Vol. 00 No. 00 xxx 2023 Journal of Pain and Symptom Management 1

*Original Article*

# The COVID-19 Pandemic: Bereavement Experiences Between Hospital and Home Deaths in Palliative Care

Elizabeth Lobb, PhD, MAppSci, BAdult Ed; Post Grad Cert Bereavement Counselling, Fiona Maccallum, PhD,
Jane L. Phillips, BSc, PGDip, PhD, RN, FACN, FPCNA, Meera Agar, MBBS FAChPM FRACP MPC PhD,
Annmarie Hosie, PhD RN, Lauren J. Breen, BSc(Hons), GradCertEd, PhD, FAPS, FCCOMP,
Jennifer Tieman, BSc(Hons) MBA PhD FAIDH, Michelle DiGiacomo, BA, MHSC(Hons), PhD, Tim Luckett, PhD,
Jennifer Philip, MBBS, MMed; Grad Dip Pal Med, PhD, Serra Ivynian, BMedSci (Hons), PhD,
Sungwon Chang, PhD, Ann Dadich, PhD,
Janeane Harlum, RN, MClinP, BAppSci, Dip Business, Dip AppSci, Cert Onc Nurs, Imelda Gilmore,
Irina Kinchin, PhD MSc, Christopher Grossman, MBBS, BMed Sci, FRACGP, FAChPM, and
Nicholas Glasgow, BHB, MBChB, MD(Hon), FRNZCGP, FRACGP, FAChPM

*IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation, Faculty of Health, University of Technology (E.L.), Sydney, New South Wales, Australia; Department of Palliative Care, Calvary Health Care (E.L.), Kogarah, New South Wales, Australia; School of Psychology (F.M.), University of Queensland, Queensland, Australia; School of Nursing, Faculty of Health (J.L.P.), Queensland University of Technology, Kelvin Grove, Queensland, Australia; Research Institute for Innovative Solutions for Wellbeing and Health (M.A.), IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation, Faculty of Health, University of Technology Sydney, Ultimo, New South Wales, Australia; School of Nursing, Midwifery, Health Sciences & Physiotherapy (A.H.), The University of Notre Dame Australia & St Vincent's Health Network Sydney, Darlinghurst, New South Wales, Australia; Curtin School of Population Health (L.J.B.), enAble Institute, Curtin University, Perth, Western Australia, Australia; Research Centre for Palliative Care (J.T.), Death and Dying (RePaDD), College of Nursing and Health Science I RePaDD, Bedford Park, South Australia, Australia; IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation, Faculty of Health, University of Technology Sydney (T.L., S.I., S.C., I.G.), Ultimo, New South Wales, Australia; Department of Medicine, St Vincent's Hospital (J.P.), University of Melbourne, Parkville, Victoria, Australia; Western Sydney University, School of Business (A.D.), Parramatta, New South Wales, Australia; District Palliative Care Manager & Service Development (J.H.), District Palliative Care Service, Liverpool Hospital, New South Wales, Australia; Centre for Health Policy and Management, Discipline of Public Health & Primary Care, School of Medicine (I.K.), Trinity College Dublin, the University of Dublin, Dublin, Ireland; Calvary Health Care Bethlehem (C.G.), Parkdale, Victoria, Australia; Australian National University College of Health and Medicine (N.G.), Canberra ACT, Australia*

## Abstract

**Background.** Australian COVID-19 public health measures reduced opportunities for people to communicate with healthcare professionals and be present at the death of family members/friends.

**Aim.** To understand if pandemic-specific challenges and public health measures during the COVID-19 pandemic impacted end-of-life and bereavement experiences differently if the death, supported by palliative care, occurred in a hospital or at home.

**Design.** A cross-sectional online survey was completed by bereaved adults during 2020–2022. Analyses compared home and in-patient palliative care deaths and bereavement outcomes. Additional analyses compared health communication outcomes for those identified as persons responsible or next of kin.

**Setting/participants.** Of 744 bereaved people; 69% (n = 514) had a death in hospital and 31% (n = 220) at home.

**Results.** The COVID-19 public health measures influenced people's decision to die at home. Compared to hospital deaths, the home death group had higher levels of grief severity and grief-related functional impairment. Only 37% of bereaved people received information about bereavement and support services. 38% of participants who were at least 12 months postdeath

---

*Address correspondence to*: Liz Lobb, PhD, MAppSci, B Adult Ed, IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation, Faculty of Health, University of Technology, 235 Jones St, Ultimo 2007, New South Wales, Australia. Tel.: +61 (02) 0402 816791. E-mail: Elizabeth.Lobb@uts.edu.au

*Accepted for publication: 24 October 2023.*

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2023.10.025

scored at a level suggestive of possible prolonged grief disorder. Levels of depression and anxiety between the two groups were not significantly different.

