

Marie Curie Research Grants Scheme

Dr Richard Harding and Dr Katherine Bristowe, Kings College London

ACCESSCare II – Bereavement outcomes for lesbian, gay and bisexual (LGB) and heterosexual partners: a population-based, cross-sectional, mixed methods study

Duration of project: 27 months

Start date: 1st June 2017

Budget: £185,345

Abstract

Background

Bereavement impacts heavily on those closest to the deceased, with caregivers 20-50% more at risk of mental health problems than non-caregivers. Bereaved partners are: less likely to seek medical attention; and have increased odds of worsening/new illness and mortality.

Lesbian, gay, and bisexual (LGB) people constitute minority groups with specific healthcare needs, including: greater all-cause mortality; higher rates of mental illness; more risk behaviours linked to discrimination; increased risk of life-limiting illnesses; increased isolation; and potentially increased palliative care needs. Partners are therefore more likely to be bereaved, and, with higher rates of mental illness, may have worse bereavement outcomes.

Despite protection under the UK Equality Act (2010), experiences of discrimination for LGB people are common in healthcare, resulting in reluctance to access healthcare, and share sexual orientation with healthcare professionals. The need to end health disparities/discrimination for LGB people was highlighted in a recent Lancet Editorial.

Many LGB people also expect discrimination in end-of-life care and in bereavement. Our recent systematic review described additional barriers/stressors in bereavement, and an absence of quantitative studies of bereaved LGB partners since 1990s, and beyond the context of HIV/AIDS. With poorer mental health outcomes, increased isolation and experiences of discrimination, we hypothesise that LGB bereaved partners have worse bereavement outcomes than heterosexual partners.

Research Question 1

Is there a difference in bereavement outcomes between LGB and heterosexual bereaved partners?

Research Question 2

How do needs, experiences, and access to bereavement services differ?

Methods

Population-based cross-sectional mixed-methods (retrospective post-bereavement survey; in-depth qualitative interviews) study of bereavement outcomes for LGB compared to heterosexual bereaved partners.

Objectives

- Test the hypothesis that among bereaved partners, levels of grief are significantly higher in LGB than heterosexual people;
- Test the hypothesis that among bereaved partners, prevalence of complicated grief is higher among LGB than heterosexual people;
- Examine whether factors (i.e. isolation, discrimination, caregiver burden) explain any differences in outcomes between LGB and heterosexual people;
- Compare access to/experiences of bereavement support in LGB and heterosexual people;
- Compare patterns of health/social service utilisation and informal care provision of LGB and heterosexual bereaved people;
- Compare health/social service utilisation, bereavement outcomes and needs of LGB and heterosexual people whose partner has died a sudden death compared to death from life-limiting illness.

Survey

Potential participants will be identified by the Office for National Statistics (ONS) via death registration data (method successfully used previously at KCL), and invited to participate in the survey 6-10 months post-bereavement (first year of bereavement, but avoiding immediate post-bereavement period/anniversary of death). Supplementary recruitment through community/media routes will be undertaken if necessary to meet sample size.

The survey will include validated measures of: grief (Texas Revised Inventory of Grief (TRIG), primary outcome); caregiver burden; psychological morbidity; discrimination; social disconnectedness/isolation; and health/social care utilisation. It will also examine: preferences for bereavement support and offer opportunities to provide free-text to explain responses.

In-depth qualitative interviews

A purposive sample of survey participants (sampled by sexual orientation, age, ethnicity, grief score, care experiences, cause of death, relationship duration/living situation), will be invited to participate in an in-depth interview, to explore needs/experiences and access to bereavement support. Interviews will also explore significant/unexplained survey findings.

A distress protocol will be utilised to protect participants, including provision of bereavement support literature and a helpline. Translation will be sought to enable participation for non-English speakers.

Analysis

Quantitative

Data will be described for LGB and heterosexual respondents, including prevalence of complicated grief, before multivariable linear regression to investigate an effect of sexual orientation on TRIG score, adjusting for gender, age, cause of death, and living situation as possible confounders (using STATA).

Qualitative

Thematic analysis of free-text survey/interview data to explore and compare experiences of bereavement for LGB and heterosexual people, understand common experiences, and examine differing needs/experiences (using NVIVO).

Data Integration

Interviews will follow preliminary survey analysis to allow directed exploration of areas of interest (divergent/unexpected survey findings). Full analysis of the survey/interviews will occur concurrently to interrogate data around common themes, and explore unexpected/contradictory findings.

Proposed findings

Findings will inform national bereavement support provision, by improving understanding of factors associated with poorer grief outcomes. We will develop healthcare professional guidance, policy documents and targeted supportive materials for LGB and heterosexual communities.