

Supporting people bereaved during COVID-19: a mixed methods study of bereaved people's experiences and the bereavement services supporting them

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Summary:

People bereaved during the Covid-19 crisis face significant challenges that shape their experiences of grief. The sudden nature of many Covid-19 deaths and infection control measures that limit family contact with patients adds to the distress of the bereaved. Whether the cause of death is Covid-19 or another illness/event, social distancing measures mean that family members grieve alone and mourning practices are disrupted. People from Black and minority ethnic groups (BAME) are particularly affected by Covid-19 and also experience barriers to accessing bereavement services. Covid-19 has also brought significant challenges for bereavement services. Social distancing requirements make usual in-person individual and group bereavement support impossible, whilst responding to abnormal bereavement requires additional competencies among staff.

This study aims to investigate the grief experiences, support needs and use of bereavement support by people bereaved during the pandemic, and the adaptations, challenges and innovation involved in delivering equitable bereavement support.

We will use qualitative and quantitative methods in three work packages:

Work Package One involves A UK wide survey administered at three time points: baseline, 7 and 13 months post-death. Recruitment will be via social media, organisations representing BAME groups, and bereavement organisations. Questions will investigate the impact of end-of-life and post-death experiences during Covid-19 and subsequent access to, needs for and experiences of bereavement support. Validated measures will assess grief and coping response, social support, prolonged grief disorder (PGD) and quality of life (QoL).

Work Package Two involves semi-structured telephone interviews with a selection of survey respondents after each survey round. The interviews will explore experiences of grief and bereavement during Covid-19, including bereavement support use and unmet needs for support. When selecting interview participants, priority will be given to people from BAME backgrounds and those whose survey responses indicate unmet needs, greater vulnerability and poorer outcomes, to enable exploration of specific challenges during the pandemic.

Work Package Three will include an online survey of bereavement service providers. The survey will identify service adaptations, key challenges and approaches to delivering accessible bereavement care during the pandemic. Survey findings will inform targeted case studies, developed via telephone interviews, to describe innovative practice.

This study will identify 'real-time' implications for the delivery of end-of-life care and bereavement support during and beyond the pandemic. It will enable us to recommend how to achieve equitable and effective bereavement support, pandemic-specific competencies needed by bereavement support workers and specific types of support that should be prioritised at regional and national levels, whilst working throughout to ensure prompt translation into practice.

Status: The first round of the online survey is now live and recruiting participants.

This is the link to the survey for people bereaved during the Covid-19 Pandemic:

<https://cardiff.onlinesurveys.ac.uk/the-grief-experiences-and-support-needs-of-people-bereaved-2>

The survey can also be made available in hard copy, Welsh and some other community languages upon request. Please contact Email: harrope@cardiff.ac.uk, Tel: 02920687184

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Research Networks: Dissemination via bereavement networks and organisations including project partners: the National Bereavement Alliance, Marie Curie, CRUSE Bereavement Care, The Good Grief Trust.