**Conclusions.** These findings highlight the need for health services to recognize bereavement as fundamental to palliative and health care and provide pre- and post death grief and bereavement care to ensure supports are available particularly for those managing end-of-life at home, and that such supports are in place prior to as well as at the time of the death. J Pain Symptom Manage 2023;000:1−10.

***Key Words***

*COVID-19, bereavement, palliative care, hospital, community, cross-sectional study*

## *Key Message*

Bereaved people who experienced a home death during the COVID-19 pandemic had higher levels of grief severity and grief functional impairment compared to hospital deaths. Health services need to ensure that supports are available to support end of life at home prior to as well as at the time of death.

## *Introduction*

Australia has well-developed palliative care services across inpatient, outpatient, and community settings. The introduction of COVID-19 public health measures in March 2020, necessary to prevent the spread of the virus and protect the healthcare workforce, challenged the capacity of many services to uphold the principles and philosophies of palliative care.[1] Clinicians were furloughed, and physical contact with family, friends and external service providers was restricted, and in some cases, prohibited.[2] Measures were regularly amended in response to events, often at short notice, which required constant attention and adaptation. At times, many palliative care inpatient services permitted just one or two nominated visitors in the last days of life. Research early in the pandemic suggested that, as a result, family members had less overall interaction with hospital-based clinicians and were at times hesitant to access healthcare for fear of COVID-19 transmission.[3] Early reports also suggested that many families opting for a home death during the pandemic were unprepared for the experience and lacked access to other professional and community supports, including carer support, likely exacerbating distress and with potentially significant negative consequences for post bereavement adaptation.[3−8] A prepandemic Australian study found that people are unprepared for a home death and models of care based on assumptions that a home death is straightforwardly beneficial may cause unintended consequences.[9]

The National Australian COVID-19 Bereavement Project ("the Project") was funded in 2020 to investigate the mental health outcomes and support needs of people bereaved from any cause during the pandemic. Prior to December 2021, Australia had one of the lowest infection rates and death rates due to COVID-19 in the world.[10] At the same time, however, over 300,000 Australians died from any cause,[11] while parts of the country experienced the most days in "lockdown" anywhere in the world,[12,13] Further, in Australia, the COVID-19 pandemic followed a prolonged drought and extensive bushfires, then flooding of major cities and towns potentially further impacting mental health. Maccallum et al.[14] reporting on participants in this National Australian COVID-19 Bereavement Project ($n = 1911$) found nearly half of participants had moderate or above levels of depression and a third had moderate or above levels of anxiety. Over 68% of participants reported their mental health had worsened since the death.[14]

In this paper, we focus on the experience of those in palliative care in the context of COVID-19 public health measures. We draw on data from the Project to examine the experiences of bereaved individuals whose close person had died either at home or in hospital while receiving palliative care during the COVID-19 pandemic. Most people with life-limiting illnesses report they prefer to die at home[15] and this choice is enshrined in Australian National Palliative Care policy and standards.[1] However, deaths may also occur in hospital, as the result of symptom factors, caring needs and resources, and patient wishes. Advance care planning discussions, which can result in an advance care plan or advance care directive are encouraged by clinicians to document patient preferences for future treatment and care.

Little is known about how the challenges faced by palliative care services in the context of COVID-19 in Australia may have impacted family's experiences of caring for the dying person, meeting their own needs, and preparing emotionally and practically for home or hospital deaths. Such information has important implications for establishing the support needs and future pandemic preparedness. Given previous data has shown that people may be unprepared for a home death,[3−9] we compared the experiences of Australians bereaved during the COVID-19 pandemic whose close person had received palliative care and died either at home or in hospital. Home care was defined as community palliative care in the home. Hospital care was defined as palliative care delivered in an in-patient specialist palliative care service/hospice or in an acute hospital by a consultative palliative care service. We aimed to understand the associations between pandemic-specific challenges including public health measures, end-of-life and bereavement experiences across these settings. We expected that those who had a close person die in hospital would more likely endorse end of life care being impacted by public health measures; that those who had a home death would more likely experience subsequent mental health impacts; and that both groups would have less information about grief and bereavement because of less contact with health professionals. We were also interested in examining whether there were differences between settings in terms of communication with healthcare professionals and appraisals of care provided for those family members and friends who could be expected to be involved in health care decisions (known as "responsible persons"). We expected those who had a hospital death, with visiting restrictions, would report less communication with health professionals because of these visitor restrictions.

