Bereavement During COVID-19

Final Report and Recommendations

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The Bereavement during COVID-19 Study

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This report contains quotes which may be confronting. Their inclusion is balanced against the need for the voices of the bereaved to be heard.

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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 system, 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.

Bereavement During COVID-19

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 exposed by this study.

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**

Executive summary

The Bereavement during COVID-19 Study

In March 2020 the World Health Organisation declared COVID-19 a global pandemic. Australia, like many countries, introduced a range of national and jurisdictional (State/Territory) "COVID-safe" measures, to slow the spread of the virus ("flatten the curve"), reduce deaths, and protect frontline workers, vulnerable members of the community, and essential industries. Measures varied across jurisdictions as circumstances changed and knowledge of the virus increased, but included social distancing and general mask wearing mandates, stay at home orders, limits to gathering in public, mandated industry shutdowns, quarantine requirements, curfews, and State and international border closures. Across health settings and aged care facilities there were also requirements for personal protective wear, visiting restrictions and periodic lockdowns, and frontline staff were relocated to other roles including contact tracing, vaccination and testing centres. Together with the widespread community fear of contracting COVID-19, there was significant disruption to culturally expected end-of-life-care and bereavement practices.

During the first two years of the pandemic 334,700 Australians died [1], with many families and friends left to grieve alone and in isolation, not able to visit the dying person and unable to either give or receive support. Coming only weeks after the Black Summer east coast bushfires and on the back of a prolonged droughts and flooding, many Australians were facing multiple and ongoing challenges at a time when community and professional support services were closed or moved to online formats.

The Bereavement during COVID-19 Study was established to document their experiences.

Aims

- To provide an evidence-base to inform bereavement planning and policy development in future pandemics; and
- To identify ongoing supports needs for those bereaved during the COVID-19 pandemic of 2020-2022.

Methods

The project employed a mixed-methods approach comprising four studies. Initially, over 2000 Australians, bereaved between 2020-2022, volunteered to complete an online survey about their bereavement experiences and mental health functioning; Of these, 100 volunteers were purposefully selected for an in-depth interview, and over 340 volunteered to completed up to three further surveys across the first 15 months of their bereavement. Additional interviews were conducted with multicultural health workers to document the experiences of under-represented populations. The study protocols were approved by the University of Technology Sydney Human Research & Ethics Committee (HREC) Ref ETH20-5447 and ETH21-5923.

Findings

Mental health

We observed high rates of grief-related distress. While grief is a normal human response to loss and is not of itself indicative of a mental health concern, specific patterns of intense and chronic grief reactions are associated with negative long-term health outcomes that can be reduced through specialist interventions. This makes identifying people experiencing intense chronic grief or those with Prolonged Grief Disorder (PGD) increasingly important [2, 3]. Over one third (39%) of our participants who were bereaved for more than 12 months had levels of grief in the range suggestive of a prolonged grief reaction. Pre-pandemic population estimates sit at 7-10%. While caution is required before generalising from our study to the Australian population, our figures are consistent with international data showing elevated levels of grief distress during the pandemic.[4, 5]

Participants also reported high rates of depression and anxiety. Almost half (45%) reported depressive symptoms within the suggested clinical range, and a third (32%) reported clinical levels of general anxiety. For comparison, this is 10-20% above rates reported in surveys of the general Australian population during the first year of the COVID-19 pandemic (excepting from Victoria, where rates were equivalent).[6, 7, 8]

Almost 20% of participants reported concurrently high levels of grief, depression, and anxiety. Difficulties providing care and social isolation and loneliness were associated with greater bereavement distress. People bereaved from deaths due to COVID-19 did not have worse mental health outcomes in this study.

Multicultural health workers described additional stressors impacting the mental health of their clients, including an inability to travel to relatives and friends, stigma and blame associated with media coverage, and challenges accessing accurate information in language.

End-of-life care
Two thirds (65%) of the participants reported the decedent as dying in hospital (e.g., specialist palliative care unit, intensive care unit (ICU), emergency departments (ED), acute hospital wards) or at home with or without community palliative care support.

Just over a third (37%) of participants receiving palliative care services (PC) indicated that the public health measures had driven their decision for a home death. They also perceived a health care system under strain, with a lack of practical home care support and information provided about the dying process.

Regardless of whether a death with PC occurred at home or in hospital, however, more than 80% of responsible person participants felt the patient had been well cared for at the time of the death. Significantly fewer participants were asked by health professionals about their stressors prior to the death (29.3%). This was significantly greater for hospital deaths (25.2% vs 38.2%). However, the rate in home PC deaths remains concerning as compared to hospital PC deaths, these participants reported greater grief-related impairment, and comparable rates of possible prolonged grief (41.5 %) as the hospital death group (38.6%) 12 months after the bereavement. Those who experienced a home death had a greater likelihood of being offered information about grief support and literature before the death.

Of the third (33%) of participants who reported a **death in a hospital without PC**, almost half reported reduced contact with their close person at end-of-life, were unable to say good-bye, unable to spend time as a family, and unable to provide care as they would have liked due to the COVID-19 public health measures. This was a source of distress.

Participants who were the patients' nominated visitors as part of the COVID restrictions, felt the additional burden of being the conduit of information and bearing witness between the patient/health system and the rest of the family/community. While some participants were granted exemptions around visiting hospitals in the last days of life, not everyone was afforded this opportunity, raising issues of equity and causing confusion.

Those who experienced sudden or unexpected deaths in hospital described a lack of follow-up care or information.

Residential aged care
During COVID-19, many residential aged care facilities (RACF) went into complete lockdown, closing their doors to all visitors. Almost one in five (19%) of participants reported a death in RACF. More than 60% reported that the public health measures impacted their ability to provide care, spend time together as a family, and have contact with their close person in the last days of life. Participants were concerned that residents were not getting the care and socialisation they needed. Their inability to enter to provide care was a main worry and related to poorer outcomes.

Deaths outside of health services or RACF
Participants who experienced a **death outside of a health facility**, which was often traumatic, reported having limited or no health care support, lack of follow-up by police and the coronial system, and in some cases inability to move from the place of death due to the lockdowns.

Participants unable to leave their State or the country to visit dying family and friends described their sense of hopelessness, anger, and confusion around navigating border rules.

Many participants also reported difficulties completing practical, financial and legal requirements, which compounded distress.

Information and Support

Participants reported unmet needs for information about the dying process, grief, managing practical matters such as bank accounts and Centrelink, and support options. Over 70% of participants whose family/friend died in a RACF received no information on grief, bereavement, or support services, despite this information being readily available through existing centralised hubs such as palliative care (CareSearch) and aged care (palliAGED and ELDAC).

Most participants' main source of support was family and friends, virtually and in-person when allowed. Many of these said this was the most helpful support (63%), but others found family and friends to be unhelpful (21%). General practitioners and psychologists were accessed by about 20% of participants, respectively. Over 50% reported unmet need for social, community and/or professional support.

> For those who pursued it, accessing professional (mental) health supports was often difficult as available appointments were limited or delayed and associated with out-of-pocket expenses.

Participants' perceptions of professional supports and telehealth varied; for some it was too impersonal and of little help, while for others it was a lifeline and highly valued. The majority expressed a preference for face-to-face appointments.

> "I hope that we didn't go through all of this without learning and leaving some learnings for the next generation. Because it would be very sad to see that."
> – 5

Discussion

This Project identified multiple impacts on end-of-life and bereavement care experiences related to the COVID-19 pandemic and also revealed multiple pre-existing gaps in related health, government and support systems.

> Health professionals were working extraordinarily long hours in difficult conditions, with reduced staffing, and balancing multiple needs involving protection of patients, families and staff.

Given this reality, the bereavement needs of patients' families were not a key priority for Services. Yet, responding to anticipatory grief and preparing families/friends for the persons' death can do much to alleviate longer-term bereavement distress.

Recognising that future health crises may be associated with a range of challenges, there needs to be national agreement on processes to facilitate safe and compassionate visiting for people at the end-of-life, inclusive of:

- redesigned spaces to enable visiting while maintaining the safety of the patient, visitors and staff (see also [9])
- telehealth initiatives to enable real and virtual visiting
- strategies to limit burdens placed on individual family members and individual health professionals implementing the public health measures
- consideration of individual grief risk factors for adverse outcomes
- Residential Aged Care Facilities need to devise strategies to enable family members and friends to continue providing practical care and support for residents. If visiting is restricted, family/friends virtual communication link(s) need to be established and readily available (e.g. phone chargers, internet (wi-fi and data), mobile devices (e.g., tablets) lent out to patient/resident and family/friends

While bereavement care needs are multifaceted, National Palliative Care Standards require palliative care services to provide, at a minimum, information on grief and bereavement and information about available support services and pandemic responses.[19]

> Health services must be supported with clear direction and staffing capacity to ensure sustainable implementation of standards

Grief and bereavement information should be stored in a central repository and be made available beyond specialist palliative care services so that organisations interacting with bereaved people can disseminate and tailor the material according to the bereaved person's support needs. Operationalising this will require investing in workforce training initiatives to increase health professionals' understanding of the potential impacts of bereavement and increase their confidence to facilitate grief and bereavement conversations. Staff in institutions that regularly interact with the bereaved also need greater grief literacy training.

Our study reinforces the need for bereavement care to span community and mental health services. Both avenues of support are vital. Despite the small proportion of bereaved individuals requiring specialist mental health care, this need appeared to increase during the pandemic. Bereaved people with prolonged grief need primary care referral and care pathways to trained mental health professionals. There is currently a lack of awareness and training for professionals across such interventions. Operationalising this will require that loss, grief, and bereavement content is embedded into all medical, nursing and allied health curricula.

The strengths of community-based services, groups and activities are of relevance during pandemics and should be fostered outside of these circumstances. Community leaders, particularly in culturally and linguistically diverse and LGBTQIA+ communities could ensure appropriate messaging and act as conduits for information and support. Drawing on public health and Compassionate Community initiatives, neighbourhood centres, Men's Sheds, cultural and community centres, faith organisations or even sporting clubs could assist, acting as avenues to increase death literacy and grief literacy[10], provide information on grief and bereavement and link bereaved people to social support to mitigate high levels of social isolation and loneliness reported in this study. This may require additional financial or technical support to "go virtual" if restrictions are required. Feedback from co-design workshops identified a need for cemetery and funeral workers to be familiar with pandemic infection control measures.

Strengths and limitations

This Project represents one of Australia's largest and most comprehensive bereavement studies which has documented decedents' families and friends and experience of bereavement during the COVID-19 pandemic, capturing a significant moment in time. However, participants were predominantly female, English-speaking, tertiary educated adult volunteers, so may not reflect the experiences of other genders, cultural groups or younger Australians. Further, the study was widely advertised via community organisations, partners, and newsletters, however, most recruitment occurred online, primarily through Facebook; as such, people with limited digital literacy and limited access to the internet or Facebook may also be under-represented in the data.. Thus while our study has provided evidence across cities and rural areas and included deaths within Australia and overseas, further research is required to understand the experiences of these under-represented populations.

We also note that convenience samples may be subject to a volunteer effect[11] which might have resulted in over-representation of people with negative experiences. Nevertheless, in open-ended questions people reported a range of experiences, including positive experiences.

It is regrettable that the Aboriginal and Torres Strait Islander component of the study could not proceed. Timelines and budgets did not allow for National consultation and whilst the Protocol for a smaller local study was approved by the University of Technology HREC, after consultation, the Aboriginal Health & Medical Research Council Ethics Committee did not consider it representative of the views and experiences of Aboriginal and Torres Strait Islander peoples throughout Australia. We are pleased to report that the Aboriginal and Torres Strait Islander investigators took ownership of this sub-study and appointed a project officer to complete the study as a quality improvement project in South Eastern Sydney Local Health District.

Conclusions

It is critical that governments take heed of the lessons learned here, and respond to the gaps identified by this Project when planning for responses for future pandemics. During pandemics, health systems need to include in their focus the implementation of basic bereavement outreach to prepare families for the death of their loved ones and support them afterwards.

Bereavement care must be elevated within the national pandemic planning processes to reduced long-term dysfunction. This will require initiation of a National Pandemic Bereavement Preparedness Plan developed in collaboration with relevant stakeholders (consumers, grief and loss professionals, health, funeral, government, and support services). This is needed to better support people who are dying, and their families, to minimise unmet needs and mitigate poorer bereavement outcomes associated with required public health measures and community responses to health pandemics.

> “I was so angry and felt incredibly let down by the government, my only need was to be allowed to travel. I'm certain that my grief would have been manageable then. ... Just 24 hours away. I am desperately sad and have lost the will to participate in life. I don't think that anyone could help with that. It happened; I cannot change that. I have to somehow manage to live with the anger and guilt.
>
> – 3757 ”

Recommendations emerging from our report

Recommendations in relation to public health measures, health care and bereavement

The COVID-19 pandemic resulted in widespread impacts to the delivery of end-of life care, funerals, and bereavement care and support. To facilitate future pandemic preparedness, organisations need to be supported to develop systems that:

- formally recognise the central role families play in providing end-of-life care in their pandemic planning
- recognise the potential for enduring negative impacts that can result from restrictions to visiting during end-of life-care and at the time of the death and seek to ameliorate these impacts
- enable caring at end-of-life to be shared amongst family members to reduce carer burden
- adjudicate visiting exceptions in a transparent and equitable manner to avoid discrimination in family access and additional strain on the clinical team relating to decision-making/policing of policies
- when visiting must be restricted,
    - ensure there are communication link(s) to family/friends
    - ensure virtual communication equipment is available and accessible e.g. phone chargers, internet (wi-fi and data), tablets to patient/ resident and family/friends
    - include systems to provide support for isolated family/friends involved in care provision
- consider facility re-design to allow for safe visiting during periods of restriction e.g. single entry and exit visiting, entry/exit away from public areas
- adjust PPE requirements and pandemic restrictions in line with evidence
- allow for PPE adjustments for people who have hearing or cognitive impairment
- revise definitions of essential workers to include in-patient bereavement support workers in acute settings and community settings (e.g. social workers)

The Clinical Communities of Practice (COPs) which were established and continue to meet across key clinical specialities in NSW and other States to support the response to COVID-19 provide a useful model to address many of these recommendations. The purpose of a COP was to: support clinicians to network and share strategies, identify local solutions and issues with respect to pandemic preparedness; prioritise and escalate issues and solutions related to COVID-19. It is recommended these COPs be expanded to include grief and bereavement experts who can identify and disseminate evidence-based supportive and end-of-life care resources to health workers for their patients and clients.

