

Out With Cancer: Negotiating Cis-Heteronormative Constructions of Cancer And Cancer Care

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Background:

Lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) communities are increasingly recognised as a marginalised population in cancer care. They experience disproportionate cancer burden and unique psychosocial challenges.

Methods:

The Out with Cancer Study is a co-design mixed-methods project involving surveys, interviews, and photo-elicitation with 430 LGBTQI patients/survivors and 132 caregivers across a range of LGBTQI identities, ages and cancer types. 357 oncology health care professionals (HCPs) in nursing (40%), medical (24%), allied health (19%) and leadership (11%) took part in a survey; 48 HCPs were interviewed. An audit of LGBTQI cancer information in Australia was conducted.

Results:

Over 40% of LGBTQI patients/survivors and carers reported high distress, 3-6 times higher than non-LGBTQI patient/survivor studies. Significantly higher distress and lower quality of life (QOL) were identified in younger, transgender, intersex, and rural participants ($p < 0.01$). Distress and QOL were associated with minority stress (discrimination, discomfort in being LGBTQI, outness), impact on gender and LGBTQI identities, lack of social support, physical concerns and sexual concerns ($p < 0.01$). Qualitative data provided insights into participants' experiences of discrimination and cis-heteronormativity in healthcare, leading to anxiety about disclosure of sexuality and gender identity, and feelings of invisibility. Many patients/survivors navigated changes in sexual and reproductive embodiment through resistance to the pinkification of breast cancer and rejection of cis-heteronormative constructions of sexual embodiment. For trans participants, cancer treatment can reinforce or disrupt gender affirmation.

HCPs reported lack of knowledge and confidence in treating LGBTQI patients, associated with absence of LGBTQI cultural competence training and practice recommendations. Only 13% of Australian cancer websites mention LGBTQI people.

Conclusion:

LGBTQI inclusive and affirmative health care is needed to address serious health inequities. Our study findings have informed LGBTQI targeted patient information and HCP practice guidelines, addressing the unique needs of LGBTQI cancer patients, including sexual and reproductive health needs.