## Methods

### Design

A cross-sectional survey study nested within the National COVID-19 Bereavement Project.

### Participants

A total of 2224 bereaved adults commenced the survey; 1559 participants were recruited via social media. General eligibility included Australian adults aged 18 years+, who self-identified as a carer, family member, or close friend of a person who died between January 2020 and February 2022, were bereaved at least two months prior to participation, and had adequate English skills to complete the survey. Additional criteria for this study were: the close person had received specialist/hospice inpatient palliative care; palliative care delivered in an acute hospital by a consultative palliative care service; or community palliative care at home. An advertisement for the study was prepared and approved by the Ethics Committee. The study was advertised via social media (Facebook and Instagram across four campaigns) and by national community and consumer organizations and bereavement services which distributed the survey invitation through their networks, including Twitter, newsletters, websites, and online fora. No incentives to participate were offered.

### Questionnaire

The questionnaire was designed and piloted by the 20-member study team of clinicians, academics, and consumers with experience in palliative care, bereavement, and public health. There were five sections. The total number of questions varied depending on participant's responses (see supplementary file). Section one included demographics about the decedent and questions about COVID-19 public health measure impacts e.g. hospital visitor limits, border closures, physical distancing, funeral restrictions before, during, and after the death. The public health measures were adapted from previous UK studies[16] and from public health restrictions that were gazette by the Australian Government during the pandemic and listed in Table 2. Like overseas restrictions, funerals in Australia during lockdown in the pandemic were restricted to only 10 persons being present, physical distancing and mask wearing. Gatherings for wakes or memorials were not permitted and many services were held on-line. Section two focused on end-of-life experiences, including perceptions of healthcare interactions, appraisals of care, and emotional and practical preparedness for the death. Those who self-reported a home death were asked "Did COVID-19 restrictions impact the decision to die at home" with options of Yes, No, Don't know or Not applicable. Analyses involving the close person's healthcare decisions and appraisals were restricted to participants who indicated they had been the person responsible for communicating with healthcare professionals. Sections three and four asked about supports accessed after the death and mental health and wellbeing, including validated screening tools. Section five indexed participant characteristics.

### Self-Report Screening Tools

The Prolonged Grief Scale-Revised[17] is a validated measure of prolonged grief symptoms (e.g., yearning, disbelief, emotional pain and numbness, meaninglessness, loneliness). Participants responded to 10 items on a 5-point scale (1 = not at all, 5 = overwhelmingly). Summed scores indicate grief severity (possible range 10−50). At 12 months postbereavement, scores of 30 or greater are suggestive of probable prolonged grief disorder.[14] In their validation study, Prigerson et al.[17] suggested that scores of 30 or greater, where at least 12 months had passed since the death, suggested probable PGD; where fewer than 12 months had passed, scores should not be interpreted as PGD, but suggest grief severity.[17] For this reason, we use the term "grief" when referring to the total sample, and "prolonged grief" when referring to the subsample of participants who were 12 or more months bereaved (Cronbach's $\alpha = 0.93$ for this study).

The Patient Health Questionnaire 9[18] is a 9-item measure of depressive symptoms experienced in the last two weeks. Participants responded on a 4-point scale (0 = not at all, 3 = nearly every day). Summed scores above nine suggest at least moderate levels of depression (possible range 0−27)[18] (Cronbach's $\alpha = 0.91$ for this study).

The Generalized Anxiety Disorder 7[19] is a 7-item scale of general anxiety severity experienced in the last two weeks. Participants responded on a four-point scale (0 = not at all, 3 = nearly every day). Summed scores above nine suggest at least moderate levels of anxiety (possible range 0−21)[19] (Cronbach's $\alpha = 0.93$ for this study).

The Work and Social Adjustment Scale[20] indexed grief-related impairment in work, household management, social leisure, private leisure, and relationships. Participants responded on a 9-point scale (0 = no at all impairment, 8 = very severely impaired). Responses are summed to provide a total score - 0 to 40[20] (Cronbach's $\alpha = 0.91$ in this study). A WSAS score above 20 is suggestive of clinical levels of impairment.

### Data Analysis Plan

Data were analyzed using IBM SPSS V26[21] Participants were grouped according to location of death (home or hospital). Chi-square tests, Fisher's exact tests, independent *t*-tests, were conducted as appropriate. Bonferroni adjustments were applied to accommodate multiple comparisons. Two multiple logistic regression analyses were conducted: The first identified which public health measure impacts were independently correlated with death at home compared to death in hospital. The second identified how communication with healthcare providers and care appraisals differed for home deaths compared to hospital deaths for the responsible persons. Univariate logistic regression was first used to identify potential sociodemographic and death characteristics for inclusion as covariates in the models. Those associated with $P < 0.1$ or identified as clinically important in prior studies were candidates for covariates for the multiple logistic regression models. Goodness-of-fit was assessed using the Hosmer-Lemeshow test.