- hospital and aged care facilities could utilise trained volunteers to undertake a “check-in and chat” follow up for isolated grieving families. Volunteers could work from home but the volunteer co-ordinator at the facility can provide training and supervision/de-briefing
- when face-to-face services are reduced (e.g., outpatient clinics), clinical staff could be re-allocated to provide clinical updates for families on patients; provide psycho-social support and information
- include training in loss, grief and bereavement as an essential component in medical, nursing and allied health curricula, and for residentail aged care facility staff to facilitate understanding and compassionate responses to implementation of any necessary restrictions
- include a clear and compassionate process with access to high level decision makers to facilitate people to leave the country where friends and family are dying. Individuals should be permitted to make informed decisions to leave the country and accept any requirements for re-entry
- funeral company services review costs for “hybrid” or virtual funerals as bereaved participants commented on the extra costs involved

Recommendations on communication of public health measures and bereavement

Confusion around communication of public health measure restrictions was identified as a significant stressor. To facilitate future pandemic preparedness it is recommended that organisations be supported to develop systems that:

- facilitate communication across local health districts (or equivalent) of locally relevant and consistent communications regarding implementation of public health restrictions. This could be achieved through a Communities of Practice model
- provide clearer definitions around "compassionate visits" that are widely distributed to bereaved family/friends and easily accessible
- utilise Community leaders in culturally and linguistically diverse and LGBTQIA+ communities to be conduits for information and social support
- provide assistance for navigating travel and quarantine restrictions to visit dying family/ friends and family/ attend funerals

Recommendations for multicultural communities

We recognise that data saturation was not reached in our interviews with multicultural health workers so firm recommendations cannot be made. However, this quote from a participant suggests a way forward, particularly, the importance of community networks and connection. We recommend:

- Providing support to CALD community leaders, faith leaders, and multicultural health workers as they are the link between Government, health services, and CALD communities. Supporting these key stakeholders will help ameliorate confusion around government messaging and facilitate equitable access to culturally appropriate bereavement supports.
- Involving CALD community representatives in decision-making and governance structures to respond to the needs of CALD communities and reduce stigmatisation.

> "But I think that the message is – have we learnt anything to be better prepared for disasters... that we don't allow the system to break down so badly. And we might have to have a stocktake of what happened and what should have been done differently or better. And I think that we have learnt how important networks are. How important to be connected as a health service with communities, and NGOs, and community." – 5

Recommendations in relation to provision of information about grief and bereavement support at end-of-life

- Establish a virtual information and support hub for family and friends to access existing evidence-based bereavement resources in multiple formats and languages for easier access for a wide range of audiences
- Location of this information should be documented for relevant agencies to access
- Existing mechanisms and systems should be leveraged to disseminate end-of-life and grief information e.g. Services NSW; Services Australia; My Gov website
- Health care professions be trained to provide evidence-based information on grief and support services that can be built on/tailored to individual needs and accessed from multiple access points (e.g. QR Codes)
- Information on the police and coronial process needs to be centralised and made available to family and friends immediately a sudden death is reported

Recommendations on provision of bereavement support

Project findings identified multiple organisations and agencies as being relevant to bereavement support and highlighted the significant challenges to bereaved families and individuals that arise when systems are shut down. To facilitate future pandemic preparedness, governments and organisations need to be supported to develop systems that:

- allow for multiple points of provision of information to increase the likelihood of family/ friends receiving the information and support they require including:
  - health services and aged care facilities consider a concierge model to help families navigate different health, support and government services when face to face contact in not available during pandemics
  - funeral industry services provide information on supports and the coronial process and timelines (for where health services had no or minimal involvement in the death)
  - consider establishment of community link worker roles to link bereaved people to community services e.g. neighbourhood centres, Men's Sheds, cultural centres as places of information and support

- incorporate a public health approach to providing bereavement support which include a role for informal, community (e.g., Compassionate Communities, "Death Cafes"), and specialist care services in pandemic preparedness plans and for usual bereavement care
- increase support services provided by the coronial process to keep families informed and ensure follow-up is provided in pandemic preparedness plans, and for usual bereavement care
- that staff in government services such as Centrelink and banks receive training to increase grief literacy and awareness about the emotional, legal and financial support needs of bereaved people; such modules are available through CareSearch, palliAGED or Grief Australia

Further recommendations to improve bereavement supports

- greater bereavement leave (i.e., more than 2 days) and for bereavement leave to be granted for the death of family members as well as friends
- provide an opportunity to acknowledge the deaths that have occurred during the pandemic with a recognised National Day of Mourning

Recommendations on professional health support use

COVID-19 resulted in elevated rates of mental health distress, including suicidal ideation, and many respondents reported difficulties accessing the care they were seeking. This is significant as specific patterns of intense and chronic grief reactions are associated with negative long-term health outcomes that can be reduced through specialist interventions.

To facilitate future pandemic preparedness, governments and organisations need to be supported to develop systems that:

- identify pathways of bereavement care through primary health care systems
- include documented systems to identify people who are at risk of, or experiencing a complex response to bereavement to avoid people getting lost between services when services may be closed during pandemics; GPs were the most used health service and as such could play an important role in primary care and triage to appropriate grief supports
- train the workforce to facilitate referrals to services and organisations that can meet identified needs and are matched with the required levels of expertisemaintain flexible delivery options, including face-to-face grief counselling where possible
- address the lack of training for psychologists and mental health professionals in delivering interventions for prolonged grief disorder

This will require:

- broader recognition and understanding among health professions of the links between bereavement and mental health outcomes, including Prolonged Grief Disorder
- training in loss, grief and bereavement to be an essential component in medical, nursing and allied health curricula
- pandemic preparedness bereavement education to be an essential component of the medical, nursing and allied health curricula.

The Report

Context

The COVID-19 pandemic disrupted many aspects of life, including how we die and how we grieve. Early in the pandemic, bereavement researchers called on governments and policy makers to prepare for the "silent epidemic" of grief they expected to follow this global crisis.[12] Lacking evidence at the time, however, it was difficult to evaluate the veracity of these claims and determine what, if any, action should be taken. Subsequent international studies have appeared suggesting that bereavement, due to any cause, may be linked with increased risk for poorer mental and social health outcomes.[5, 13-15]

Bereavement during the COVID-19 pandemic, whether attributable to the virus or not, introduced a range of additional risk factors for poor mental health. In addition to community-wide fears of contracting and dying from the illness, the Australian government, like many around the world, introduced a range of "COVID-safe" measures to slow the spread of the virus ("flatten the curve"), reduce deaths, and protect workers in frontline and essential industries. These included but were not limited to stay at home orders, indoor and outdoor social distancing restrictions, industry closures, curfews, border closures and quarantine requirements. Health and residential aged care facilities were often the first to "lockdown" during an outbreak, excluding all non-essential staff, and also had strict limits on visiting and mandatory wearing of personal protection equipment for staff and visitors. Face-to-face services were moved online where possible and frontline staff were reassigned other roles, including contact tracing, testing and vaccination hubs. Together, these factors significantly disrupted end-of-line care, culturally accepted grief rituals, and accessibility of support services.

While pre-pandemic data indicated that most bereaved people find ways of coping with their loss and do not experience chronic distress, 7-10% will experience a chronic and disabling form of distress which was recently termed Prolonged Grief Disorder. This equates to approximately 44 000 Australians annually each developing chronic and debilitating mental health impairments following the death of a family member or close friend ('close person').[16] Coming only weeks after the Black Summer east coast bushfires and on the back of a prolonged droughts and flooding, COVID-19 came at a time many Australians were already facing multiple challenges to their mental health. The Bereavement during COVID-19 Study was established to index the mental health and support needs of Australians who were bereaved during the COVID-19 (2020-2022).

The overarching objective of the Project was to document the experience of those bereaved during this time, to establish an evidence base to inform pandemic policy makers to ensure that Australia's agencies and services were prepared for future global crises. This report outlines our research questions, major findings, and recommendations.

Research questions

1. How did pandemic-specific challenges and public health measures impact end-of-life and bereavement experiences across different health services and death settings?
2. What helped or hindered people's ability to grieve, during the pandemic, including use of community and professional supports?
3. How were experiences for people from culturally and linguistically diverse backgrounds similar or different?
4. What action is needed to prepare Australian health and bereavement sectors for future pandemics or global crises?

The project was funded by the Medical Research Future Fund (MRFF) – Coronavirus Research Response – 2020 COVID-19 Mental Health Research Grant Opportunity- MRF2005576.

The study protocols were approved by the University of Technology Sydney Human Research & Ethics Committee (HREC) Ref ETH20-5447 and ETH21-5923

Approach and methodology

The study adopted a mixed-methods approach, combining quantitative and qualitative methods across four discrete yet linked studies (see below). Studies 1-3 were nested within a sample of bereaved Australian participants. Study 4 focussed on the experiences of multicultural health workers.

Study 1: Cross-sectional survey
Study time: T1

Outcome measures

Current mental health and functioning
- PG-13-R
- PHQ-9
- GAD-7
- EQ-5D
- WSAS

Mental health support usage and needs
Predictors and risk factors

Study 2: Longitudinal Survey
Study time: T2, T3, T4

Outcome measures

Current mental health and functioning
- PG-13-R
- PHQ-9
- GAD-7
- EQ-5D
- WSAS

Mental health support usage and needs
Predictors and risk factors

Study 3: Semi-structure interviews
Purposive sampling

Individuals whose deceased family member or friend:
- Received palliative in a private home (n=20)
- Received palliative care in a hospital setting (n=20)
- Died in aged care facility (n=20)
- Died in an acute hospital setting (n=20)
- Traumatic or sudden death (n=20)

Study 4: Semi-structured interviews
Purposive sampling

Interviews or focus groups with multicultural health workers and aboriginal health workers

Investigate perception of the experience of their respective bereaved communities through the COVID-19 pandemic (minimum n=20)

Date integration and meta-inference
Generation of recommendation for policy, education, practice and research

Participant recruitment

Recruitment commenced in April 2021. It was initially planned to recruit through the Australian Funeral Directors Association. A recruitment strategy was developed in consultation with the Director. A letter of invitation was sent to 600 members of the Association and an article about the study was featured in the Association's newsletter. A per operator payment was offered. By September, 2021 of the 150 people who had completed the survey, 13 were recruited through funeral directors. A new recruitment strategy was developed, and a social media campaign ran through Facebook and Instagram from September to December 2021. 1,500 survey responses were received. Further campaigns ran for 2 weeks in December 2021 and 4-week campaign from 14 February to 14th March 2022. Recruitment closed in April 2022. A total of 2,224 completed surveys were received. Two thirds of surveys were completed in 2021 and one third were completed in 2022.

Study 1
A cross-sectional community cohort study of mental health and supports needs following bereavement during COVID-19 aimed to recruit at least 2000 bereaved Australians to complete a 20-minute online survey indexing end-of-life caring experiences and use of different support services during the COVID-19 pandemic. Questions were informed by the study aims and international research investigating bereavement during the global pandemic. This survey also included widely used standardised self-report measures of mental health distress and functioning, including measures of prolonged grief symptoms, grief-related functional impairment, major depression, general anxiety, and quality of life (See Appendix B: Description of measures).

Eligibility: Australian adults, aged 18+ years who experienced a death (from any cause) of a family member or friend from January 2020- February 2022; were at least 2 months post-bereavement and had an adequate level of English language comprehension to complete the survey. People who did not have English as their first language could nominate an interpreter to assist them.

Recruitment: for Study 1 was via social media (Facebook and Instagram), relevant national community organisations, consumer organisations and bereavement support services. Organisations distributed the survey information through their own social media networks; Twitter; newsletters, websites; or online forums. No incentives were offered. Most participants were recruited through Facebook (86%). Potential participants for Study 1 were directed to the study information webpage, which outlined the study purpose, its voluntary and anonymous nature, length, data use, participation risks, and relevant supports. (See Figure 2: Recruitment diagram Flow Chart) for response rates and completion.

Participants who completed Study 1 were eligible to participate in Studies 2 and 3. They were given the opportunity to do so by providing an email address (or other contact details) at the conclusion of Study 1.

Study 2
A longitudinal cohort study of mental-health outcomes aimed to map support use and mental health outcomes of 350 Australians at four time points across the first 15 months of their bereavement. Surveys contained questions assessing support use since the previous survey and standardised measures of mental health distress and functional impairment (~10 minutes).

Surveys for Studies 1 and 2 were administered online via REDCap, hosted by the University of Technology, Sydney. For Study 2, participants were sent an email by the research team with a direct link to the participant information page.

Study 3
A qualitative study of mental health and support outcomes following bereavement during COVID. Semi-structured phone or video interviews were undertaken with a subgroup of 100 Study 1 participants, about their experiences with death, funeral, social supports and mental health support to identify gaps, strengths and supports. Participants were selected via purposive sampling based on place of death (reported in Study 1). This included deaths that occurred within an acute hospital, palliative care service, community setting, a residential aged care facility, or elsewhere (including sudden deaths) (n~20 in each group).

Eligible participants were sent up to 2 invitations to participate in Study 3. Verbal consent was obtained prior to the commencement of the interview, which lasted 45-60 minutes. Recruitment continued until no new data were collected and no new codes integrated into the coding framework.

Study 4
The bereavement experiences of under-represented populations during COVID-19. Interviews with Multicultural Health Workers from local health districts (n=11) were held to explore their experiences as a member of their own cultural and linguistically diverse background community, and as conduits for their clients who were accessing the health system or whose relatives died overseas. This proxy approach was taken as the immediacy of

the pandemic and funding timeline of study was not sufficient to ensure the cultural/language compatibility of Study 1-3 measures for under-represented individuals from Culturally and Linguistically Diverse communities or Aboriginal and Torres Strait Islander communities.

Recruitment: Participants were recruited through our partner (Multicultural Health Service NSW) in the first instance and via snowballing techniques. A letter of invitation was circulated through the Multicultural Health Service NSW and to Diversity Coordinators in local health districts. Information on the study was also included in a newsletter sent to multicultural support workers.

Consultations were held with Aboriginal and Torres Strait Islander community and academic leaders – (see Appendix C). A meeting was held with the Agency for Clinical Innovation's Ministry of Health Aboriginal Workforce Unit in May 2021 who advised that given the timeline and budget it would not be possible to involve communities nationally. Additionally, at that time, isolated and remote communities were in lockdown. It was recommended we approach one Local Health District where we could work closely and develop a snapshot of the impact of the pandemic on this community. A protocol was developed in consultation. Invitations for participation, information and consent forms were developed in consultation. Community Elders were approached to be members of a Reference Group. An ethics application was submitted to the Aboriginal Health & Medical Research Council Ethics Committee in August 2021. An application was submitted to UTS and approved in May 2022 (ETH22-7037) and re-submitted to AH&MRC in May 2022. The AH&MRC Committee met in June 2022, and recommended in August 2022 that the project not proceed due to lack of National representation.

Project development and consultations

Key organisations identified as partners at the commencement of the project were regularly consulted. They attended quarterly meetings, received project newsletters reporting on the progress of the study, and at the completion of data collection they were invited to a Co-design workshop to contribute to the development of the recommendations (Appendix C)

Survey and interview development: Surveys and interview schedules were developed and pilot tested by the project investigators who are clinicians, academics, and consumers with expertise in palliative care, psychology, behavioural science, public health and bereavement. A separate interview schedule was developed in consultation with the Multicultural Health Service staff for Study 4. Interviewers were trained, supervised and debriefed by the Project Manager Dr. Serra Ivynian and CIA Professor Elizabeth Lobb.

Ethical considerations: Given the sensitive content of the study attention was given to identifying grief support services. The contact details for these services were included in the approved Participant Information and Consent Forms and provided to interviewees at the end of the interview. Distress protocols for participants and researchers were developed and approved by the HREC. Participants were encouraged to contact the study Project Manager Dr. Serra Ivynian or CI Professor Elizabeth Lobb (a trained grief counsellor), if they experienced distress. Two people made contact for that reason and were referred to appropriate counselling services.

Interpretation and recommendations: A full day face-to-face workshop with key stakeholders (n=50) was held in Sydney in August 2022, and a virtual workshop for interstate participants (n=31) was held in September 2022. The aims were to present the data and generate recommendations.

Data analysis

Study 1 and 2

Quantitative survey data from Study 1 and 2 were analysed using parametric and nonparametric analytic procedures as appropriate to the data type. Analyses were overseen by Dr Fiona Maccallum and Dr Sungwon Chang and undertaken using IBM SPSS Statistics for Windows, Version 27.0 and Mplus Version 8[17] to determine levels of psychological distress (e.g., prolonged grief, depression, anxiety), sociodemographic and pandemic related correlates of distress, support use, support preferences and unmet needs.

