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Those bereaved during pandemic inform national end of life care survey

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The first national UK study focused on those bereaved during the COVID-19 pandemic has found individualised, compassionate palliative care is challenging, but not impossible.

Bereaved relatives said being unable to visit dying loved ones compounded their distress—especially in a hospital or care home setting. However, most believe health and social care teams were doing an exemplary job in the face of huge difficulties.

The survey focused on those bereaved during the COVID-19 pandemic, has highlighted the importance of individualised and compassionate end-of-life care.

Researchers at the Universities of Liverpool, Oxford and Sheffield, surveyed those who lost loved ones during the global pandemic to understand their experiences of care and support provided to them and their relatives who were in the last days of life.

In the study, published in the journal Palliative Medicine, bereaved relatives said that being unable to visit their loved ones compounded their distress, especially in the hospital and care home setting.

Not being able to visit also impacted on perceptions about how well prepared and supported individuals felt. However, most thought that health and social care teams were doing an exemplary job in the face of huge difficulties.

Dr. Stephen Mason, study co-principal investigator and Research and Development Lead for the Palliative Care Unit at the University of Liverpool, said: "As with the analysis from our interview studies, the report data here highlights areas for improvement that are achievable, but require considered development and structural support to enable health and social care professionals to meet the needs of those in the last days of life, and their family and friends."

Lead author, Dr. Catriona Mayland from the Department of Oncology and Metabolism at the University of Sheffield, said: "We need to be able to listen and learn from bereaved people about the key practices which need to be prioritised and adopted during a pandemic. It is by doing so, that we can help enable meaningful, personalised care even in times where this is extremely challenging. Lessons must be learned to ensure that practice attenuates to the challenges of the current, and future, pandemics."

The study makes important recommendations for health and social care professionals to protect and prioritise time to regularly inform family members and friends about their loved one's condition and to be able to recognise when a person is approaching the end of their life, to help prepare relatives and enable visits to be facilitated.

Study author, Dr. Jeff Hanna, Department of Psychiatry at the University of Oxford, said: "Our national survey reports important recommendations for healthcare staff as they provide end-of-life care during the pandemic.

"They have a pivotal role in facilitating vital interactions between relatives and their loved ones. The vast number of deaths in the UK means this work provides salient lessons for supporting families in their grief."

More information: Catriona R Mayland et al, Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic, *Palliative Medicine* (2021). DOI: 10.1177/02692163211019885

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