### Ethical Considerations

The survey was administered online via Research Electronic Data Capture (REDCap), hosted by the University of Technology, Sydney, potential participants were directed to an information webpage detailing the study purpose, its voluntary and anonymous nature, length, proposed data use, potential participation risks, relevant grief supports, and contact details for the research team. Users who selected, "I have read the information above and agree to take part in this survey," continued to the survey. The checklist for reporting results of internet e-surveys was followed.[22] The study protocol was approved by the University of Technology, Sydney Human Research Ethics Committee (ETH20-5447).

## Results

### Participant and Death Characteristics

Of those who completed the study, 744 (mean age = 56.1, SD = 11.5) indicated their close person had received palliative care services. Most were women (93.7%), born in Australia (80.3%), partnered (55.6%), educated beyond year 12 (85.1%), employed (60.3%), and lived in a major Australian city (56.9%). About one third lived alone (31.7%). The most common death was of a partner (42.3%), followed by parent (22%). The most common cause of death was cancer (65.3%), followed by chronic health conditions (17.1%). More died in hospital (69.3%) than at home (30.9%). Mean age of the decedent was 70.7 years (SD = 16.7) and, 46.7% of participants were the nominated "responsible person." In terms of end-of-life preparation, almost 28.0% of decedents were reported to have an Advance Care Plan, 19.6% an Advance Care Directive (see Table 1). Thirty six percent (36.1%) indicated the COVID-19 measures influenced the decision for a home death. There were no differences between the home and hospital death groups in terms of mean age, gender, relationship status, education, employment status, relationship with the deceased, mean time since death and the likelihood of being the "responsible person." The home deaths were more likely to be from cancer ($P < 0.001$), and participants in this group indicated a higher mean level of practical, but not emotional, preparedness ($P < 0.001$) (Bonferroni adjusted alpha = 0.002).

### Experience of COVID-19 Public Health Measures on End-of-life and Bereavement Experiences

Table 2 shows the frequencies with which participants experienced impacts related to public health measures. The home death group was less likely than the hospital death group to have: been unaware of what was happening to the deceased ($P = 0.003$); reduced contact due to restrictions in last day of life ($P < 0.001$); unable to spend time with them and the family as a whole ($P = 0.002$), say goodbye as they would have liked ($P = 0.002$), or be present at the time of death ($P < 0.001$) (Bonferroni adjusted alpha = 0.004).

Table 3 shows results for the first multiple logistic regression determining COVID-19 public health measures that independently correlated with home or hospital deaths (adjusting for significant demographic and death characteristics). Model fit was acceptable (Hosmer-Lemeshow's test, $P = 0.37$). The home death group was more likely than the hospital death group to be present at the time of death and have had contact