Study 3 and 4

Qualitative data from Study 3 and 4 were analysed according to Braun and Clarke's Thematic Analysis, using an inductive approach.[18] Four researchers contributed to the development of the coding framework. Where Study 1 and 2 included qualitative data in the form of open-ended free text responses the same qualitative methods were applied to this data. Qualitative analyses were undertaken in NVivo version and were overseen by Dr Serra Ivynian and A/Professor Michelle DiGiacomo. For this report findings from the quantitative and qualitative components are presented together.

Findings and recommendations

A snapshot of our participants

Participants were on average aged 55 years (range 19-90 years), women (95%), born in Australia (79%), partnered (59%), living in a major city (67%), employed at the time of completing the survey (61%), and educated above year 12 (56%) (see Table 1). The majority were living in New South Wales (41%), Victoria (30%) or Queensland (10%). Twenty six percent were living in single person households; a variable we indexed as it represented an additional risk factor in the context of COVID-19 home lockdowns. Five percent spoke a language other than English at home, and 2% endorsed having Aboriginal and Torres Strait Islander backgrounds. In describing these characteristics, we note that women were over-represented, people from culturally and linguistically diverse backgrounds were under-represented, and levels of education were higher in our participants than in the general Australian population.

Close to half of participants (45%) completed the survey about the death of a parent; approximately, 20% the death of a partner, and 9% the death of a child. Nearly 10% reported multiple deaths during the study window. Most deaths were health-related (either cancer, chronic health conditions, or sudden illness), however, accidents, injuries and suicide accounted for around 12% of deaths. "Suspected or confirmed COVID-19" was selected by only 3% of participants. This is consistent with the low rate of COVID-19 deaths in Australia during the study window (January 2020-February 2022). Almost half of the deaths occurred in a hospital setting (49%), which included specialist palliative care, emergency departments, intensive care units, other specialist wards and general wards; 25% occurred at home, 19% in an aged care facility, and 5% occurred in different location (e.g., car). For comparison, we note that in 2019, half (51%) of deaths in Australia occurred in a hospital/medical service area and 30% occurred in a residential aged care facility. "Other" specified locations were the least common place of death (1.4%).[1] The average time since death in our study was 10 months [range 2 - 22 months].

The experience of pandemic-specific challenges and public health measures (n = 2,224)

The COVID-19 pandemic introduced a range of challenges for those caring for someone nearing end-of-life or who were bereaved unexpectedly. In response to the threats to life posed by the COVID-19 virus, State and Federal Governments implemented a range of measures to reduce potential exposure to the virus and protect health workers. These included social distance rules, restrictions on leaving the home, restrictions of gathering size, industry shutdowns, and State and International border closures. There were also restrictions on visiting health and aged care facilities, requirements for Personal Protective Equipment (PPE), and isolation and quarantine requirements. These measures varied across jurisdictions and were both tightened and loosened across time in response to changes in pandemic circumstances, and mental health concerns (for example, the introduction of singles bubbles in August 2021).

When combined with widespread community fear of contracting the virus, the ability of health services and other organisations to meet the core elements of a "good death," was significantly tested. The core elements of a "good death" include the ability of family members to receive information about what is happening to their close person, to say good-bye, and to be present at the death4[19]. They are considered "core" in that they are thought to facilitate the process of coming to terms with the death, and so prevent adverse effects associated with ambiguous loss and lack of preparedness. In addition, funerals and culturally accepted death rituals, social support, community supports, and formal bereavement supports services were impacted by these circumstances.

To explore the relationships between pandemic-related challenges and end-of-life and bereavement experiences, we asked participants to indicate whether they had experienced a range of COVID-19 related impacts before, during and after the death, for example visiting restrictions, border closures and limits on funeral attendence (as outlined in Figure 2).

> "Ridiculous adherence to lockdown rules. We had to fight tooth and nail to get them to let us visit her. She couldn't feed, toilet or move herself, and whilst they did have people coming around every 2 hours to give her attention, it wasn't enough. She needed one of us with her at all times as she was distressed and we weren't allowed in. It was only when it was too late and she had hours to live that they relented. If we'd been able to visit more often, I feel we all would have coped better with the whole bereavement process. We know they are busy and under pressure, but the only contact I had from them was a day after … they emailed to ask when I could clear out … room as they had an urgent admission. …They also moved … stuff into the carpark on the day …Their thinking was that this was helping, as movers couldn't enter the facility, but it felt like she had been evicted. Just thoughtlessness wrapped in good intentions."
>
> – 1212

Table 2 presents frequency data outlining the experience of pandemic challenges according to where the person died (e.g. home palliative care, Intensive Care Unit (ICU) aged care facility), including statistically significant differences. In terms of pandemic impacts prior to the death, people who reported a home death with palliative care were the most informed about what was happening with their close person, and with or without palliative care, participants who reported a home death were less frequently impacted in their ability to care for the close person as they would have liked. The ability to care for the close person was most impacted in cases where the person died in an aged care facility (endorsed by 60%). This group also had the highest frequency of participants who said they had reduced contact in the last days of life (66%), were unable to spend time together with the close person as a whole family (65%) or be present at the death (46%). Deaths in ICU or Emergency Department (ED) had the highest frequency of people who said they were unable to say goodbye as they would have liked (56%).

In terms of challenges faced after the death, the settings did not differ in likelihood of having limited contact with family and friends, with approximately 50% of people endorsing this experience. They also did not differ in likelihood of funeral restrictions (average of 69% across settings). The groups did differ in terms of experiencing social isolation and loneliness. Surprisingly, the group RACF with the lowest frequency on this variable was aged care facility deaths (37%). The reason for this is not immediately apparent. It may reflect that the person who died had been living separately from the participant at the time of their death and that the participant's home support systems were still in place. We do note, however, that this experience of social isolation and loneliness was still endorsed by almost 40% of those who reported aged care deaths (compared to an average of 49% across the other settings).

In describing their experiences of the restrictions, interview participants reported concerns about the care of their close person in their absence, and the deteriorating mental health of their close person due to lack of social interaction. Visiting restrictions were sometimes relaxed at the end-of-life as death approached, to enable in-person goodbyes. This was viewed as very important. The decline of the close person was described as shocking and rapid in the absence of being able to visit and participants found this distressing.

> "For his birthday we were able to see him through the window, but even that was very unsatisfactory; he was wearing a mask, we were all wearing masks. All we could do was wave. ...but that's really very unsatisfactory."
>
> – 748

> "Access issues over the last few months and no chance to say goodbye in person due to restrictions in place. Government does not fully understand mental and physical issues associated with not being able to visit aged care facilities."
>
> – 1019

Interestingly, the interviews also revealed an unforeseen consequence for those who were able to visit during end-of-life. Participants in this situation, who were the nominated visitor, described the increased burden they felt in keeping other family members informed, making decisions, and advocating for their relative/friend without support of others, all while managing their own emotional responses. Further, for some in this role, it was not one they would have chosen but was the result of other factors such as location, expectation from others, and lower perceived risk.

> "But the difficulty of being the only one that could go in and carry the responsibility then of keeping everybody else informed and trying to be as calm and relaxed with her as I could, but knowing there was a lot that had to be taken care of in those two hours."
>
> – 844

Interview participants also expressed frustration with the frequently changing and inconsistent rules across health settings. When restrictions in aged care facilities and hospitals were enforced, participants highlighted challenges communicating via technology and with hearing or cognitively impaired residents/ patients when PPE was required.

> He was very hard of hearing and, with everybody wearing masks, it was all terribly bewildering for him. We had to more or less shout to him sharing this very sensitive information and having to be so loud.
> – 977

> I mean, the carers, they were wonderful, but they were wearing gloves and they didn't have time to hug residents and give them the love that we would give them. That was really hard, seeing her devoid of all of that.
> – 432

Those who lived interstate/overseas from the close person often had to apply for travel exemptions and were required to quarantine. This was not always possible or practicable and had perceived impacts for mental health. The process of applying was an additional stress that some were not able to manage at the time.

> Border closures and quarantine regulations for interstate travel were too confronting to manage when I was so distressed ... death is not predictable the requirement to apply for border entry and quarantine beforehand was not practical.
> – 3973

> I was so angry and felt incredibly let down by the government. My only need was to be allowed to travel. I'm certain that my grief would have been manageable then. ...Just 24 hours away. I am desperately sad and have lost the will to participate in life. I don't think that anyone could help with that. It happened; I cannot change that. I have to somehow manage to live with the anger and guilt.
> – 3757

Interview participants also commented on ways in which the COVID-19 public health measures disrupted many of the administrative processes associated with death, including dealings with funeral directors, financial and legal institutions, and telecommunication companies. Participants described barriers to completing required procedures and very slow processing times.

> The legal stuff was a nightmare... ... they just didn't seem to have any capacity to get around the rules for the Estate, for the life insurance.
> – 13

> And I'd gone outside to have a smoke because I needed it ...there were two managers and one of the managers said to me – no sorry for your loss, condolences or empathy or anything. She just said to me, "So, because of COVID, She said "We'll pack it up." And I said, "No, ... I need to do it.
>
> So I'm picking up everything around her. Absolutely, absolutely everything. nobody could come and be with me
>
> – it made me feel like they just wanted to clear her out. Let's just wipe any evidence of existence. It was really, really traumatic and I wasn't able to grieve properly because I had to pack everything up.
> – 432

The inability to recruit any help to complete practical tasks such as clearing out the deceased's residence and sorting their belongings is disruptive to post death processes with emotional, financial and family impacts. This was perceived as having significant implications for their mental health.

> Cleared my parents whole estate/ house on my due to COVID social distancing rules and the fact services weren't collecting goods e.g., furniture/ Salvation Army. I had no one to turn to for assistance and it negatively affected my physical and mental health.
> – 1128

Both survey (see Table 9) and interview participants also expressed a need for timely and clear communication of changing restrictions; clear instructions on how to obtain travel exemptions. The confusion over public health restrictions resulted in worry and concern.

> "I had called the NSW health hotline for clarification of compassionate grounds at one point but found them useless. They could not give a straight answer and said it was up to me to decide if it's justified...it all felt too hard, so I just stayed by myself... – 1544"

> "I was very worried and concerned that the police would be called by neighbours about the people visiting me following the death ... and that I would have to explain to police the trauma/loss I had just experienced. It's an added worry on top of the grief.
>
> No flexibility around picking up the cremated ashes- only one person can attend which is wholly inappropriate- not something I could do alone- too traumatic. There needs to be better process
>
> Having some professionals advise me that I wasn't allowed to have family support due to covid 19 restrictions was really troublesome- I was in a very bad way and needed support. Fortunately, my GP had common sense.
>
> – 2727"

Public reactions to the lockdowns also were also identified as problematic.

> "Understanding and compassion from friends and the media and the community who spent all their time complaining about lockdown and public health measures when I had seen how important they were. I mean where is the memorial to Covid victims? Where is the public support? People are openly aggressive to me challenging how my family member died as they don't want to believe Covid is real and it could affect them. We are the hidden victims.
> – 549"

Health care perceptions and interactions with professionals at end-of-life

Clear communication from health and social care professionals about the close person's illness/declining health and involvement in decision-making and other core aspects of end-of-life-care may have been impacted during the COVID-19 pandemic.[20-22] We examined a number of aspects of end-of-life care, including communications with health care professionals (HCPs) and perceptions of care across different death settings for the subsample of participants who indicated they were the nominated responsible person (previously nominated next of kin) for their close person's health care (n = 920; 44%).

Encouragingly, regardless of death setting, most nominated responsible persons reported that they had been involved in healthcare decisions; that they knew contact details of the HCPs involved in the care; that their relative/friend was well-supported; and that they received information about the approaching death. In terms of their own needs, approximately three quarters of those whose close person was receiving palliative care felt they were well supported at this time (77%). This was lower in among responsible people for deaths in ED/ICU, general hospital wards and aged care facilities where health care was involved (~60%). Across all settings, fewer responsible persons reported that health care professionals had asked them if they had experienced significant stressors before the death (see Table 3).

Interview participants described observing the struggle of health services and providers to maintain high quality clinical care whilst maintaining public health and staff safety measures. Lack of information, and practical support and resources, was particularly noted in cases where home care support was required.

> "We talk about actively dying, but nobody goes into the details. I wanted somebody to tell me the details, this is what this is, this is what this smell is, this is what this noise is. This is what is going on. They all just talk about it's very peaceful and they're not in any pain, and da da da, which is fine, but it doesn't make you feel any better when you've got someone gurgling in front of you. It was just quite awful.
>
> – 1190"

> We used the [Name] community palliative care service when he left palliative care, but due to very limited staffing, they were not able to attend much until his last few days when there was a short visit once a day. What little time we saw them, they were beyond amazing. If they had been able to attend more, the following may have been avoided: - Not having a full understanding of medications I was supposed to prepare and administer. - Not knowing how to help him toilet, wash, avoid bedsores, back issues, etc when he was bedbound. - Feeling isolated and alone, worrying there was more I could have been doing, but having no idea what. - Not being able to ever take a break or have more than a couple of hrs sleep at a time as we did not have a back-up carer, or any access to respite care.
> – 644

Workshop attendees described how definitions of "essential workers" impacted bereavement care. For example, in the early stages of the pandemic chaplains were not considered "essential" workers in aged care facilities and so were not permitted to attend; this decision was later rescinded. Others commented that in many acute hospitals social workers were not deemed "essential" workers so were not permitted on the wards. Survey respondents commented on the lack of social work availability.

> The palliative care social worker was telephone only. Not very helpful.
> – 3225

> I was even in a hospital and got no support. No social worker NO ONE, and they couldn't even despite multiple requests organise a simple thing so I could watch it [the funeral]
> – 1439

> Felt caught in the hospital system. Hard to access a social worker. System stressed by demand
> – 1672

Preparedness for the death

Greater preparedness for a death is associated with long-term well-being. [23]. This can be facilitated through end-of-life discussions, encouragement of advanced care planning and support for family caregivers' distress before the death. [24, 25] During COVID-19 many of these factors were impeded. To understand how prepared our participants were we asked about any end-of-life plans that had been made such as funeral arrangements, advanced care plans, and Wills, and to rate how practically and emotionally prepared they felt for the death on a 7-point scale (1=not at all, 7=prepared; Table 4).

The mean scores show that, overall, participants felt slightly more practically prepared than emotionally prepared for the death. Participants who reported a home death (with community palliative care) or a death in an aged care facility felt the most practically prepared, whereas those who reported the death at home without palliative care support (e.g. if someone died at home suddenly) or in another place (e.g. died in a car in motor vehicle accident) were the least practically prepared. In terms of emotional preparedness, participants with deaths that occurred in aged care facilities or at home with palliative support were the most prepared, and again those who reported death at home without palliative care or other death settings or in the emergency department or ICU were the least emotionally prepared. Further analysis showed that preparedness was also related to mental health outcomes and is presented later in this report.

Overall, 84% of participants indicated some form of planning: 25% of people who died had made funeral arrangements; over 50% had a Will, 20% had an advance care plan; and 14% had an advance care directive (living will). Further, while not necessarily associated with end-of-life care but indicative of preparation for care, 42% has nominated a power of attorney and 20% had a guardianship in place (see Table 5).

In terms of how pandemic challenges impacted the ability to follow these plans, close to 45% of participants who reported plans reported that these wishes were fulfilled as planned; 13% said that wishes were fulfilled but delayed; and 13% they had not been fulfilled because of COVID-19 restrictions and 3% for other reasons.

