

Report highlights experiences of lesbian, gay and bisexual people with cancer

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Credit: University of Leeds

Lesbian, gay and bisexual people tend to report having a poorer experience as a cancer patient than heterosexual people, according to a study.

Researchers, including Professor Richard Neal from the University of Leeds, conducted a secondary analysis of the 2013 UK National Cancer Patient Experience Survey to investigate the responses of lesbian, gay and bisexual (LGB) people in particular.

Compared with heterosexual survey respondents, significant differences

were found on survey questions which related to poorer patient-centred care, less involvement in treatment decision-making and the suitability of information resources.

Bisexual respondents particularly found it difficult to contact their dedicated nurse specialists and to get understandable answers from them.

They reported that they were dissatisfied with their interaction with nurses on hospital wards, and the care and help provided by both health and social care services after leaving hospital.

Despite wanting to be more involved in treatment decision-making, these respondents indicated that they were not given a choice of treatments.

Professor Neal, a Professor of Primary Care Oncology in the School of Medicine at the University of Leeds, said: "This is the first research highlighting the cancer care experiences of gay, lesbian and bisexual patients.

"It shows that whilst [health professionals](#) must try to provide a good experience as possible for all patients, particular attention should be paid to the specific needs of gay, lesbian and bisexual patients.

"The findings of this research also direct health professionals as to how they may best do this."

A worrying picture of social isolation was also painted through the findings, the researchers said.

A higher proportion of LGB respondents said that either no family or friends were involved, or that that they did not want their family or friends involved in their cancer care experience, compared with heterosexual respondents.

This could be a deliberate strategy to protect family and friends from negative consequences of continued homophobia and discrimination, the researchers said. It is possible that choosing to exclude their loved ones is regarded by the patient as a 'safer' option.

Professor Nick Hulbert Williams, Professor of Behavioural Medicine at the University of Chester, led the study, which is published in the European Journal of Cancer Care.

He said: "Across all aspects of cancer care, there is an important drive to explore the effects of population diversity so that we can ensure all patients receive the same standard of care.

"Research into the experiences of all groups of sexual orientation is essential to identify, understand and address cancer care inequality.

"This is important, not least, because the LGB group is at increased risk of some specific cancers. Health professionals rarely ask patients about their sexual orientation which may be adding to the perceived discrimination and negative cancer care experience.

"Many of the findings from this study relate to communication, in its various forms, between patients and healthcare teams.

"Previous research advocates a need for more training to support healthcare professionals in providing cancer care to sexual minority groups and our findings add further weight to this.

"Such training may be beneficial in creating an environment in which comfortable communication exists and where psychosocial support needs can be understood and met."

Martin Wells, a cancer survivor and co-founder of Out with Prostate

Cancer said: "I'm of the generation where being gay was illegal, a prisonable offence.

"Of the age where to disclose my sexuality in the early 1980s would mean no life insurance (because of HIV and AIDS, so no mortgage), of the age of "section 28" and where, up until recently, being gay was considered a mental disease. So when confronted with outing myself to help secure good health care with a health professional I have a lot of baggage to contend with."

The findings from this study suggest that these contextual factors may continue to have a pervasive effect.

This study is the first of its kind within the UK cancer context. Although other recent work has demonstrated inequalities in the patient-reported experience arising from variation in age, gender and ethnicity, far less was known about the impact of [sexual orientation](#) on cancer care experiences prior to this study being undertaken.

Given recent legislative changes in the landscape for sexual equality in the UK, it is both timely, and useful, to explore potential inequality in cancer experiences in a UK sample, the researchers said.

Distributed annually to all patients who receive cancer treatment in the UK, the results of the National Cancer Patient Experience Survey are intended to drive improvements in a patient's experience of cancer care, and to inform service providers. Almost 70,000 people responded in 2013, of whom 0.8% identified as lesbian, gay or bisexual.

Ben Heyworth, who chairs the LGBT Cancer Support Alliance, added: "On behalf of the LGBT Cancer Support Alliance, I welcome the publication of this research, a welcome addition to the continuing discourse around health inequalities that affect many LGBT people.

"Going forward, my hope is that healthcare professionals will begin to think more deeply about the specific needs of LGBT people affected by cancer."

The research team who led the work acknowledges that there are limitations to the study because they did not have control over which questions were asked in the original survey.

The findings are also based on a comparatively small sub-sample of those identifying as LGB but this may highlight ongoing issues with disclosure of sexuality within a healthcare setting.

Professor Hulbert-Williams says that this underlines the need for further research.

He added: "These findings have important clinical implications.

"Lesbian and gay respondents were more likely to indicate that they were not 'treated with dignity and respect' through their [cancer care](#), and bisexual respondents were more likely to indicate that they felt treated as 'a set of symptoms' rather than as a whole person. These are worrying findings that must be addressed as a priority."

Provided by University of Leeds

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