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Patient-reported outcomes of sexual and gender minority cancer survivors in Australia

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Five key points:

- This is the first population-based survey of Australian cancer survivors to include LGBTI identity.
- Few respondents (1.6%) identified as LGBTI, less than half the reported prevalence in Australia.
- LGBTI respondents were more likely to be younger, employed and born in Australia.
- LGBTI people may experience more problems with anxiety/depression, body image and financial benefits, and greater needs for diet and lifestyle information.
- Commonly used patient-reported outcome measures may not be sensitive to LGBTI issues; areas for future enquiry are proposed.

Introduction

Minority stress theory proposes that social stressors, prejudice and stigma experienced by sexual and gender minority individuals contribute to poorer mental and physical health.[1] Lesbian, gay, bisexual, transgender or intersex (LGBTI) people with cancer may therefore be at risk of inferior outcomes. Recent studies from the United States and United Kingdom suggest that, compared with people who identify as cis-gender and heterosexual, sexually and gender diverse survivors experience more depression and social difficulties,[2] as well as inferior outcomes across care-related domains, including not feeling they were treated with respect and dignity by healthcare professionals.[3]

Evidence to inform care for LGBTI people with cancer in Australia is limited, and questions of sexual orientation and gender identity (SOGI) are not typically included in cancer registries or population-level surveys. We present secondary analysis of a registry-based Australian sample with the aim of describing patient-reported outcomes

(PROs) in people identifying as LGBTI with a prior diagnosis of breast, colorectal or prostate cancer, melanoma or non-Hodgkin lymphoma.

Methods

Full study methods have been described previously.[4] The Victorian Cancer Registry was used to identify eligible cancer survivors diagnosed from 2009-2013. By law, all cancer diagnoses must be reported to the registry. Data were collected from 2013-2014. The registry provided basic demographic (age, sex (recorded as male or female in the registry)) and disease data. Questionnaires were developed for each cancer type, and collected additional demographic data, quality of life (QoL), social difficulties and information needs using both validated and study-specific measures, replicating a study conducted in England.[3]. SOGI was determined by the question “Do you identify as being gay, lesbian, bisexual, transgender or intersex?”, with options of *Yes*, *No* or *Prefer not to answer*. Statistical tests were undertaken of the null hypothesis (no difference between groups) using the Wilson score interval with continuity correction in R. Ethics approval was granted by the Cancer Council Victoria Human Research Ethics Committee (Project No: HREC1307).

Results

Overall survey response rate was 45.3% (2115/4674)[4]; only 33 (1.6%) answered 'yes' to the LGBTI item and 89 (4.2%) declined to answer (Table 1). Some significant differences were observed between groups based on responses to the LGBTI item. Participants who answered 'yes' tended to be younger than those who answered 'no', and those who responded to the item (either yes or no) tended to be younger and employed, compared with those who declined to answer.

Quality of life: A higher proportion of LGBTI respondents reported problems with anxiety/depression (45%) compared with non-LGBTI respondents (35%), though this was non-significant (Table 2).

Social difficulties: LGBTI respondents vs non-LGBTI respondents reported fewer problems with financial services (8% vs 18%; $p \leq 0.5$), communicating with those closest (12% vs 22%; $p \leq 0.5$) and difficulty with where they live (2% vs 7%; $p \leq 0.5$), though reported more difficulties with financial benefits (36% vs 21%) and body image (42% vs 30%).

Information needs: LGBTI respondents vs non-LGBTI respondents reported greater diet and lifestyle information needs (42% vs 19%; $p \leq 0.5$) and fewer information needs about support groups (2% vs 10%; $p \leq 0.01$).

Discussion

Our study suggests differences across domains of QoL, social difficulty and information

needs between LGBTI and non-LGBTI cancer survivors in Australia, warranting further exploration.

Findings are limited by the low number of people identifying as LGBTI, which is not unique to this study. Recent Australian data indicate that between 3.2% of men and 3.8% of women identified as other than heterosexual [5], substantially greater than the 1.6% identifying as LGBTI here. Challenges in sampling LGBTI populations are well-documented, and can lead to overrepresentation of certain demographic groups.[6] Though our sample is registry-based, the relatively high non-response ('prefer not to answer') compared to positive response to the LGBTI item ('yes') suggests that our sample may not represent the broader LGBTI cancer survivor population. We present these results, however, due to the absence of population-based PRO data from LGBTI cancer survivors in Australia, and to raise important issues for consideration by clinical and research communities.

Low response to the LGBTI item may be due to perceived stigma, or feeling that SOGI is private or irrelevant to care.[7] This may be particularly pertinent for older people who may have accumulated more homophobic experiences. Indeed, fewer older adults identified as LGBTI in our and other surveys,[5] although it may be that LGBTI people are diagnosed at a younger age, which has been reported among gay men.[8] Lack of trust in data handling and use, and privacy issues in completing paper-based surveys may also contribute. Past experiences of adding SOGI items to longitudinal surveys has

shown increasing response rates over time;[9] consistent and widespread inclusion of SOGI items may normalise these questions and improve response in the future. We echo previous recommendations [3, 9] and strongly advocate for increased SOGI collection in research, cancer registries and clinical practice.