Further analysis of palliative care services

For specialist palliative care services, care of the family during the illness and death of the patient, including the provision of bereavement support, are an integral part of their mission. Palliative care in Australia is provided in a range of health care settings including in-patient, outpatient, and community services and by specialist and non-specialist providers. In-patient provision may include in-patient care in specialist palliative care sub-acute hospitals or in dedicated palliative care beds in an acute care hospital. Alternatively, palliative care may be provided as a consultancy service in acute care hospitals for patients with various end-stage illnesses. 744 participants indicated palliative care had been involved in the death; of these, 514 deaths occurred in an in-patient setting and 230 occurred at home. The most common relationship for this group was of a partner followed by a parent. The most common cause of death was cancer (65%), followed by chronic health conditions (17%). The average age of these descendants was 70.7 years.

A key concern for provision of health care was the extent to which hospital restrictions stemming from public health measures had impacted the decision to die at home. One third of participants (37%) who received palliative care and reported a home death indicated these restrictions had influenced the decision to die at home. Deaths in this setting, however, were not without a range of challenges.

> “Palliative care team was great supplying equipment but not always available when needed as they were very short staffed e.g. had not completed the process for end-of-life pain medication therefore correct medication not available and he died in pain and no plan had been completed therefore we had to have the police here all night because he died at home without a plan. Someone I didn’t know came the next day as a representative from palliative care. Home care supplied by the palliative care package was inappropriate and way less hours than required. The staff themselves were fabulous but the system was ineffective.”
>
> – 4335

Participants who reported a home death (with support from community palliative care) were significantly more likely to have an advance care plan than those who had a hospital death had a significantly higher mean level of practical (not emotional) preparedness.

We undertook multivariate analysis to explore differences in demographics, death characteristics and communication and care appraisals across home and hospital palliative care deaths.

Results of these multi-variate analyses (Lobb et al 2023) were that, among those supported by specialist palliative care:

- Home death participants more likely to have had contact with the close person in the days before the death, be present at the time of death and have had funeral restrictions in place at time of death than hospital death participants
- Home death responsible persons were more likely to have had limited contact with family and friends and have been offered information about grief support services and literature
- Home death and hospital death participants did not differ on mean levels of grief distress, depression or anxiety. The home death group had higher grief-related functional impairment.
- Close persons who died at home were also more likely than hospital deaths to have died from cancer or chronic illness and to have had advance care plans in place suggesting that implications of their disease trajectory were addressed.

Funerals

Participants generally reported positive interactions with funeral directors but expressed frustration and fatigue in relation to orchestrating a COVID-safe event whilst in a state of emotional turmoil. Social distancing was often described as cruel, as attendees were not able to provide or receive physical comfort.

> “...not being able to hug people or sit close to people or put your arm around somebody other than the people in your immediate household; that felt quite upsetting really. That was the upsetting bit. It wasn’t the number of people there, it was more the fact that you couldn’t really do that normal interaction that you might have had.”
>
> – 17

In many cases, funeral proceedings were live streamed or recorded. This became a less cumbersome process as the pandemic continued. Participants had mixed responses, with some describing upsetting technological failures, and high cost and a feeling of "unreality" associated with online funerals, while others commended the opportunity for people to be involved at a distance.

> "I think I needed to attend the funeral(s) in person. It felt like the whole situation was not real. I never left my home but found out a friend had passed away from suicide. I sat through 2 online funerals and never left the house or saw friends and family in person. It was surreal."
>
> – 421

> "...my god, why did it take us, as a community, all this time to figure out we could use this technology for people to dial in to a funeral and feel part of it, you know what I mean? So I actually think that's a big positive."
>
> – 394

Overseas deaths

The inability to be with other family members for the death, attend funerals and perform cultural practices, was particularly distressing when the death occurred overseas or when overseas travel was restricted.

> "I lost half of my family ... I am still a wreck and sickened by the whole covid process. I have been told I need professional help...and meds to sleep."
>
> – 232

> "Practical support to enable us to travel at a time of intense need for my family. I am a dual national and Australia locked me up and refused to let me go ."
>
> – 669

> "My family could not come. ...she did not get the normal send-off she would have received had her family been able to come They had to watch via video link which was very sad. They sent over a pre-recorded video to show"
>
> – 367

Recommendations in relation to public health measures, health care and bereavement

The COVID-19 pandemic resulted in widespread impacts to the delivery of end-of life care, funerals, and bereavement care and support. To facilitate future pandemic preparedness, organisations need to be supported to develop systems that:

- formally recognise the central role families play in providing end-of-life care in their pandemic planning
- recognise the potential for enduring negative impacts that can result from restrictions to visiting during end-of life-care and at the time of the death and seek to ameliorate these impacts
- enable caring at end-of-life to be shared amongst family members to reduce carer burden
- adjudicate visiting exceptions in a transparent and equitable manner to avoid discrimination in family access and additional strain on the clinical team relating to decision-making/policing of policies
- when visiting must be restricted,
  - ensure there are communication link(s) to family/friends
  - ensure virtual communication equipment is available and accessible e.g. phone chargers, internet (wi-fi and data), tablets to patient/ resident and family/friends
  - include systems to provide support for isolated family/friends involved in care provision
- consider facility re-design to allow for safe visiting during periods of restriction e.g. single entry and exit visiting, entry/exit away from public areas
- adjust PPE requirements and pandemic restrictions in line with evidence

- allow for PPE adjustments for people who have hearing or cognitive impairment
- revise definitions of essential workers to include in-patient bereavement support workers in acute settings and community settings (e.g. social workers)

The Clinical Communities of Practice (COPs) which were established and continue to meet across key clinical specialities in NSW and other States to support the response to COVID-19 provide a useful model to address many of these recommendations. The purpose of a COP was to: support clinicians to network and share strategies, identify local solutions and issues with respect to pandemic preparedness; prioritise and escalate issues and solutions related to COVID-19. It is recommended these COPs be expanded to include grief and bereavement experts who can identify and disseminate evidence-based supportive and end-of-life care resources to health workers for their patients and client.

- hospital and aged care facilities could utilise trained volunteers to undertake a "check-in and chat" follow up for isolated grieving families. Volunteers could work from home but the volunteer co-ordinator at facility can provide training and supervision/de-briefing
- when face-to-face services are reduced (e.g., outpatient clinics), clinical staff could be re-allocated to provide clinical updates for families on patients; provide psycho-social support and information
- include training in loss, grief and bereavement as an essential component in medical, nursing and allied health curricula; and for residential aged care facility staff to facilitate understanding and compassionate responses to implementation of any necessary restrictions
- include a clear and compassionate process with access to high level decision makers to facilitate people to leave the country where friends and family are dying. Individuals should be permitted to make informed decisions to leave the country and accept any requirements for re-entry
- funeral company services review costs for "hybrid" or virtual funerals as bereaved participants commented on the extra costs involved

Recommendations on communication of public health measures and bereavement

Confusion around communication of public health measure restrictions was identified as a significant stressor. To facilitate future pandemic preparedness it is recommended that organisations be supported to develop systems that:

- Facilitate communication across local health districts (or equivalent) of locally relevant and consistent communications regarding implementation of public health restrictions. This could be achieved through a Communities of Practice model
- Provide clearer definitions around "compassionate visits" that are widely distributed to bereaved family/friends and easily accessible
- Utilise Community leaders in culturally and linguistically diverse and LGBTQIA+ communities to be conduits for information and social support
- Provide assistance for navigating travel and quarantine restrictions to visit dying friends and family/ attend funerals

The experience of culturally and linguistically diverse communities with public health restrictions

Australians faced some of the strictest COVID-19 public health measures globally. With international borders closed, the experience of culturally and linguistically diverse (CALD) people living in Australia bereaved during the COVID-19 pandemic may differ. To understand the experience of bereaved people from CALD communities living in Australia during the COVID-19 pandemic, we interviewed multicultural health workers in New South Wales who provided psychosocial support to bereaved people from CALD backgrounds during COVID-19. Multicultural health workers (n=11) gave accounts of their clients' experience of media bias, blame, stigma, hypervigilance, and fear, which was exacerbated by previous cultural histories and language barriers.

Stigma and blame

Select Local Government Areas (LGAs) in Sydney experienced higher COVID-19 cases than others during 2021 and subject to more severe public health measures. Interview participants felt that media coverage during this time blamed these LGAs for spreading COVID-19 and created a stigma against CALD communities.

> "I think they felt like they were being blamed that this COVID outbreak or everyone having to stay in self-isolation was because of them, that they're not doing the right thing. I think that was why they were so keen on following the rules and doing the right thing because there was this message that it's because of them that we're in this mess." – 1

Participants also described stigma and shame in relation to COVID-related deaths, seeking professional mental health supports, and substance use which was more difficult to conceal during lockdown.

> "They are ashamed of that. They feel something, like a stigma. So, yeah, so they don't want to go closer to counsellors, because some person or – would say to them that you are crazy, that's why you are going to a counsellor." – 2

Communication of restrictions

Participants described how language barriers compounded confusion about restrictions. Participants described it was common for people to watch the news from their home country rather than where they lived and that older members of their communities often relied on second hand information from younger generations and so risked not being fully informed.

> "Most of the people, let's say, the elderly, they don't understand English. Even they will hear that they – well, they will not understand, what they are getting second-hand information, which is maybe from the kids or grandkids." – 2

Hypervigilance and fear

Participants described growing police presence and helicopter surveillance in these LGAs which was triggering for CALD people who had immigrated from war-torn or controlling governments. CALD communities feared leaving their homes.

> "Her and her husband were like, "We don't want to get in trouble with the police." I think the messaging just scared everyone, and I think this community has come from regimes of governments where you're going to get thrown in jail and beaten up if you don't do the right thing. – 1

Another major unforeseen implication of border closures during COVID-19 was visa expiry. Participants described how community members were terrified of being discovered as 'illegal' in cases where visas expired during this time. As a result, participants described avoidance of seeking help from services where needed.

> "...they didn't want to disclose that they had overstayed their visa. Which is no fault of their own, they couldn't go anywhere, anyway. But once their Visa finished, they felt , "I'm illegal now". So people were carrying that load...nobody thinks about what happens when you shut down a country... I had communities and individuals that felt very scared and afraid and were feeling that they couldn't ask for help, saying they were not going to get any help because they were illegals and how they treat illegals in this country is not very good. So they know that they have to be careful because they will send you to a minimal detention centre or asylum." – 5

In some cases this also resulted in extended periods of mandatory isolation due to delays in receiving clearance letters from the government.

> At that time, they were sending the police to people's homes to make sure they were self-isolating. So, even though it was past the 14 days, because New South Wales Health was so overwhelmed, they didn't get letters to people within the 14 days, and there were people still self-isolating 21 days onwards. So every time I would call them, and because they spoke other languages, they would just say, "Please, please don't leave me, I need you to please, because every time the public health unit or a nurse calls me, they promise me they're going to give me this letter, then they don't and I'm going crazy at home.
> – 1

Health literacy and digital literacy

Participants described challenges with the switch from face-to-face to online funerals and support was difficult as some did not own or have access to computers or phones. Others did not have the digital literacy skills required to operate this technology without support (which was often provided by children). This was especially relevant for people from CALD communities who are more reliant on their children. This may impact availability of information dissemination in the future hence there is a need for brokering to people who do not use computers.

> We couldn't meet with people anymore, there was no community groups running, and we couldn't hold it online or on Zoom because a lot of people, either they don't have computers or they're not computer literate. Or even if they're a bit confused on the phone they couldn't open Zoom, it was very difficult to communicate with people.
> – 4

> With older people it was even worse because some, they may not speak English, and also because the knowledge of digital literacy, sometimes they might have a mobile phone sometimes but they – some of them of course, but they have limited knowledge of how to conduct, how to use telehealth here.
> – 3

Community advocacy and support

Participants also spoke about the importance of advocacy from local governments who defended CALD communities in the media and were described as hero's who stepped up and developed community initiatives to support their people during COVID-19.

> I think they felt well supported by the community, and I think it was just nice – who had been shamed in the media constantly about these people who don't want to get vaccinated or this and that, and felt like their council had their back. We're not going to abandon you, we're proud and we're going to do our best to support you through this. They all did so well at the end of that because they didn't feel like they were being abandoned.
> – 1

> What was really good was that they had culturally appropriate food, so they catered for different cultural dietary requirements. So I think it was really nice in that sense seeing that community come together and help out because they would set up community kitchens and just get these meals out to people.
> – 1

Recommendations for multicultural communities

We recognise that data saturation was not reached in our interviews with multicultural health workers due to their excessive workloads during the pandemic and so firm recommendations cannot be made. However, this quote from a participant suggests a way forward, particularly, the importance of community networks and connection.

> But I think that the message is – have we learnt anything to be better prepared for disasters… that we don't allow the system to break down so badly. You know? And we might have to have a stocktake of what happened and what should have been done in hindsight, what should have been done differently or better. I hope that we didn't go through all of this without learning and leaving some learnings for the next generation. Because it would be very sad to see that. And I think that we have learnt how important networks are. How important to be connected as a health service with communities, and NGOs, and community.
> – 5

Provision of information about grief and bereavement support

We asked participants if they were offered information about how and where to get bereavement support before and after the death (see Table 6). Across the sample, most participants reported that they were not offered any information about grief or support services at any time (61%, including almost 40% of participants who received PC). This compares to a pre-pandemic Australian study where 63% of people were offered information about grief and bereavement prior to the death[26] This suggests the pandemic influenced provision of information which is concerning as Palliative Care National standards cite that all families and carers should be provided with information about loss and grief and have access to bereavement support services. It is possible that some participants were provided with information but did not recall this in the context of general stressors surrounding the death. At a minimum, however, services need to recognise bereavement as fundamental to palliative and health care, provide pre- and post-death information on grief and bereavement.

> “Even if... someone had sent us information about the grief process. Like, I understand the grief process, so not so much for me, but someone to send me something to maybe look at things a little bit differently in the grief process - you'll be happy; you'll be sad; you'll be angry; you'll be annoyed; why this has happened; or whatever. Just some information - where to go to; what groups you could contact. More so for other people than for me because I was able to cope with it, but yeah, just the bereavement process I suppose, some sort of general information people can go to, or a guide that is sent out in the mail to them”
> – 816

Consistent with these figures, many participants described a lack of follow up from those who were involved in the care of the deceased and did not know where to turn for support as a result.

> “Information, like where are the bereavement services in my region? Do they exist? What are the pathways for people? What are some basic resources?... No one at the public hospital connected me at all.”
> – 557

> “Asked me how I felt but provided no support. Don't ask me how I feel if you can't support me”
> – 2210

> “I think a checklist, what needs to be done and even if they had people within organisations who were specialists, bereavement specialists or death specialists. Somebody who you could contact ... guide you through the process.”
> – 148

There is also the need to build a bridge to bereavement support as people transition out of the healthcare system. Participants described the need for health care professionals, particularly the ones involved in the care of their dying relative/friend to connect them with information and resources regarding appropriate bereavement support once their close person died. Workshop participants noted that high quality resources exist but are often only within individual settings or organisations.

