

Bereavement during COVID-9 Study - Summary

We are pleased to submit this report on an MRFF funded study through the University of Technology, Sydney which assessed the mental outcomes and support needs of people bereaved during the COVID-19 pandemic from January 2020 to February 2022. The study was undertaken by Nationally and Internationally respected researchers including, psychologists, clinicians, social workers, bereavement counsellors as well as consumers.

The study has made over 100 recommendations which were co-designed at National workshops with stakeholders. We have been working on preparing reports and publications related to this project.



To cite this publication: Bereavement outcomes in Australia during the COVID-19 pandemic: Final report & recommendations. Lobb, EA., Maccallum, F., Ivynian, S. Sydney 2023.

Funded by the Medical Research Future Fund
- Coronavirus Research Response - 2020 COVID-19 Mental
Health Research Grant Opportunity - MRF2005576







We thank the bereaved participants who gave so generously of their time in completing our surveys and participating in interviews. We thank the multicultural health workers who gave of their time in interviews, Aboriginal and Torres Strait Islander investigators and the members of the reference group and the Community Elders who were willing to be involved in Study 4.



Context

The COVID-19 pandemic changed how we live, die and grieve. During the first two years of the pandemic 334,700 Australians died in these circumstances, including 2,251 from COVID-19.^[1]

Australians faced some of the strictest COVID-19 public health measures globally. End-of-life care and bereavement practices were significantly disrupted due to community fears of contracting the virus, public health measures introduced to reduce infection rates and protect healthcare workers, and the re-deployment of frontline workers to other roles. The burden of such strict public health orders was experienced differently by States, regions and cultural groups.

Many families and friends were left to grieve alone and in isolation, unable to visit their dying person, and unable to either receive or give physical support to each other. Many face-to-face support services closed or switched to online delivery, and mental health support services were overwhelmed by general demand within the community. The cumulative impacts of these circumstances on end-of-life care and bereavement responses raise the potential of significant negative mental health costs for the person themselves, the health care systems, and society.

The Bereavement during COVID-19 Study documented the experiences of Australians bereaved, from any cause, during the first two years of the COVID-19 pandemic. The aim was to hear their stories, establish their mental health and support needs, and inform policy planning for future pandemics. In doing so the study also identified a range of pre-existing cracks within the system.

Interviews were also held with multicultural health care workers. Recommendations based on the findings were developed in collaboration with consumers, key stakeholders and community organisations.

Over 2000 people responded to an online survey and 100 of these participated in additional interviews

Multicultural health workers were interviewed about the experience of their communities

Recommendations were developed in collaboration with consumers, key stakeholders and community organisations.



Conclusions

The COVID-19 pandemic introduced extraordinary challenges for individuals, society and for end-of-life and bereavement care, and simultaneously exposed significant pre-existing gaps within healthcare, administrative and support systems.

The lessons learned from this pandemic can help us better prepare and coordinate our approach to death and dying to minimise negative consequences of public health measures and fragmented systems.

Specific patterns of intense and chronic grief reactions are associated with negative long-term health outcomes that can be reduced through specialist interventions.



Bereavement care must be elevated within pandemic planning and health care processes to address the gaps



Basic bereavement outreach should be implemented to prepare families for the death of their loved ones and supporting them afterwards is essential

To achieve this, a National Pandemic Bereavement Preparedness Plan, created in collaboration with relevant stakeholders (i.e., consumers, grief and loss professionals, health, funeral, coronial services, government and support services) is required.

This is essential to mitigate poor bereavement outcomes and better support people who are dying and the grief of their families.

Bereavement During COVID-19

Key findings



Many bereaved people experienced high levels of grief, depression and anxiety, indicating the pandemic and related restrictions were associated with adverse impacts on bereavement.



Disruptions to the ability to care for the dying person and the experience of social isolation and loneliness were linked with worse mental health outcomes



Inconsistent and changing rules across States, Territories and health settings were a source of confusion, fear, frustration, anger, guilt, stigma, and despair for the bereaved



Services and supports were often not available, not offered, or varied in their quality. This was a source of distress



Although high quality resources have been developed, there was a **lack of provision of information** about grief and support services



Many reported unmet needs for social, community and professional supports



There were long waitlists for accessing support from mental health professionals and mixed experiences with the consultations. Experiences with telehealth, support lines, and self-help resources were also mixed



Interactions with many government services and administrative processes were experienced as lacking in compassion or an understanding of grief and bereavement