*Table 1*

**Participant and Decedent Demographics by Hospital Death versus Home Death ($n$ = 744)**

| Participant Characteristics | Total | Hospital Death<br>$n$ (%) | Home Death | *P*-Value |
|---|---|---|---|---|
| | 744 (100) | 514 (69.1) | 230 (30.9) | |
| Age (years); M(SD) | 56.1 (11.5) | 56.4 (11.3) | 55.6 (11.9) | 0.42 |
| Women | 610 (93.7) | 420 (92.9) | 190 (95.5) | 0.37 |
| Relationship status | | | | 0.13 |
| Single | 92 (14.2) | 61 (13.5) | 31 (15.7) | |
| Married/partnered | 350 (54) | 249 (55.2) | 101 (51.3) | |
| Separated/divorced | 51 (7.9) | 41 (9.1) | 10 (5.1) | |
| Other relationship | 155 (23.9) | 100 (22.2) | 55 (27.9) | |
| Living in major Australian city | 422 (56.7) | 301 (58.6) | 121 (52.6) | 0.13 |
| Living in single person dwelling | 207 (31.7) | 145 (31.9) | 62 (31.3) | 0.89 |
| Australia born | 484 (80.3) | 343 (81.5) | 141 (77.5) | 0.03 |
| Education | | | | 0.02 |
| Year 12 or below | 97 (14.9) | 79 (17.4) | 18 (9) | |
| Undergraduate degree | 188 (28.8) | 126 (27.8) | 62 (31.2) | |
| Postgraduate degree | 368 (56.4) | 249 (54.8) | 119 (59.8) | |
| Employment status | | | | 0.27 |
| Employed | 394 (60.3) | 270 (59.5) | 124 (62.3) | |
| Looking for work | 16 (2.5) | 14 (3.1) | 2 (1) | |
| Not in work force | 243 (37.2) | 170 (37.4) | 73 (36.7) | |
| Relationship of the bereaved person | | | | 0.80 |
| Partner | 315 (42.3) | 224 (43.6) | 91 (39.6) | |
| Parent | 175 (23.5) | 118 (23) | 57 (24.8) | |
| Sibling | 80 (10.8) | 56 (10.9) | 24 (10.4) | |
| Child | 24 (3.2) | 14 (2.7) | 10 (4.3) | |
| Other family | 94 (12.6) | 63 (12.3) | 31 (13.5) | |
| Friend/not a family member | 56 (7.5) | 39 (7.6) | 17 (7.4) | |
| Age (years); M(SD) | 70.7 (16.4) | 71.6 (15.4) | 68.8 (18.5) | 0.05 |
| Time since death (months); M(SD) | 10.0 (6.0) | 9.8 (6.0) | 10.4 (6.0) | 0.17 |
| Cause of death | | | | <0.001[a] |
| Cancer | 486 (65.3) | 309 (60.1) | 177 (77) | |
| Chronic health condition | 127 (17.1) | 91 (17.7) | 36 (15.7) | |
| Other illness | 131 (17.6) | 144 (28.0) | 17 (8.7) | |
| Sudden health event or illness | 88 (11.8) | 78 (15.2) | 10 (4.3) | |
| COVID-19 related | 11 (1.5) | 11 (2.1) | 0 (0) | |
| Accident/Injury/Suicide | 13 (1.7) | 10 (1.9) | 3 (1.3) | |
| Other | 19 (2.6) | 15 (2.9) | 4 (1.7) | |
| Responsible person (Next of Kin) | 347 (46.6) | 239 (46.5) | 108 (47) | 0.91 |
| End-of-life plans in place | | | | |
| Advance care plan | 208 (28) | 127 (24.7) | 81 (35.2) | 0.003 |
| Advance health directive (a “living will”) | 146 (19.6) | 94 (18.3) | 52 (22.6) | 0.17 |
| Funeral arrangements | 226 (30.4) | 148 (28.8) | 78 (33.9) | 0.16 |
| A will | 519 (69.8) | 351 (68.3) | 168 (73) | 0.19 |
| Enduring power of guardianship | 149 (20) | 99 (19.3) | 50 (21.7) | 0.43 |
| Others (e.g., donated body to science; scattered ashes at sea) | 36 (4.8) | 25 (4.9) | 11 (4.8) | 0.96 |
| Subjective preparedness for death | | | | |
| Practical; M (SD) | 4.1 (1.9) | 3.9 (1.9) | 4.5 (1.9) | <0.001[a] |
| Emotional; M (SD) | 3.2 (1.8) | 3.1 (1.8) | 3.2 (1.9) | 0.45 |

Subjective preparedness was rated on a Likert-type scale where 1 = not at all and 7 = prepared.

[a] Bonferroni adjusted $P = 0.002$.

with the decedent in their last days of life. They were also more likely to have experienced restricted funeral arrangements.

### *Interactions with Healthcare Professionals at the End-of-Life*

Health communication during end-of-life care included conversations and written information provided by healthcare professionals while the decedent was under their care. Most responsible persons indicated that the deceased person was well-supported at end-of life (82.1%), that healthcare professionals had always or usually involved them in care decisions (79.5%), and that they had been informed of the approaching death (77.8%). Most also reported that they themselves had been well supported (70.4%), although 30% indicated this was not the case. There were no differences between the home and hospital death groups on these variables (see Table 4). However, only 29.3% of participants reported being asked specifically by clinicians about any psychological distress they may be experiencing prior to the death, and this was more likely for the home death group than the hospital group ($P = 0.02$).

About one quarter of responsible persons (25.1%) reported being offered grief support information

*Table 2*
**Impact of COVID-19 Measures on Death and Bereavement Experiences—Group Comparisons**