Recommendations in relation to provision of information about grief and bereavement support at end-of-life

- establish a virtual information and support hub for family and friends to access to existing evidence-based bereavement resources in multiple formats and languages for easier access for a wide range of audiences
- location of this information should be documented for relevant agencies to access
- existing mechanisms and systems could be leveraged to disseminate end-of-life and grief information e.g. Services NSW; Services Australia; My Gov website
- health care professions be trained to provide evidence-based information on grief and support services that can be built on/tailored to individual needs and accessed from multiple access points (e.g. QR Codes)
- information on the police and coronial process needs to be centralised and made available to family and friends immediately a sudden death is reported

Bereavement support and coping

Pre-pandemic literature has shown that most people cope with their bereavement with help from friends and family or community organisations. Others may seek help from general practitioners and mental health professional.[27, 28] Concurrently, this same work has shown that many of those who may benefit from specialist grief interventions often do not receive them or are unaware they exist. [27, 29]. The COVID-19 pandemic presented a unique set of challenges for accessing support with face-to-face social and community gatherings limited or prohibited, and formal mental health supports being inundated. For example, in April 2020 Lifeline received 90,000 calls to their service, a 20% increase from usual call volumes; Beyond Blue saw a 40% increase in calls since before the pandemic [30]. A key aim of this national study was to understand the support use, both formal and informal, of bereaved Australians during COVID-19 as well as their unmet needs, in order to develop an action plan to meet these needs for future pandemics.

In this section we describe which bereavement supports people used, how helpful (and unhelpful) they found them, and what needs went unmet.

Participants first indicated which supports they had used from a list derived from previous studies[15, 27, 28] and investigator knowledge, including an option to name supports not on the list. They were then asked to identify which had been most helpful for them and provide a free text response as to why. This was followed by an opportunity to describe in free text any unhelpful supports they had accessed.

The most frequently used supports are presented in Table 7. The most helpful and unhelpful supports are presented in Table 8. Interestingly, many of the most helpful supports were also the most nominated unhelpful supports (e.g., friends and family, general practitioners, psychologists, online support groups).

The following sections present participants' responses as to why the found supports helpful or unhelpful.

Family and friends

Family and friends were the most used support. Participants considered them helpful as they represented pre-existing relationships with shared histories and a shared sense of grief. Friends and family also met needs for togetherness and physical comfort during their grief. Technology (text messages, phone and video calls) and social media (e.g., Facebook) facilitated desired social connection when physical connection was not possible.

The introduction of "compassionate visits" and "singles bubbles" was seen as valuable as it allowed participants to give and receive support during this time.

> "Family and friends had travelled the journey with me and knew me very well- When to step up and when to give me space. My family were all similarly affected by the passing so we all understood each other and respected each other's feelings"
> – 159

Others had nominated family and friends as most helpful because they saw it as the only available option at the time. Family and friends were also experienced as an unhelpful support. The most common reasons for this were lack of understanding and family conflict.

> "I was blown away by the huge number of people who could not bear to talk about my ...this was incredibly upsetting."
> – 645

> "Friends have no idea about listening. They prefer to tell you about their bereavement... they just made me frustrated, because they refused to listen to me when I tried to explain."
> – 3353

Self-help resources

Self-help resources (primarily online resources) were the second most used support. Reasons for finding these resources helpful included ease of access and ability to meet individual needs. For others they were perceived as the only available source of additional support given restrictions and lockdowns. Others found them unhelpful and felt the quality varied and content was not backed by evidence.

> "Reading about others' journeys created a sense of community and gave me ideas for coping and ways of looking at my grief."
> – 795

> Stuff seemed to be mostly opinion-based, and caused more stress than help! Every situation is different, and they weren't much help.
> – 539

> All have different perspectives, very confusing
> – 1565

Internet/online community support groups

Although access to face-to-face support groups was limited, some online support groups were available and were accessed by many of our participants. They were perceived as helpful as they were easily accessible and available during lockdown, and some liked their anonymity. Others found them unhelpful and described them as impersonal or distressing.

> Easy to access from home, especially with changing COVID restrictions
> – 1466

> Good to interact with people who have experienced the same
> – 1014

> The online sessions were during work times when I could not even try them. I felt very isolated and that. All the self-help I tried said "well normally we could help but we can't right now.
> – 1148

> Also watching other people grieve in a Facebook group has been hard, because they seem lost in that grief for many years, debilitated by it and that's horrifying to think that could be me, and difficult because I can't do anything to help them.
> – 588

General Practitioner (GP)

GPs were the most common point of healthcare access. As with the other forms of support, experiences were mixed. The following statements illustrate the range of views expressed.

> My GP knows me. I was struggling. She knew I needed immediate support and gave that to me.
> – 1063

> It hasn't been overly helpful. I feel very helpless in this situation and don't feel anyone or anything can help me
> – 212

> My GP was able to refer me to grief counselling, provide medication and organise Centrelink medical certificates.
> – 1721

> The doctor was able to reassure me that we did everything we could medically
> – 2017

Psychologists

Psychologists were also a frequently accessed form of formal support. Participants perceived psychologists as helpful because they were skilled professionals, independent, and provided coping strategies. However, many participants also experienced their psychologist as unhelpful. The following illustrate the range of views expressed regarding psychologists.

> Someone who was not in my daily life so I could say whatever I felt & cry without feeling the person didn't quite know how to deal with my emotions
> – 63

> I've been receiving ongoing support prior to and after and feel I possibly would have ended my own life if I hadn't received this kind of support.
> – 3582

> Psychologist. I thought it was a waste of time and don't see the point of one-sided conversations, i.e. me talking; her listening and nodding a lot.
> – 966

> They understood childhood trauma that was triggered by death.
> – 3379

In response to the pandemic, Medicare rebates for private psychological services were extended to telehealth, and rebated sessions were increased from 10-20. Nonetheless, a main challenge reported by participants was difficulty accessing professional (mental) health supports due to limited availability of appointments/long waiting lists, and out of pocket expenses. This suggests that while the Medicare extension was helpful for some people seeking assistance, it was not seen as an available support service for others in need: that is, psychologists were able to extend the sessions for their current clients but were not available to take on new clients.

> “A GP visit a few months later made it clear I was still finding the situation tough to deal with, counselling was suggested but the wait at the time was many months so I did not arrange it.
> – 339”

> “Just that if I wanted to see a psychologist the waits are insane. Over six months here. And that’s sort of not helpful when you need it within a short space of time. COVID has really impacted seeking mental health services I would say. Hugely.
>
> – 440”

Perceptions of telehealth varied; for some people telehealth was not helpful and perceived to be too impersonal for others it was a lifeline. Overall, however, the most expressed a strong preference for face-to-face appointments for both themselves and/or family members.

Grief counselling

Grief counsellors were accessed by 10% of participants. Grief counselling was listed as a separate support to “psychologist” as the care pathways for psychological services can differ to that of a grief counsellor. Also, where grief counsellors are typically focussed on grief and bereavement issues, psychologists cover a broad range of mental health conditions. Training pathways and minimum qualifications also differ between the two professions. However, it is the case that a psychologist may work in the role of a grief counsellor. It may also be the case that clients are not specifically aware of qualifications and training held by a counsellor holds. Thus, some of the views expressed about grief counselling may be relevant to understanding psychological services and vis-a-versa.

As with the forms of support already discussed, grief counsellors were seen as both helpful and unhelpful and experiences with telehealth were mixed.

> “Counselling helped when my grief was at its most raw. It was initially via telehealth and, while it was not ideal, it provided me a reasonable avenue for communication. I feel that, if restrictions were not in place, family and friends would have been most helpful but during lock down I was not wanting to speak to friends over the phone.
> – 137”

> “Grief counselling from the Palliative care team when I really hit rock bottom they weren’t available and hard to reach then when they did make contact I wanted face to face but the only offer was over the phone or Telehealth, this was not helpful at all in time of need.
> – 3361”

> “I was alone, … Being able to access telephone counselling at a time convenient to me allowed me to pour my sadness and distress out to someone who really listened, and was able to provide validation and perspective.
>
> – 789”

> “They had no idea about grief. I would suggest they not include it as a skill set if they had not experienced it.
>
> – 4160”

> “I had contact with 2 psychologists/ counsellors. The EAP provider was not helpful in that, despite repeated explanations of my circumstances, over 3 separate sessions, they did not remember .Having to repeat the story to the same person every time we had an appointment was soul destroying
> – 3598”

Other mental health supports

Relatively few of the participants accessed advice and support lines such as Lifeline and Beyond Blue. Those that did reported a mix of experiences. Access was greater among those with higher levels of distress.

> "I was feeling very depressed and anxious mainly at night time or hours where my GP was not available, calling the helplines and knowing I can count on any time was very important. – 2565"

> "I called Lifeline but was on hold for over an hour and a half so I hung up. I needed help so I ended up googling information – 1588"

> "I think because they only have about 15 mins to offer you because I'm assuming they are very busy. It felt rushed and I hung up a bit lost, like I'd not really achieved anything. – 1697"

Similarly, few participants saw a psychiatrist for bereavement support but rates were higher among those with higher distress.

> "Having specific mental health to support me through my grief by a DR who knew me was invaluable – 210"

Multicultural health workers also became advocates for their clients seeking support, enabling access to culturally appropriate support.

> "Yeah, I felt a really key thing that was missing, and I felt really horrible dealing with the bereavement cases because these people needed counsellors or psychologists that could speak their language. It's just going to add another barrier if you have to use an interpreter on top of that, and it was really difficult – 1"

> "Sometimes I'll call their GP and just be like, "Can you do a mental health care plan and then refer them to an ... speaking psychologist or counsellor." And go that extra mile because generic bereavement services weren't going to cut it for our client group. – 1"

Unmet Support Needs

> "Support was virtually unavailable – 112"

A series of questions asked participants about their unmet bereavement support needs. Half of Study 1 participants (52.2%) indicated that they had some unmet needs.

Participants were asked to reflect on what they hadn't used but thought might have been helpful if they could have accessed it. They were provided with a list of alternatives and given additional space to nominate other needs. From the list

- 10% responded yes to information would have been helpful to them
- 25% responded that community-based supports would have been helpful
- 25% responded that professional support (psychologist, counsellor) would have been helpful,
- 23% responded that were not sure what could have helped, and
- 21% did not think anything else could have helped them

Approximately half of participants also provided an open-text response describing their unmet needs. The mostly commonly described needs were for social support and professional mental health support. These were nominated twice as often as other unmet needs. (See Table 9)

Other needs which were mentioned at least 100 times included need for clearer communication from government and health professionals, the need to commemorate the deceased, and the need for more practical support after the death.

Interview participants who were caring for their family/friend described needing practical guidance about the next steps after then death.

> "It was hard knowing what to do initially - whether I needed to contact a funeral home, the coroner, etc. the police and ambulance officers were supportive on the day, but I needed something to tell me what to do in the immediate days afterwards. – 1787"

> “ Help and assistance with financial support, virtually being plunged into poverty because the bank froze all of our bank accounts but being expected to still make repayments on the mortgage and loss of employment because of Covid and trying to survive on Centrelink payments that don’t cover mortgage and bills. ” – 1371

> “ I’m the one that’s been dealing with Centrelink. They owe us money… The minute I notified them , they ceased speaking to me, and they won’t provide any information. ” – 1538

Participants also expressed a need for greater workplace support including:

- the need for greater bereavement leave (i.e., more than 2 days)
- bereavement leave to be granted for the death of friends as well as family members
- greater compassion and support upon return to work, including additional support for those working remotely, and
- greater recognition of the potential impact of grief during COVID-19 on capacity to maintain workload after the death

> “ Work only provides 2 days bereavement leave, with no appreciation that I had just lost a close immediate family member and that I was not able to be present during her time in hospital or during death/funeral to support family members who were under extreme pressure and grief dealing with the death …It was just business as usual after my 2-day leave and you are expected to function as if you haven’t just gone through and are still going through something very traumatic. ” – 89

> “ An employer who understood just because I wasn’t there when he died, I still need time to process and grieve ” – 1820

Recommendations on provision of bereavement support

Project findings identified multiple organisations and agencies as being relevant to bereavement support and highlighted the significant challenges to bereaved families and individuals that arise when systems are shut down. To facilitate future pandemic preparedness, governments and organisations need to be supported to develop systems that:

- allow for multiple points of provision of information to increase the likelihood of family/ friends receiving the information and support they require including
  - health services and aged care facilities consider a concierge model to help families navigate different health, support and government services when face to face contact in not available during pandemics
  - funeral industry services provide information on supports and the coronial process and timelines(for where health services had no or minimal involvement in the death)
  - consider establishment of community link worker roles to link bereaved people to community services e.g. neighbourhood centres, Men’s Sheds, cultural centres as places of information and support
- incorporate a public health approach to providing bereavement support which include a role for informal, community (e.g., Compassionate Communities, “Death Cafes”), and specialist care services in pandemic preparedness plans and for usual bereavement care
- increase support services provided by the coronial process to keep families informed and ensure follow-up is provided in pandemic preparedness plans, and for usual bereavement care
- that staff in government services such as Centrelink and banks receive training to increase grief literacy and awareness about the emotional, legal and financial support needs of bereaved people; such modules are available through CareSearch, palliAGED or Grief Australia

Further recommendations to improve bereavement supports

- greater bereavement leave (i.e., more than 2 days) and for bereavement leave to be granted for the death of friends as well as family members
- provide an opportunity to acknowledge the deaths that have occurred during the pandemic with a recognised National Day of Mourning

Mental health outcomes and functioning

Grief, comprising a mix of emotional, behavioural, physiological, and cognitive reactions, is a normal human reaction to the loss. Pre-pandemic research has repeatedly demonstrated that, over time, the majority of bereaved people find ways of living with their loss and experience neither chronic distress nor require specialist mental health interventions for their grief.[28, 31, 32]

However, research also shows that a substantial minority of bereaved people do experience their grief as chronic and overwhelming, and struggle to find any ongoing meaning or purpose in life. Termed Prolonged Grief Disorder (PGD) the condition has recently been included as a new diagnostic category in both major mental health diagnostic systems (the Diagnostic and Statistical Manual 5-TR of the American Psychiatric Association[3] and the International Classification of Diseases 11 of the World Health Organisation.[33]. Prolonged Grief Disorder is distinct from other mental health conditions such as depression and anxiety.[34, 35] and has been linked to a range of independent negative health outcomes, including higher rates of suicide. [36, 37]

> “Yeah, surprised about how bad I grieved. I didn’t expect it. The grief was intense. So, far more intense than when I lost my … And I surprised myself, I’m like, really, this is – you’re going to do this, you’re going to get that upset over it. Shocked myself with the depth of grief that I had.
> – 338”

PGD is characterised by intense and overwhelming longing or yearning for the deceased, disbelief about the death, a confused sense of self and purpose, emotional pain, emotional numbness, difficulties reengaging with life, meaninglessness, and loneliness. These reactions are not thought to be qualitatively different from “acute grief” reactions, but rather differ in their frequency, intensity, chronicity, and level of associated impairment. Bereaved individuals who experience these severe reactions more days than not, for more than 12 months after the death may have PGD, and benefit from referral to specialist treatment for the condition.[38] Notably, PGD is less responsive to treatments for major depression.[39, 40]

Pre-pandemic literature estimated that 7-10% of bereaved individuals are at risk for developing PGD. In Australia, this has been estimated at 44 000 people each year. [16]

> “It was very hard to access medical services because so much of the community infrastructure had been impacted by the fires, then we were in lockdown, and it was all Telehealth. … I was alone and isolated and in shock for months after. There was no local support available, and everyone was in lockdown. All support had to be by phone and zoom. Administration was made almost impossible by lockdown and everything having to be done remotely and on the internet. It was HELL. I wanted to die every day, the only thing that stopped me killing myself was the thought of what it would do to …
> – 148”

This study indexed prolonged grief, depression and anxiety using validated self-report scales, along with general and health related quality-of-life and personal growth. Almost 2000 (1,911) people completed these measures as part of Study 1 (mean time since loss 10 months). A subsample (n = 1118; 59%) agreed to receive additional surveys across the first 15 months of their bereavement (Study 2). As of September 2022, 587 (52%) of this subsample have completed at least one additional survey and are included in the longitudinal findings reported below, and 303 have completed their involvement in Study 2.

