improve care received by many more TGD people.

Conclusion

A multi-method co-design process resulted in the development of an evidence-based Guideline for Working with Trans and Gender Diverse People and two Diversity Stories. Most importantly, using a co-design approach ensured that the resources were developed and informed by the experiences of TGD people themselves.

The evaluation indicated the usefulness of the resources and the resources address the identified lack of guidance to support aged care workers at XXX to understand and respond to the needs of TGD clients and residents.

The project highlighted that the needs of older trans men and trans women are quite distinct and need to be considered separately to be appropriately addressed. The project also confirmed the extensive barriers to health and aged care based on the multiple diversity characteristics experienced by people who are TGD.

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