| Participant Characteristics | Total | Hospital Death | Home Death | [a]*P*-Value<br>[b]Sig |
|---|---|---|---|---|
| | | *n* (%) | | |
| | 744 (100) | 514 (69.1) | 230 (30.9) | |
| Impacted ability to care | 349 (46.9) | 244 (47.5) | 105 (45.7) | 0.69 |
| Unaware of what was happening | 83 (11.2) | 69 (13.4) | 14 (6.1) | 0.003[b] |
| Unable to say goodbye as would have liked | 288 (38.7) | 222 (43.2) | 66 (28.7) | <0.001[b] |
| Unable to be present at time of death | 227 (30.5) | 182 (35.4) | 45 (19.6) | <0.001[b] |
| Reduced contact due to restrictions in last days of life | 297 (39.9) | 232 (45.1) | 65 (28.3) | <0.001[b] |
| Unable to visit at all due to restrictions | 167 (22.4) | 124 (24.1) | 43 (18.7) | 0.11 |
| Unable to visit as they tested positive/waiting for COVID-19 result | 15 (2) | 11 (2.1) | 4 (1.7) | 1.00 |
| Unable to spend time with them and family as a whole | 370 (49.7) | 273 (53.1) | 97 (42.2) | 0.007 |
| Restriction on funeral arrangement and numbers | 499 (67.1) | 334 (65) | 165 (71.7) | 0.08 |
| Restrictions on travel to location due to border closures | 161 (21.6) | 120 (23.3) | 41 (17.8) | 0.10 |
| Travel restrictions on my family to travel | 359 (48.3) | 239 (46.5) | 120 (52.2) | 0.15 |
| Contact with close relatives/friends was limited | 386 (51.9) | 254 (49.4) | 132 (57.4) | 0.05 |
| Experienced social isolation and loneliness | 367 (49.3) | 250 (48.6) | 117 (50.9) | 0.58 |

[a] Fisher's exact test.
[b] Bonferroni adjusted *P* = 0.004.

before the death, and 38.6% reported being offered grief support information after the death. Almost 40% (38.9%) of participants were not offered any grief support information, before or after the death. The home death group was more likely to be offered grief support information before the death (*P* = 0.002), or at any time than the hospital group (*P* = 0.02). (Bonferroni adjusted alpha <0.009)

After adjusting for cause of death and two public health measures—reduced contact due to restrictions in the last days of life and limited contact with close relatives/friends—we observed a greater likelihood of being offered information about grief support services and literature before death, which was associated with a higher likelihood of experiencing a home death (Adjusted Odds Ratio [AOR]: 1.89, 95% Confidence Interval [CI]: 1.10, 3.24).

### *Mental Health Distress and Impairment*

Table 5 presents grief severity, depression, anxiety and grief impairment for home and hospital deaths. Mean grief severity scores are presented for the full sample and rates of probable prolonged grief are reported for participants at least 12 months bereaved. A two setting: (Hospital vs Home) × 2 (time: <12 months; >12 months bereaved) analysis of variance on grief severity scores revealed a significant main effect for setting (*F*(1684) = 4.55, *P* = 0.033) and marginal effect for time (*F*(1684) = 3.70, *P* = 0.055) only. Overall, those in the home death group had reported had a higher mean level of grief severity than those in the hospital death group. Those less than 12 months bereaved (M = 28.57, SD =10.12) had a marginally higher level of grief severity than those bereaved 12 months or more (M = 27.19, SD = 9.86). Overall, 37.6% of participants who were at least 12 months postdeath scored at a level suggestive of possible prolonged grief disorder. The difference between home and hospital deaths were not significant (41.9 % compared to 35.0%, *P* = 0.169). Mean levels of depression and anxiety did not differ between the home and hospital death groups. Mean total scores on the Work & Social Adjustment Scale indicated that the home death group had significantly higher grief functional impairment across the domains of work, household management, social leisure, private leisure, and relationships (*P* = 0.02) than the hospital death group.

*Table 3*
**Independent Correlates of Those Who Experienced Home Death Receiving Palliative Care**

| Public Health Measures | Adjusted Odds Ratio (95% CI) |
|---|---|
| Experience of COVID-19 public health measures | |
| Unable to be present at time of death | 0.58 (0.37, 0.92) |
| Reduced contact due to restrictions in last days of life | 0.48 (0.32, 0.72) |
| Restriction on funeral arrangement and numbers | 1.74 (1.16, 2.63) |

CI = confidence interval; adjusted for education, Australia born, cause of death and advanced care plan was in place.

## *Discussion*

Our results indicate that pandemic-specific challenges and public health measures during the COVID-19 pandemic were setting specific and affected end of life and bereavement experiences differently if the death, supported by palliative care, occurred at home compared to a death in hospital setting. Our findings support previous data that pandemic-related measures changed the way that people died and grieved.[23–27] Similar to the findings from UK studies,[4] the home death group was less likely than the hospital death