Mean levels of prolonged grief symptoms, depression and anxiety for Study 1 participants are presented in Table 10.

Note: We refer to “probable Prolonged Grief Disorder” as mental health disorders should not be diagnosed based solely on self-report. Clinical assessments are needed to confirm whether an individual fully meets criteria. Further, we also note the criteria for PGD have changed across time and this raises issues for comparison with previous studies. For further discussion see.[41, 42]

Prolonged Grief symptoms

764 (41%) of participants were 12 or more months bereaved when they completed Study 1. Time since loss was only weakly correlated with grief severity, (r = -.05) indicating time since bereavement was not a major factor associated with grief severity.

- 39% of participants 12 months or more bereaved scored in the range suggestive of prolonged grief disorder on the PG-13R (30+)[38]
- 43% of participants bereaved for less than 12 months bereaved also scored 30 or more on the PG13-R. While not an indication of Prolonged Grief Disorder, these participants may be at higher risk of developing the condition[43]
- Mean prolonged grief symptom severity decreased over time, however those with higher symptoms when they first participated continued to have higher symptoms at a later time points (Study 2)
- 37% (n = 111) of participants who have completed Study 2, scored in the range suggestive of PGD on the PG13-R

Time since loss was only weakly correlated with grief severity, (r = -.05) indicating time since bereavement was not a major factor associated with grief severity. The high rates of prolonged grief symptoms and grief related distress reported in our study are comparable to similar international studies undertaken during the pandemic [14, 15, 44, 45]. We explore predictors of mental health outcomes in more detail below.

Grief Impairment

We assessed whether participants felt their grief impaired their functioning across work, household management, social leisure, private leisure, and relationships domains using the Work and Social Adjustment Scale[46]. Social leisure was the most frequently impaired domain in Study 1. 44% of participants reported definite impairment in at least 2 domains, and 17.5% reported definite impairment on all domains. Impairment was correlated with severity of grief. (r = .80, p = <.001).

Depression and suicidal ideation

A score of 10 or more on our measure of depression (PHQ-9) indicates probable clinically significant levels of depression. [47] Nearly half (45%) of participants endorsed levels of depression that were within this range. For comparison, reported rates among Victorians during Melbourne's extended lockdowns in 2021 were 44%, and for other states combined at the same time were 32%.[8] In Study 2 mean levels of depression fluctuated across time points. This may indicate that symptoms of depression were more sensitive to environmental factors and changes in restrictions across the course of the study.

Concerningly, one quarter of Study 1 participants (24%) reported "thoughts they would be better off dead or of harming themselves in some way" at least several days in the two weeks prior to completing the survey. These rates are comparable to those reported in an Australian sample during the extended Melbourne lockdown in 2021.[8]

General Anxiety

A score of 10 or more on our measure of anxiety (GAD-7) indicates probably clinically significant levels of anxiety. [48] Of our participants, 32% scored within this range. For comparison, reported rates among Victorians during Melbourne's extended lockdowns in 2021 were 34%, and for other states combined at the same time were 23%.[8] As with depression mean levels of general anxiety fluctuated across time points in Study 2, which again may have reflect that anxiety symptoms fluctuate with changes to restrictions across the course of the study.

Mental health comorbidity

Patterns of comorbidity were examined using latent class analysis (LCA) (Maccallum et al, in press). Four patterns of co-morbidity (groups) were identified (see Figure 3). The largest group had participants with few if any symptoms (Low: 46.1%), a second group comprised participants with primarily grief symptoms (Grief 17.6%), a third primarily depression and anxiety (Depression/Anxiety: 18.1%) and the fourth compromised participants with symptoms from all three conditions (Grief/Depression/Anxiety 18.2%). The three symptom groups reported greater functional impairment than the low symptom group, with the latter group reporting the highest levels.

> "It was hard to accept ... as I hadn't seen him for 16 months. There's no closure, no grieving. It was all put aside due to COVID
>
> – 2406"

Socio-demographic and Pandemic Specific Challenges and Mental Health

Our analysis identified several sociodemographic factors that were related to symptom group membership. The following differentiated at least one of the symptom groups from the low symptom group.

- death of a child or partner
- younger age of the deceased

- younger age of the participant
- single or separated
- less likely to have tertiary education
- looking for work or out of the workforce for reasons other than retirement

Lower subjective preparedness for the death also differentiated each of the groups with the grief/ depression/anxiety group reporting the lowest preparedness.

Death from COVID-19 did not predict worse outcomes in our participants, however, we note only 3% of deaths were due to COVID-19.

These findings provide some information to identify those who may be at greater risk for poorer outcomes. However, from this analysis it is not possible to determine the direction of the relationship, for example, whether mental health impacted employment status of vis-a-versa.

The four groups differed in the extent to which they experienced impacts pandemic specific challenges (listed in Table 2). Adjusting for sociodemographic and death related factors, which may have impacted the likelihood of experiencing pandemic challenges, the most consistent predictors of group membership were

- the inability to care for the person as I would have liked
- experiencing social isolation and loneliness

> "I think that aged care underestimate how much family, family do for people in aged care and the role they play in their upholding their care and maintaining their care. Because when it's gone, there's no one really to do it. I mean yes, of course, they have staff, but there's no way the staff would have been able to achieve the care that she needed. There's just – there's not enough of them and they're certainly not trained – they just don't have the clinical knowledge to manage that."
>
> – 15

> "– that's everyone's fear. To be in pain and alone. And she had none of that. I was very lucky that I was with her, and I feel very, very grateful for that and that's – I was so grateful that these nurses were able to get me in, because she would have died alone."
>
> – 835

Many also provided free-text descriptions of the impact of social isolation and loneliness on their ability to grieve.

> "Living alone is so, so hard. Not being able to have friends with me when I needed them because they lived in another LGA has been so, so hard."
>
> – 734

> "6 months later I was still very sad. People assumed I should be over it in a month."
>
> – 13

> "Lockdown has kept me isolated from my family and contributed to my anxiety and depression which has worsened recently. I feel like I'm only just starting to grieve the loss."
>
> –1860

Unexpected and sudden deaths including death from suicide

While many participants in our study described their experiences of bereavements associated with existing health conditions, 31% of deaths were the result of less expected causes, including a sudden health condition (e.g. heart attack or stroke 15%), suicide (6%), accident/injury/homicide (5%), medical procedure complications (1%), birth complications (1%), or with an unknown cause (2%). The latter includes participants who indicated they were waiting for a cause and/or a Coroner's report.

Pre-pandemic has linked unexpected, traumatic, or death by suicide with with worse mental health outcomes. [49, 50-54] Cause of death did not emerge as an independent predictor of outcome in this large analysis, however, there was a degree of overlap between the predictors in the analysis which may have resulted in some redundancy. For example, deaths from suicide were often deaths of a child or partner, further lower preparedness was a predictor of poorer outcomes. It may also be that while cause of death did not impact group membership, it did influence symptom severity within each group and we will examine these possibilities in future analyses.

Qualitative responses identified a range of challenges experienced by those reporting a sudden death. These included:

- experiences with public health measures that appeared to compound distress
- difficult interactions / lack of information and follow up by police and the coroner's system, and
- practical financial and legal challenges

> "Being COVID I couldn't leave the scene of his death and we couldn't have visitors"
>
> – 2323

> "I also don't feel like I can really start to grieve properly until the coronial investigation is complete (whenever that might be) because we are very much reliving it every day so it still doesn't feel real yet"
>
> – 1836

> ". ...virtually being plunged into poverty because the bank froze all of our bank accounts but being expected to still make repayments on the mortgage and loss of employment because of Covid .... Not being able to access food relief schemes because of Covid or because we were ineligible as a "home owner""
>
> – 1371

> "The [hospital] never followed up on support services. They failed to tell me I would be interviewed by the police due to sudden unexplained passing . The only thing they wanted to talk about was the coronial inquest. The information regarding counsellor was given to us in a booklet to read when we were ready. You are never ready so a follow up call would have been good. An offer for someone to support while being interviewed by police would have been helpful. Arrived home from the hospital in shock and several hours later the police came to my door ..."
>
> – 2028

Help seeking and Prolonged Grief Disorder

The public health model of bereavement care acknowledges that most bereaved individuals will not require help from professional mental health services in coping with their loss. However, Previous Australian reports have highlighted the gaps in services for individuals reporting grief within the probable PGD range.[16, 28]. In this section we explored help seeking behaviour among this group during the pandemic

Encouragingly, those 12 months bereaved whose grief was within the PGD range were more likely than those with lower grief levels to have accessed a GP, psychologist, grief counsellor or psychiatrist. The most common health professional accessed was the GP, followed by psychologist and grief counsellors. They were also more likely to have sought out self-help grief resources, support lines such as Lifeline, grief support groups, online community support groups, and social support groups for bereaved people. Those within the PGD range were also more likely to have been prescribed medications.

Whereas most participants in the full sample reported that the services they had accessed were at least "quite helpful" for them. Many of those in the probable PGD range considered that the support had been only "a little" or "not at all helpful".

Delivery mode

Most appointments were face-to-face; however, telehealth appointments were accessed by more than half of respondents. Qualitative data indicated mixed experiences with telehealth.

Recommendations on professional health support use

COVID-19 resulted in elevated rates of mental health distress and many respondents reported difficulties accessing the care they were seeking. This is significant as specific patterns of intense and chronic grief reactions are associated with negative long-term health outcomes that can be reduced through specialist interventions, and there was frequent suicidal ideation.

To facilitate future pandemic preparedness, governments and organisations need to be supported to develop systems that:

- identify pathways of bereavement care through primary health care systems
- include documented systems to identify people who are at risk of, or experiencing a complex response to bereavement to avoid people getting lost between services when services may be closed during pandemics; GPs were the most used health service and as such could play an important role in primary care and triage to appropriate grief supports
- train the workforce to facilitate referrals to services and organisations that can meet identified needs of and are matched with levels required expertise
- maintain flexible delivery options, including face-to-face grief counselling where possible
- address the lack of training for psychologists and mental health professionals in delivering interventions for prolonged grief disorder

This will require:

- broader recognition and understanding among health professions of the links between bereavement and mental health outcomes, including Prolonged Grief Disorder
- training in loss, grief and bereavement to be an essential component in medical, nursing and allied health curricula
- pandemic preparedness bereavement education to be an essential component of the medical, nursing and allied health curricula

Growth and positive reflections

Our survey included several questions indexing growth and resilience. Most will be analysed as part of the longitudinal study analysis (Study 2). In response to a question in Study 1 asking participants if they had experienced any changes they saw as positive in their life, 12.5% of participants responded yes. These fell into three main categories: recognising priorities and acting (22.5%), career and job changes (20.4%) and a greater focus on relationships (19.5%).

> “The pandemic also makes you think that life is short and you really need to do what you mean to, do some things that you need to do in your life. Make yourself happy and not put up with miserable life situations because that might be the end of it.”
>
> – 615

Strengths and limitations and future directions

This study represents one of the largest and most comprehensive bereavement studies undertaken in Australia where public health restrictions were amongst the strictest globally and has documented the experience of bereavement during the COVID-19 pandemic, capturing a significant moment in time. While our study provided evidence across States and Territories, city and rural areas and deaths within Australia and overseas, we acknowledge that our participants were predominantly female, English-speaking, tertiary educated adult volunteers. Future research is needed to determine how findings generalise to other genders and cultural groups. Further, there is also a need to understand the experience of bereaved children. Although the study was widely advertised and paper copies of the survey were available, most recruitment occurred online, primarily through Facebook; as such, people with limited digital literacy and limited access to the internet or choose not to have a Facebook profile may be under-represented in the data. Finally, we note that convenience samples may be subject to a volunteer effect[11] which might have resulted in overrepresentation of people with negative experiences. Nevertheless, in open-ended questions people reported a range of experiences, including positive experiences.

It is regrettable that the Aboriginal and Torres Strait Islander component of the study could not proceed. Timelines and budgets did not allow for National consultation and whilst the protocol for a smaller local study was approved by the University of Technology HREC, after consultation, the Aboriginal Health & Medical Research Council Ethics Committee did not consider it representative of the views and experiences of Aboriginal and Torres Strait Islander peoples throughout Australia. We are pleased to report that the Aboriginal and Torres Strait Islander investigators took ownership of this sub-study and appointed a project officer to complete the study as a quality improvement project in South Eastern Sydney Local Health District.

> “It’s so hard to separate the issues from grief versus the issues from the pandemic because it’s all about loss. The loss of freedom and the loss of vision of the future, the loss of positivity, it’s all about loss. So pandemic grief versus death grief is all so intertwined and it’s hard to untangle from what is what”
> – 1190

Summary and conclusions

The National Bereavement during COVID-19 study is one of the largest bereavement studies undertaken in Australia. It captured a significant moment in time and has significantly advanced our understanding of end-of-life care and bereavement support in Australia. The findings highlight the challenges introduced because of the circumstances of the COVID-19 pandemic but also shone a light on pre-existing bereavement care cracks within the health system and the community. Our findings suggest that many of those bereaved during this time experienced conditions that did not meet the minimum recommendations for a "good death", and that despite the significant efforts of health staff and other workers, care systems fell apart and let people down. Further, our findings suggest that bereavement during COVID-19 was a risk factor for poor mental health outcomes and many bereaved people did not get the support they felt would have helped them.

In addition to pandemic specific issues, our findings highlighted significant gaps within current bereavement care systems including the siloing of services and a lack of grief literacy among government services and medical, nursing and allied health professionals. Encouragingly, however, many of these gaps involve modifiable factors, for example, the inclusion of loss, grief, and bereavement content in training curricula. Improving end-of-life and bereavement care will require a multifaceted approach, with support from multiple levels of government to facilitate a range of universal, community level, and specialist mental health care initiatives. Further funding is required to evaluate any proposed initiatives and a health economics evaluation undertaken of their implementation.

These initiatives will require funding for evaluation.

To improve respsonses for future pandemics we have made key recommendations about:

- implementation of public health measures for mainstream and multicultural communities
- communications with health professionals
- provision of information about grief and bereavement support at end-of-life
- improving mental health support and functioning
- improving professional health support use

Our overarching recommendation is the development of a co-designed national pandemic bereavement plan inclusive of a workforce strategy to ensure that the required health, funeral, and support services can be mobilised to ensure the community has access to the national, state, and local level supports primary care and coronial bereavement pathways.

