What makes it worth the investment to say it? – Care experiences of lesbian, gay, bisexual and/or trans* people facing life-limiting illness: A qualitative interview study

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Introduction People who identify as lesbian, gay, bisexual and/or trans* (LGBT) have increased risk of certain life-limiting illnesses. Evidence suggests they may not receive the care and support they need towards the end of life and into bereavement.1,2

Aim To inform training and resources to improve care experiences of LGBT people facing life-limiting illness, by eliciting experiences of: sharing identity (sexual identity/gender history) in healthcare settings; accessing services; discrimination/exclusion; and examples of good practice.

Methods In-depth qualitative interview study. Participants were recruited across the UK (England, Wales, Scotland) via clinical teams, social media and community networks. Interviews were transcribed verbatim and analysed using thematic analysis.

Results 40 LGBT people were interviewed: 20 patients, 6 informal carers, 14 bereaved informal carers; 21 described cancer experiences, 16 non-cancer, 3 co-morbid cancer/non-cancer; and mean age was 60 (range 27–94).

Five main themes emerged: 1) palliative care needs that may require additional or different consideration for LGBT people; 2) communicative or service level barriers and stressors, including heteronomative assumptions, and homophobic/transphobic behaviours; 3) internalised or invisible barriers and stressors, including fears, or experiences, of discrimination, 4) which shape individuals’ preferences for disclosure and exploration of identity; and 5) communicative or service level facilitators to accessing care and support.

Conclusions Despite recent legislative change for LGBT people, experiences of discrimination and exclusion in advanced disease and palliative care are still evident. A resource, co-designed with the LGBT community, is being piloted, and learning events being delivered nationally.