The younger age of LGBTI respondents may explain why fewer QoL issues (with the notable exception of anxiety/depression) were reported, and higher levels of employment in this group may influence financial issues. Furthermore, as 'outness' is associated with improved physical and psychological health and greater social support, being 'out' may also elevate outcomes for this group.[10]

It is possible that PRO measures used were not sensitive to LGBTI-specific issues. Differences between PROs of LGBTI and non-LGBTI cancer populations have been identified by research using study-specific measures [2, 3]; however, similar to our results, other studies have found few differences when using overall or generic QoL measures.[11] Research on LGBTI cancer survivorship that is both rigorous and poses the right questions is needed.

What are the right questions? Our findings suggest that mental and emotional wellbeing, body image and access to financial benefits should be investigated. A recent systematic review of qualitative data identified issues including preferences for SOGI disclosure, fear of discrimination, willingness of clinicians to discuss LGB sexuality,

inclusion of partners in care, and relevance of available information.[7]. Future studies investigating experiences of LGBTI people with cancer should explore these domains.

Even more fundamental is the SOGI disclosure question itself. Combining SO and GI into a single item may lead to ambiguous results. Furthermore, people identifying as gay or lesbian report different outcomes from those identifying as bisexual[3], therefore future studies should ask specific questions appropriately separating sexual and gender identity.

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Table 1. Selected characteristics of participants, by response to LGBTI item

Characteristic	Yes	No	Not stated	Difference between groups	
	n (%)	n (%)	n (%)	Yes vs No	Yes/No vs Not stated
Sex (registry data)					
Male	19 (57.6)	1065 (53.4)	39 (43.8)		
Female	14 (42.4)	928 (46.6)	50 (56.2)		
Age					
<60 years	22 (66.7)	721 (36.2)	20 (22.5)	***	**
60-69 years	9 (27.3)	686 (34.4)	28 (31.5)		
≥70 years	2 (6.1)	586 (29.4)	41 (46.1)	**	***
Employment					
Employed (full or part-time)	17 (51.5)	692 (34.7)	14 (15.7)		***
Unemployed / Other	16 (48.5)	1301 (65.3)	75 (84.3)		***
Country of birth					
Australia	28 (84.8)	1472 (73.9)	61 (68.5)		
Other / Not stated	5 (15.2)	521 (26.1)	28 (31.5)		
Total respondents	33	1993	89		

p≤0.01, *p≤0.001

Table 2. Weighted % of: 1) problems with QoL; (2) social difficulties; and (3) information needs, by response to LGBTI item

Item	Yes	No	Difference between groups Yes vs No
	n (%)	n (%)	
1. QoL (EQ-5D-5L)			
Mobility	6 (17.8)	406 (21.1)	
Personal care	1 (2.4)	129 (6.8)	
Usual activities	11 (29.9)	535 (27.5)	
Pain/discomfort	13 (35.8)	671 (33.7)	
Anxiety/depression	15 (45.4)	694 (35.1)	
2. Social Difficulties (SDI)			
Everyday living			
Maintaining independence	6 (16.6)	279 (14.6)	
Domestic chores	12 (31.1)	572 (29.3)	
Personal care	3 (8.9)	160 (8.5)	
Looking after dependents	9 (26.7)	480 (24.6)	
Getting around	7 (16.8)	305 (16.3)	
Recreational activities	10 (27.7)	503 (25.8)	
Money matters			
Benefits	11 (35.5)	422 (21.3)	
Financial difficulties	5 (14.1)	444 (22.1)	
Financial services	3 (7.7)	363 (18.3)	*
Work	10 (31.9)	753 (37.9)	

Planning for future	7 (21.8)	480 (24.4)	
Self and others			
Support for those closest	10 (28.4)	442 (22.3)	
Communicating with those closest	5 (11.6)	428 (21.9)	*
Communicating with others	5 (11.6)	337 (17.3)	
Body image	15 (42.3)	604 (30.4)	
Isolation	7 (21.9)	515 (26.2)	
Single items			
Sexual matters	18 (52.4)	1036 (51.6)	
Plans to have a family	18 (56.5)	1151 (57.9)	
Living location	1 (2.1)	146 (7.5)	*
Travel	11 (29.5)	605 (31.1)	
Other	9 (24)	476 (24.1)	
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3. Information needs			
Diet and lifestyle	14 (41.7)	375 (18.9)	*
Exercise	7 (19.9)	312 (15.9)	
Financial help	4 (13.9)	200 (10.4)	
Cost of prescriptions	4 (13.2)	152 (7.4)	
Returning/staying in work	3 (8.4)	102 (5.6)	
Information for family/friends/carers	5 (14.2)	176 (9.2)	
Support groups	1 (2.4)	197 (10.1)	**
Pain management	1 (4.5)	147 (7.5)	
Physical aspects of cancer	9 (23)	474 (24.2)	
Psychological/emotional aspects of cancer	10 (29)	423 (21.6)	

None	18 (56.7)	1022 (50.9)
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*p≤0.05, **p≤0.01