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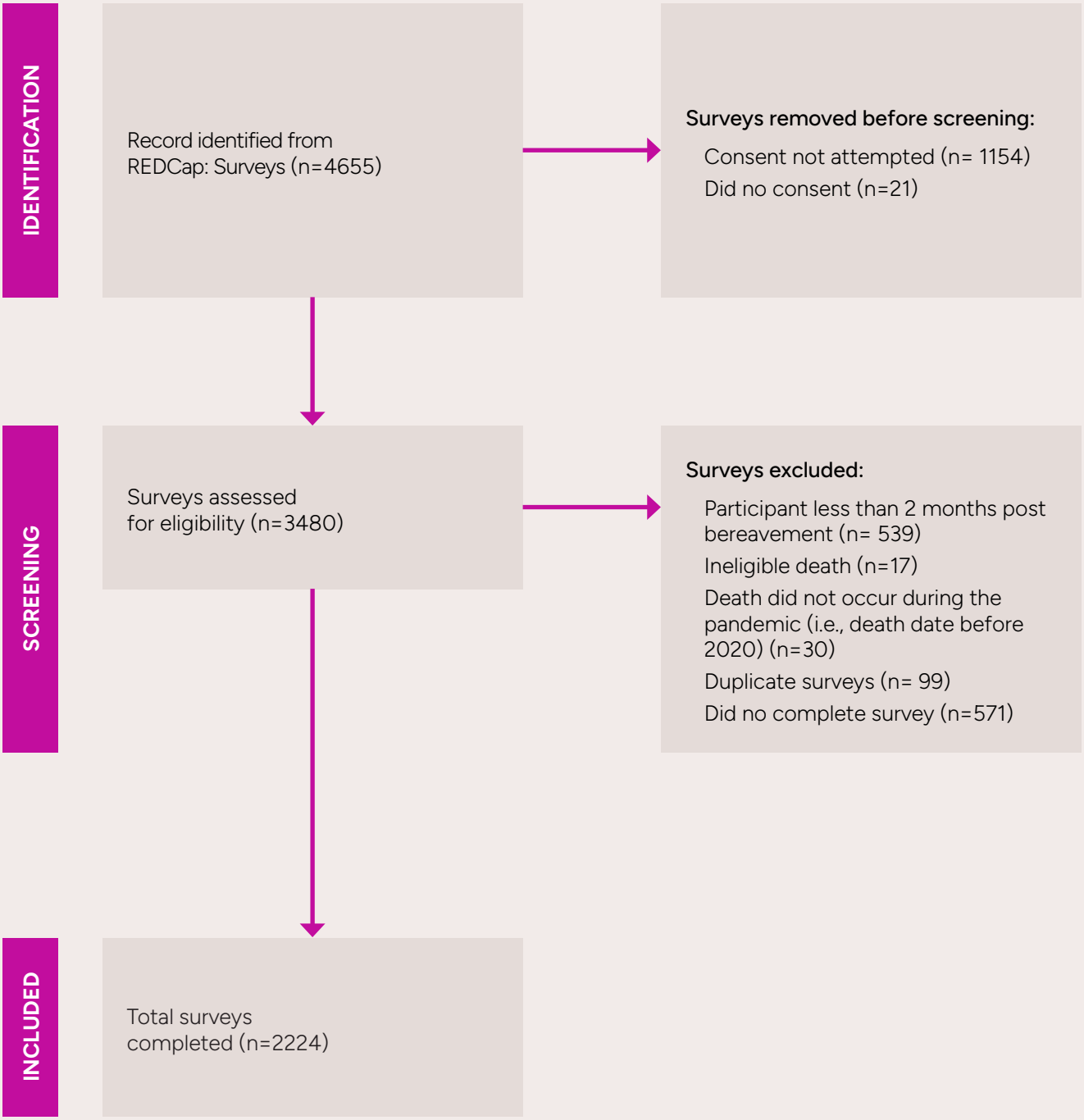
Appendix A: Figures

Figure 1: Recruitment diagram Flow chart



Based on: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Figure 2: Frequency of impacts experienced due to COVID-19 public health measures

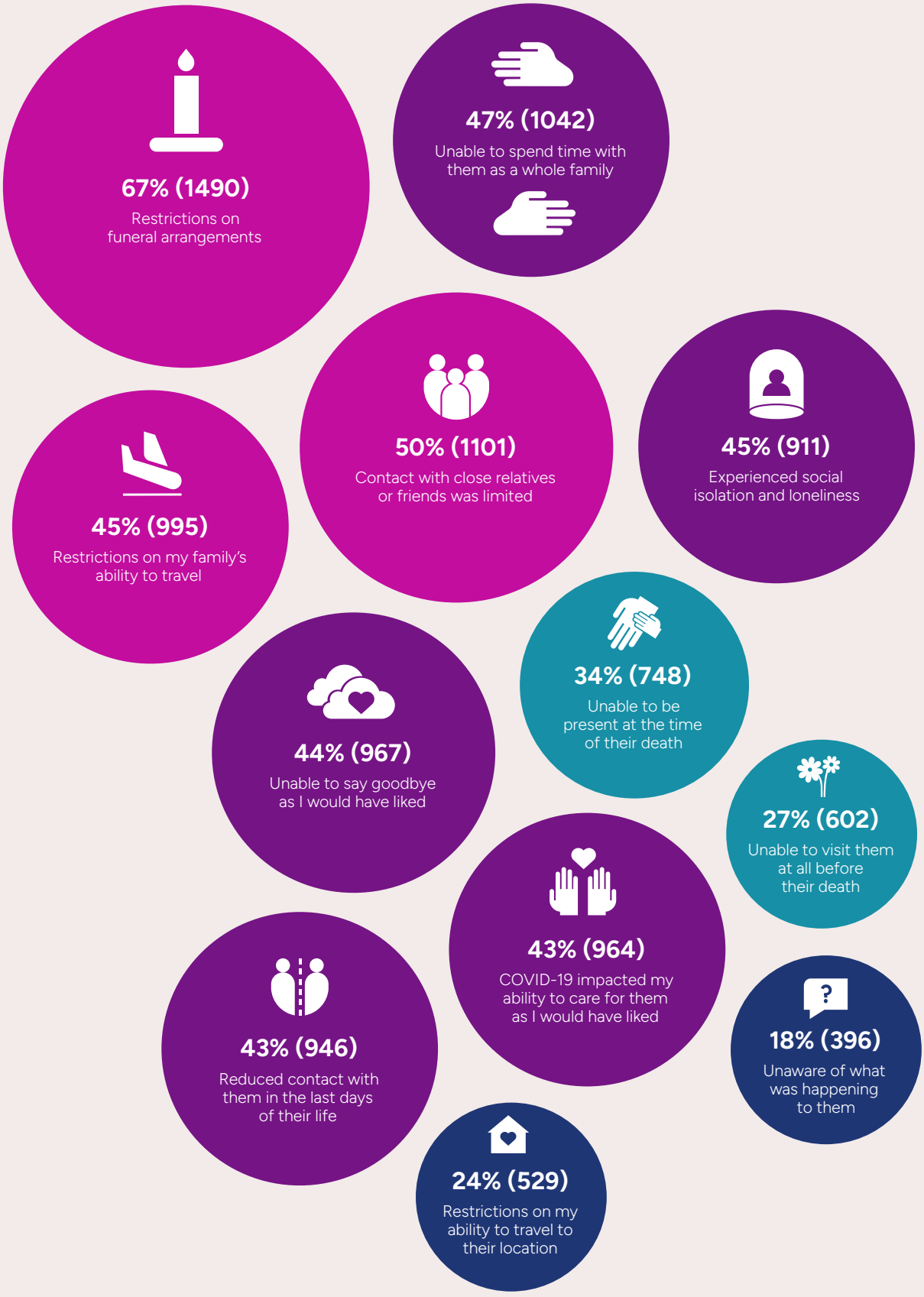
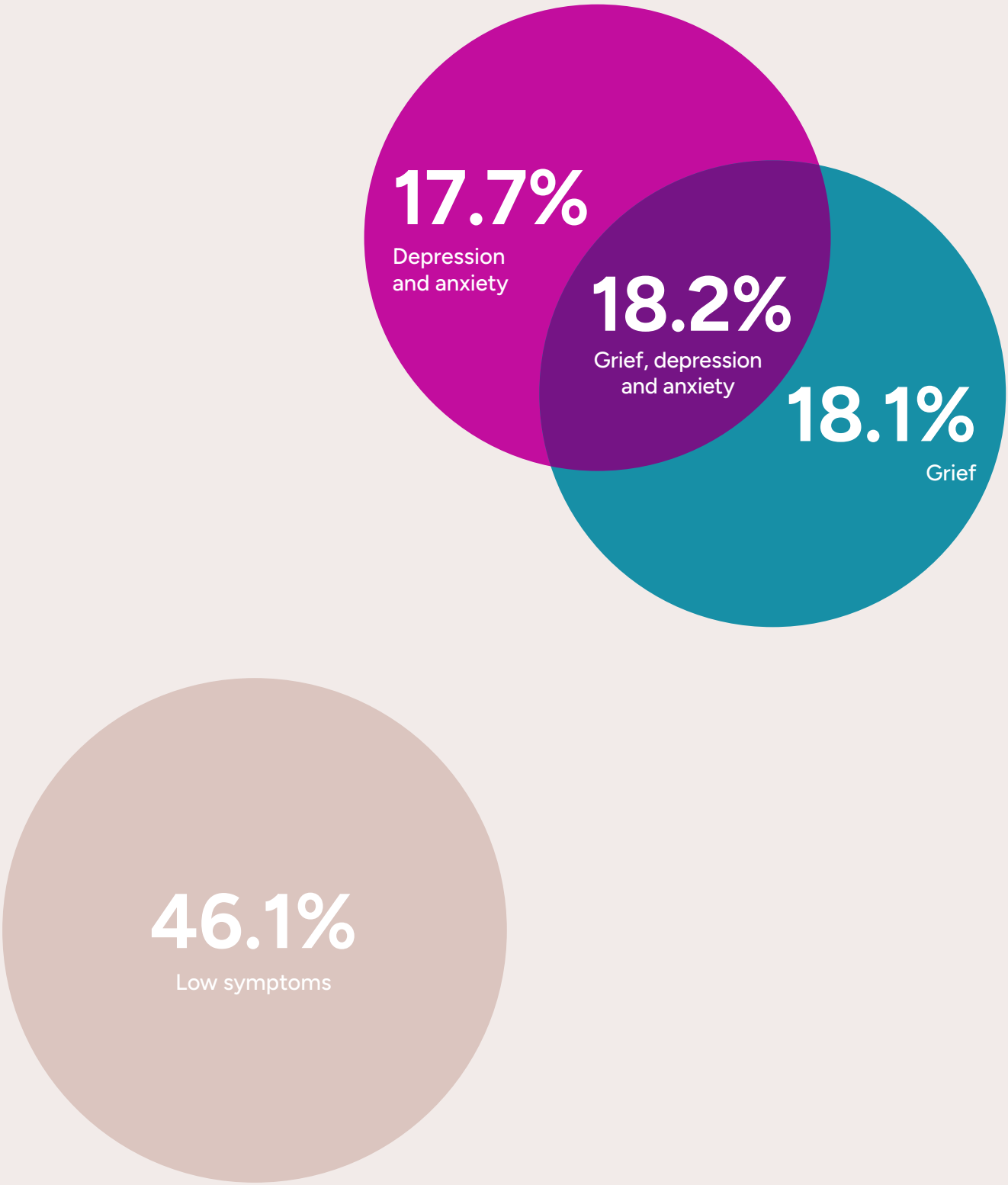


Figure 3: Mental health Study 1 (Latent class analysis percentages)



Appendix B: Tables

Table 1: Participant characteristics (n =2,224)

	VALID CASES	MEAN (SD) OR %
AGE (YEARS)	1732	55.19 (12.11)
Median [quartiles]		57 [47:64]
Range		Range 19-90
GENDER	1821	
Female		94.8%
Male		4.7%
Country of origin Australia	1684	79.2%
Speak other than English at home	1815	5.1%
PARTICIPANT STATE	1812	
NSW		40.6%
VIC		29.7%
QLD		10.9%
WA		6.5%
SA		5.4%
ACT		3.3%
TAS		2.7%
NT		0.8%
Geographic location	1810	
Major City		66.6%
Inner Regional		25.2%
Outer Regional/ Remote/Very Remote		8.1%
HIGHEST EDUCATION	1825	
High School or below		43.6%
Bachelor degree equivalent		24.7%
Post-graduate degree		31.7%
CURRENT RELATIONSHIP STATUS*	1820	
Single		13.7%
Married/Partnered		59.3%
Separated/divorced		9.1%
Widowed		16.9%
* 2% (9) LGBTQI partner deaths		
Living in single person household	1819	26.2%

EMPLOYMENT STATUS	1828	
Employed		61.0%
Looking for work		3.4%
Retired		21.8%
Not employed for other reasons		13.7%
RELATIONSHIP OF DECEASED	2224	
Parent		44.6%
Partner		16.5%
Child		7.9%
Sibling		9.3%
Other family member		14.7%
Close Friend/ Not a family memeber		7.1%
Age of deceased	2216	69.77 (22.29)
		75 [60:86]
		Range 0-104
CAUSE OF DEATH	2136	
Cancer		31.4%
Chronic health conditions		23.2%
Sudden health event or illness		15.5%
COVID-19 related		3.4%
Accident/Injury/Suicide		11.0%
Other cause (e.g. perception of vaccination		5.2%
PLACE OF DEATH	2133	
At home		26.8%
Choice of home death influenced by visiting restrictions		36.4%
Specialist palliative care unit		16.2%
Hospital ED or ICU		14.8%
Hospital: Other ward		18.4%
Residential aged care facility		19.4%
Other location		4.4%
Time since death (months)	2224	10.15 (5.96)
		[10; 2-31]

Note: "Other family members" includes all other family relationships not listed; "Other" cause of death includes nominated causes with small n's including "elderly", "natural causes" and unknown), Gender: 5 participants "used a different term and 4 preferred not to answer. 'Partnered" includes partnered not living together, "Other" employment status = out of workforce for health reasons, carer role, "taking a break", home duties.