*Table 4*
**Communication with Healthcare Professionals at the End-of-Life for Responsible Persons (n = 347)**

| | Total | Hospital Death *n* (%) | Home Death | *P*-Value [a]Sig |
|---|---|---|---|---|
| | 347 (100) | 241 (69.5) | 106 30.5) | |
| Involved in healthcare decisions | 276 (79.5) | 185 (76.8) | 91 (85.8) | 0.06 |
| Informed about approaching death | 270 (77.8) | 186 (77.2) | 84 (79.2) | 0.78 |
| Bereaved respondent indicated their relative/friend was well supported at end-of-life | 276 (82.1) | 193 (82.8) | 83 (80.6) | 0.64 |
| Bereaved respondent indicated they were felt supported by professionals at end-of-life | 231 (70.4) | 154 (68.1) | 77 (75.5) | 0.19 |
| Staff involved in care of relative/friend asked if participant experienced any significant stress, emotional or psychological problems before the death | 96 (29.3) | 57 (25.2) | 39 (38.2) | 0.02 |
| Grief support information before death | 85 (24.5) | 47 (19.5) | 38 (35.8) | 0.002[a] |
| Grief support information after death | 134 (38.6) | 94 (39) | 40 (37.7) | 0.91 |
| Not offered grief support information | 135 (38.9) | 104 (43.2) | 31 (29.2) | 0.02 |

[a] Bonferroni adjusted alpha *P* = 0.009.

group to have: been unaware of what was happening to the deceased; have reduced contact due to restrictions in last day of life; be unable to spend time with them and the family as a whole; been more likely to say goodbye as they would have liked or be present at the time of death. Meeting the needs of family members or friends of a person who is dying is thought to facilitate better psychological adjustment before and after the death.[6,7,16] Despite the challenges to care posed by the pandemic, and contrary to our expectations, it was encouraging to find that most responsible persons felt involved in health care decisions involving their close person and that this person had been well supported at end-of-life. This differs from the UK findings[4] however, with fewer COVID-19 deaths, it is likely that Australia's public health system, while stretched, did not have the same pressures as seen in many other countries with high infection and death rates.[10] While one might expect that fewer pressures from COVID-19 related deaths would have allowed more space for communication, our results suggest that communication was in fact reduced during this time with participants reporting not being asked specifically by clinicians about any psychological distress they may be experiencing prior to the death. However, some differences in communication and care appraisals for home and hospital deaths were observed. Participants in the home death group were more likely to indicate their close person had an advance care plan (albeit only 28% with an advance care plan and 20% with an advance care directive) and reported higher levels of practical preparedness than those in the hospital group. It may be that for others, informal planning discussions took place, but were not documented formally. However, with many family members being unable to be as present at the hospital bedside, these discussions may not have occurred or were not communicated.

Despite being somewhat less impacted by the public health measures such as physical distancing and visitor restrictions, the home death group had worse bereavement outcomes than the hospital death group. Those who reported a hospital or home death experienced reduced services during the pandemic, however, responsible persons in the home death groups

*Table 5*
**Mean Levels of Grief, Depression, and Anxiety Symptoms, and Grief-Related Impairment**

| | Overall Sample | Hospital Death Mean (SD) | Home Death | *P*-Value |
|---|---|---|---|---|
| | N = 744 | N = 514 | N = 230 | |
| Depression (PHQ-9) | | | | |
| Mean (SD) | 10.0 (6.9) | 9.7 (7.0) | 10.8 (6.9) | 0.07[b] |
| Moderate depression (10 or more) | 405 (61.6) | 273 (59.5) | 132 (66.3) | 0.10[c] |
| Anxiety (GAD-7) | | | | |
| Mean (SD) | 7.4 (5.9) | 7.3 (5.8) | 7.7 (5.9) | 0.39[b] |
| Moderate depression (10 or more) | 309 (47.0) | 213 (46.6) | 96 (48.0) | 0.80[c] |
| Grief related Impairment (WSAS)—Mean total score | 13.2 (10.7) | 12.5 (10.5) | 14.6 (11.0) | 0.02[b] |
| Grief Severity (PG-13-R)[a] | | | | |
| Mean (SD) | 27.98 (10.03) | 27.48 (10.07) | 29.14 (9.88) | 0.033 |
| 12 or more months bereaved n = | 317 | 205 | 112 | 0.17[c] |
| Probable PGD[a] (%) | 120 (37.6) | 73 (35%) | 47 (41.9) | |

Note: sample sizes vary in this table as completion rates of mental health measures varied.
[a] Frequency includes only participants 12 or more months bereaved.
[b] Independent sample t-test.
[c] Fisher Exact Test.

reported feeling less supported by health professionals at the decedent's end-of-life, and being less likely to be asked specifically by clinicians about any psychological distress they may be experiencing prior to the death. This supports our earlier finding the people may be less prepared for a home death.[9]