Table 2: The experience of the public health measures compared across the different death settings

BEFORE DEATH	HOME PC	HOME NO PC	ED/ICU	HOSPITAL WARD	SPECIALIST PC UNIT	RACF	OTHER
Impacted my ability to care for them as I would have liked**	28.3%	28.4%	44%	44.7%	46.2%	66.3%	19.1
I was unaware what was happening to them**	6%	25%	21%	18%	17%	20%	23%
Restrictions on my family's ability to travel due to border closures	52%	45%	44%	46%	50%	46%	43%
There were restrictions on my ability to travel to their location	18%	27%	27%	25%	23%	27%	21%
I was unable to visit them at all before their death due to restrictions**	19%	27%	35%	27%	27%	35%	11%
We were unable to spend time as a whole family**	42%	27%	50%	56%	54%	65%	16%
AT THE TIME OF THE DEATH:							
I was unable to be present at the death**	20%	26%	39%	38%	38%	46%	18%
I was unable to say goodbye as I would have liked**	29%	41%	56%	48%	44%	51%	33%
Reduced contact with them due to restrictions in the last days of life**	28%	28%	45%	48%	46%	66%	19%
AFTER THE DEATH:							
My contact with close relatives or friends was limited	57%	50%	44%	51%	54%	53%	52%
I experienced social isolation and loneliness	51%	47%	43%	49%	52%	37%	52%
There were restriction on funeral arrangements	72%	68%	66%	66%	69%	75%	71%

**<.001
RACF = residential aged care facility; Other = death outside of home or health facility

Table 3: Interactions with health care professionals by where the person died (responsible person only)

	HOME PC	SPECIALIST PC UNIT	ED/ICU	HOSPITAL WARD	RACF
INVOLVEMENT IN HEALTHCARE DECISIONS					
Always/ usually	91.3%	26.7%	80.2%	79.4%	80.2%
Sometimes	9.4%	17.0%	19.8%	20.6%	19.8%
INDICATED RELATIVE/FRIEND WAS WELL SUPPORTED AT END-OF-LIFE					
Very/ fairly well	82.8%	87.3%	77.4%	78.9%	82.5%
A little/ not at all	18.5	17.2%	22.6%	21.1%	17.5%
INDICATED THEY FELT WELL SUPPORTED AT END-OF-LIFE					
Very/ fairly well	75.5%	68.1%	62.3%	62.2%	58.8%
A little/ not at all	23.5%	31.8%	37.7%	37.8%	41.2%
Health Care Professionals (HPCs) asked if they had significant stress, emotional or psychological problems before the death	38.2%	25.2%	19.8%	13.3%	13.0%
Knew contact details of the HCPs involved	94.1%	73.0%	60.4%	60.6%	86.4%
Received information about the approaching death	80.0%	77.2%	66.0%	65.6%	69.9%

RACF = residential aged care facility

Table 4: Subjective practical and emotional preparedness by where the person died (all participants)

	HOME PC	SPECIALIST PC UNIT	HOME NO PC	ED/ICU	HOSPITAL WWARD	RACF	OTHER	TOTAL
MEAN PRACTICAL PREPAREDNESS SCORE	4.45 (1.91)	3.90 (1.83)	1.77 (1.47)	2.33 (1.78)	3.40 (2.00)	4.35 (1.91)	1.90 (0.42)	3.27 (2.08)
Mean emotional preparedness score	3.24 (1.88)	3.13 (1.75)	1.60 (1.23)	1.95 (1.45)	2.85 (1.84)	3.76 (1.88)	1.09 (0.41)	2.70 (1.85)

Ratings were made on a separate Likert-type scales 1 = not at all prepared to 7 = prepared; RACF = residential aged care facility; Other = death outside of home or health facility

Table 5: Preparation for End-of-life plans

	HOME PC	HOME NO PC	ED/ ICU	HOSPITAL WAR	SPECIALIST PC UNIT	RACF	OTHER	TOTAL
PLANS								
Funeral arrangements	33.9%	13.5%	20.6%	23.2%	34.1%	33.2%	3.2%	25.2%
A Will	73.0%	37.8%	52.5%	67.4%	70.5%	76.0%	24.5%	61.4%
Enduring power of Attorney	47.0%	17.6%	32.3%	46.6%	49.4%	66.8%	5.3%	42.4
Enduring power of Guardianship	21.7%	7.9%	12.7%	20.4%	20.2%	26.8%	1.1%	19.7%
Advance Care Plan	35.2%	7.3%	10.1%	14.0%	28.0%	37.5%	0.0%	20.9%
Advance Health Directive	22.6%	6.5%	11.7%	12.7%	19.1%	19.1%	0.0%	14.3%
Don't know	6.1%	25.8%	17.4%	9.4%	12.4%	8.2%	23.4%	13.7%
WISHED FULFILLED								
Yes, as planned	56.1%	22.3%	30.7%	43.0%	44.5%	50.8%	16.0%	39.8%
Yes, but delayed	9.6%	8.8%	13.9%	12.0%	15.0%	12.8%	4.3%	11.8%
No, as a result of COVID-19 restrictions	7.8%	6.2%	11.1%	13.0%	14.2%	16..5%	1.1%	11.4%
No, for other reasons	3.5%	2.3%	2.5%	2.3%	4.0%	3.9%	1.1%	3.0%
Don't know	1.3%	2.1%	2.8%	3.3%	1.7%	2.2%	2.1%	2.3%

RACF = residential aged care facility; Other = death outside of home or health facility

Table 6: Provision of information on grief, and bereavement support at end-of-life (all participants)

	HOME PC	HOME NO PC	ED/ ICU	HOSPITAL WAR	SPECIALIST PC UNIT	RACF	OTHER	TOTAL
Offered information about grief/ support **before the death**	23.0%	1.5%	7.0%	7.9%	12.1%	5.1%	2.1%	8.3%
Offered information about grief/ support **after the death**	22.6%	21.7%	21.8%	20.4%	24.6%	4.6%	50.0%	20.0%
Not offered information about grief/support **at any time**	46.5%	59.2%	59.2%	63.1%	55.8%	79.4%	39.4%	61.0%
Not relevant for my situation	8.3%	16.1%	10.4%	8.1%	6.6%	6.3%	4.3%	9.0%

RACF = residential aged care facility; Other = death outside of home or health facility

Table 7: The 10 most commonly used bereavement supports used

MOST FREQUENTLY USED SUPPORTS	% (N)	
Family and friends	79%	(1746)
Self-help resources e.g. information on grief-related websites, books	25%	(545)
General Practitioner	20%	(445)
Psychologist	18%	(393)
Internet/online community support groups e.g. Facebook	16%	(352)
Grief counselling	10%	(218)
Religious leaders/organisations	8%	(167)
Legal professionals	7%	(147)
Advice or support line e.g. Beyond Blue, Lifeline	3%	(71)
Financial professionals	3%	(71)

Table 8: Helpful and unhelpful bereavement supports

	MOST HELPFUL SUPPORTS (N=2224)	UNHELPFUL SUPPORTS (N=1429)
1	Family and friends – 45% (1018)	None were unhelpful – 28% (398)
2	Psychologist – 6% (139)	Family and friends – 24% (341)
3	Self- help resources – 3% (74) e.g. information on grief-related websites, books	Government and lockdown – 6% (67)
4	Grief counseling – 3% (73)	Psychologist – 5% (67)
5	Internet/online community support groups e.g. Facebook – 2% (44)	GP – 4% (51)
6	General Practitioner – 2% (36)	Legal/financial support – 2% (34)
7	Religious leaders/organisations – 1% (25)	Grief counselling – 2% (32)
8	Other – 1% (21) e.g. meditation, hypnotherapist, alcohol	Aged care – 2% (30)
9	Psychiatrist – <1% (12)	Palliative care – 2% (28)
10	Palliative care service – <1% (10)	Self-help resources – 2% (24)

Note: Percentages are calculated based on n for each column

Table 9: Unmet needs: Free text responses

UNMET NEED CATEGORY	N = 2224	
Need for social support after death and during lockdown	16.5%	(368)
Need for professional mental health support	13.4%	(300)
Need for togetherness at the time of death and the chance to say goodbye	7.5%	(166)
Need clear communication from government and health care professionals	7.5%	(165)
Need to commemorate (e.g. funerals, memorials and rituals)	6.4%	(142)
Need for practical support after the death	4.8%	(107)
Need for carer support before and after the death	4.3%	(96)
Need for improved quality of care for the dying	2.4%	(54)
Need for support from workplaces	1.6%	(37)
Need for information and advice about grief	<1%	(15)
Need for increased access to palliative care	<1%	(8)
Need for government and public acknowledgment	<1%	(3)

Table 10: Mental health outcomes: Means and severity ratings

MEASURES	FREQUENCY (N) / MEAN (SD)
GRIEF	
Full sample mean (PG13-R)	27.51 %(10.26)
Possible Prolonged Grief Disorder*	39.2% (n = 307)
Grief impairment	
TOTAL SCORE (WSAS) "DEFINITE" IMPAIRMENT IN**	12.6% (11.21)
Work	16.8%
Household management	22.8%
Social leisure	29.2%
Private leisure	22.6%
Relationships	17.8%
DEPRESSION	
Mean severity (PHQ-9)+	9.90% (7.06)
Moderate depression^	18.5%
Moderately severe^^	26.3%
GENERAL ANXIETY	
Mean severity (GAD7)	7.40% (6.02)
Moderate anxiety ^	16.5%
Moderately severe ^^	15.4%
SELF RATED HEALTH	
IMPROVED	7.6% (146)
STAYED AT HOME	23.9% (456)
A BIT WORSE	41.5% (794)
A LOT WORSE	26.9% (515)
EQ-VAS	58.85% (20.91)

Note: Grief was measured by the PG-13R[38], depression was measured using the Public Health Questionnaire – 9 (PHQ-9)[47], General Anxiety was measured by the General Anxiety Disorder -7 GAD-7 [55], and grief related impairment was measured by the Work and Social Adjustment Scale (WSAS) [46]; EQ-VAS is a measure of subjective health that is included in the EQ-5D-L[56] * only includes of participants bereaved at least 12 months (n = 764). ** definite impairment = a score of 4 or more on the scale item. ^ a total score between 10 - 14 inclusive; ^^ a total score of 15 or greater.

Appendix C: Description of measures

Current Mental Health and Wellbeing: The following measures were used to measure different domains of mental health and wellbeing in Study 1 and/or Study 2:

Prolonged Grief Disorder-13 (PG-13-R):[38] contains ten items assessing reactions aligning with the DSM-5-TR PGD diagnostic criteria [3]. Prigerson and colleagues [38] suggest that where at least 12 have passed since the death, scores of 30 or greater are suggestive of probable PGD; where fewer than 12-months had passed, scores should not be interpreted as prolonged grief disorder, but can indicate grief severity (Cronbach's α=.93).Participants rate symptom occurrence over the past month on 5-point Likert scale.

Patient Health Questionnaire-9[57]**:** A self-rated 9-item measure that assesses the severity of depressive symptoms during the previous 7 days. Each item is rated on a 4-point Likert scale. The total score ranges from 0-27 with the higher scores indicating greater severity of depression. Scores above ten are suggestive of moderate levels of depression (Cronbach's α=.92).

The Generalised Anxiety Disorder 7 (GAD–7)[48]**:** A 7-item measure that assesses the severity of generalised anxiety during the previous 7 days.. Each item on the measure is rated on a 5-point Likert scale. Scores above ten suggest moderate levels of anxiety (Cronbach's α=.93).

The Work and Social Adjustment Scale (WSAS[46]**);** indexed grief-related impairment across five domains (work, household management, social leisure, private leisure, and relationships). Participants responded on nine-point scales (0=not at all impaired, 4=definitely impaired, 8=very severely impaired). Scores were aggregated to indicate overall impairment) (Cronbach's α=.93).

Quality of Life and Functioning – EQ-5D-5L: A generic 16 item measurement of QoL across five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) with lower scores indicating more impairment on a 1-5 scale for each dimension. The EQ-5D-5L is extensively used in international clinical and economic evaluations of health care as well as in population health surveys. This will enable comparison with international data.

Alcohol Use Disorders Identification Test (AUDIT-C): A 3-item screen to identify persons who are hazardous drinkers or have active alcohol use disorders. It is scored on a scale of 1-10. In men, a score of 4 or more is considered positive; in women, a score of 3 or more is positive. Generally, the higher the score, the more likely is that the person's drinking is affecting their safety.

The Post Traumatic Growth Inventory – Short Form[58]**:** A 10-item scale assessing positive responses to trauma regarding: relationships with others; new possibilities; personal strengths; spiritual change; and appreciation of life. The scale shows good reliability with a Cronbach's alpha of .90.

Appendix D: Communication

Formal letters were received from Palliative Care Australia; Calvary Health Care; Flinders University; the Australian Centre for Grief and Bereavement; Central & Eastern Sydney Primary Health Network; South Western Sydney Primary Health Care Network; SPHERE, Multicultural Health Service NSW; Carers Australia; Groundswell; Meaningful Ageing Australia and National Palliative Care In Prison's Project.

Quarterly meetings were held with Investigators and progress reports were circulated. Fortnightly meetings were held with the research team.

Quarterly Newsletters were distributed to investigators and partners. A website was developed to provide background information on the study; a study specific email was established for queries and these were highlighted in communication about the study.

Co-design workshop

A full day face to face workshop attended by 50 participants was held in Sydney in August 2022 and a Virtual Workshop with 31 participants who were interstate were held in September 2022. The aim of the workshop was to present the data and make recommendations. At the Sydney workshop summary data were presented, interpretation of the data discussed and recommendations were then workshopped in small groups. Feedback and discussion was held. Participants attending the co-design workshops offered numerous recommendations about the provision of information, noting that much of this information already existed and what is needed is a centralised repository where evidence based and current information can be located. Participants also recommended specific training in grief and bereavement was needed for health professionals to facilitate confidence and a sense of efficacy around discussing grief and bereavement with families where the primary role had been focussed on keeping the close person alive. Other attendees commented on the usefulness of recently established outreach programs involving nurse practitioners to increase bereavement and grief literacy among staff in Residential Aged Care Facilities.

This feedback was collected on butcher's paper and summarised. Over 100 recommendations were received. These recommendations were then further synthesised to be presented at the shorter Virtual Workshop and recommendations were further developed and discussed.

After the workshops the recommendations were further synthesised and distributed to investigators, partners and workshop participants to comment, add to and to prioritise. These recommendations are included in the Report.

Presentations

On-going presentation of data and discussion of findings with decision makers were held at all stages of the project.

- The study was presented to clinicians at Liverpool Grand Rounds in March 2021
- The study was presented to the Australian COVID-19 palliative care working group (ACPCWG) in August 2021
- Grief in the time of COVID-19 presented in October 2021 to the University of Tehran
- Early preliminary data were presented to key stakeholders at the Commonwealth Department of Health in December 2021 and to the ACI Palliative Care Executive Committee in March 2022. Feedback was received.
- Further data were presented at Grand Rounds at St. George Hospital June 2022 - "The Way We Were" - Dying and grieving during the COVID-19 pandemic
- Preliminary data were also presented at the Palliative Care Nurses Association Conference in June 2022
    - Grief and bereavement in 2022 - Challenges and Opportunities
    - The experience of a palliative care death during the COVID-19 pandemic
- Preliminary data presented at The Australian and New Zealand Society of Palliative Medicine Conference in September 2022 – The experience of the COVID-19 pandemic and the effects on families and bereavement
- Palliative care and bereavement experiences during the COVID-19 pandemic presented in September 2022 to PalSpectives
- Invited presentation at the Carers NSW conference in October 2022 – The experience of carers at the end-of-life during the COVID-19 pandemic
- Presentation at the Australian Association for Cognitive and Behaviour Therapy conference – Suicide bereavement during the COVID-19 pandemic
- Four presentations at the Palliative Care NSW Conference in November 2022.

- "We needed a set of eyes and we weren't being given that information." – Experiences of communication of family members bereaved during the COVID-19 pandemic in palliative care
- Bereavement during COVID-19: A qualitative study to explore supports and coping strategies used by grieving Australians during the pandemic
- How bereaved Australians navigated risk during the COVID-19 pandemic.
- The mental health of bereaved Australians during the COVID-19 pandemic

Dissemination

- A dissemination plan was developed. A distribution list was formulated and circulated to investigators to expand.
- A summary of findings was included in the December Newsletter for the study
- A designer was engaged for the report
- The Study Report will be circulated to key stakeholders, policy makers, consumer organisations, support services, the media.
- It will be sent to the Australian Palliative Care COVID-19 Working Group (APCCWG) \
- It has capacity to inform the deliberations of the Australian Health Protection Principal Committee in this area. CI Agar the Chair of the APCCWG will present the study findings to aid impact into practice and future pandemic planning to the network of clinical leads across States and Territories.
- The Report will be circulated to relevant agencies to directly inform implementation of key elements of the Fifth National Mental Health and Suicide Prevention Plan, the National Palliative Care Strategy 2018 and the Aged Care Quality Standards 2019.
- Manuscripts have been prepared and submitted for peer review
- Presentations to relevant audiences are ongoing (conferences, consumer organisations etc)

Partners

Calvary

Australian Funeral Directors Association

australian centre for grief and bereavement

Carers NSW Australia

Flinders University

phn South Western Sydney – An Australian Government Initiative

NSW Government Multicultural Health Communication Service

Maridulu Budyari Gumal – Working together for good health and wellbeing

Meaningful Ageing

phn Central and Eastern Sydney – An Australian Government Initiative

The Groundswell Project

End of report.