### *Communication With Health Professionals at End-of-Life*

Across home and hospital deaths, participants perceived the level of information provision to be low, at around 39% but those who had a home death had a greater likelihood of being offered information about grief support prior to the death. Provision of information on grief and bereavement is a key component of the Australian National Palliative Care Standards[1] and compares to a prepandemic study where 63% of bereaved carers reported being offered information about grief and bereavement prior to the death.[28] If information was less forthcoming because opportunities for face-to-face discussion were limited, then one recommendation for a future pandemic is to put in place alternative processes for communication such as routine email or telephone correspondence, as was reported to work well by a small number of palliative care services in a recent Australian survey.[29]

### *Distress*

Both groups experienced high levels of grief but, contrary to expectations, those in the home death group had higher levels of grief severity and grief functional impairment than those in the hospital death group. 37.6% of all participants who were at least 12 months postdeath scored at a level suggestive of possible prolonged grief disorder. Prepandemic population-based and cohort studies in Australia and Europe that showed that 6%−8% of bereaved people met criteria for probable prolonged grief disorder at six months postbereavement.[28] The data are therefore indicative of a potential "shadow pandemic"[30] of prolonged grief that current services and policies are not equipped to manage and that the provision of grief information alone will not be adequate support strategy.[31] In the context of mass deaths and disruptions resulting from COVID-19, much higher rates of chronic distress were predicted, with calls for policymakers to recognize the "shadow pandemic" of grief anticipated in the wake of this global event.[30]

This contrasts with recent studies of other settings showing higher levels of distress in relatives of a close person who died in hospital than at home.[4,23,24] This may reflect differences in the causes of death across studies. In line with the low rates of COVID-19 deaths in Australia during the study window, our sample had relatively few deaths from COVID-19; instead, most deaths were due to cancer or chronic health conditions. Having a close person die at home means carers were aware of what is happening, and our findings suggest they were perhaps not emotionally prepared for the dying process. Although general levels of anxiety and depression did not differ between the home and hospital death groups; nearly half met the cut off score for at least moderate anxiety and depression, and this proportion is 10%−20% higher than that reported in a general sample of Australians during 2020.[25,26] The home death group also experienced more restrictions funerals suggesting home deaths may have occurred at a time when pandemic restrictions were greater on both hospital visiting and funeral services.

Despite greater apparent practical preparedness, the home death group reported greater levels of grief-related functional impairment. It may be that people had external limits such as limiting visitors to the home for fear of contracting COVID-19, thus affecting their ability to give or receive support contributing to greater impairments. It is noted that people who experienced a home death were less likely to be asked specifically by clinicians about any psychological distress they may be experiencing prior to the death. The lack of a psycho-social assessment of carers preparing for a home death, which again is a key component of palliative care,[1] but was hindered by lack of access to psycho-social staff such as social workers during the pandemic, may mean that health professionals were unaware of any pre-existing distress or support needs that could have been addressed or supported prior to the death. These findings highlight the need to ensure supports are available for those managing end-of-life at home and that such supports need to be in place prior to as well as at the time of the death.

### *Limitations*

While our study provides compelling evidence about the experience of palliative care deaths during the COVID-19 pandemic in Australia, we recognize that 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, research is required to understand the experiences of these populations. Further, most recruitment occurred through Facebook; people with limited digital literacy, access to the internet, who are socially disadvantaged, or choose not to have a Facebook profile may be underrepresented in the data although Australia has a high rate of active smartphone and internet use (>91%), and social media use.[32] Convenience samples may also be subject to a volunteer effect,[33] which might have resulted in people with negative experiences being more likely to participate in this study. Findings may therefore not generalize to all carers, family members, and close friends caring for persons at end-of-life. Further, this analysis did not include palliative care delivery in residential aged care because, while important, we could not be sure if participants could correctly identify if palliative care was provided at end-of-life and facilities were subjected to different restrictions. This setting is the focus of a future subgroup analysis of the Project. We did not capture the characteristics of social support prior to death/COVID-19. We are also undertaking longitudinal data collection to determine the extent to which observed relationships are maintained over time.

## Conclusions

During the COVID-19 pandemic in Australia, there were variations over time and between jurisdictions in government policies, hospital practices, and isolation requirements. The challenges of providing end-of-life care to those with palliative diagnoses during a global pandemic resulted in international collaboration to learn from others' experiences and guide responses to ensure optimal palliative care.[34] Our findings contribute to the ongoing body of work and is in line with recommendations from other researchers in the United Kingdom[6,35] that health services should expand their focus from infection control to include a consideration of grief and postbereavement adjustment. We recommend that all hospitals implement bereavement outreach to prepare families for the death of their loved ones and support them afterwards.[3] At a minimum, services need to recognize bereavement as fundamental to palliative and health care, provide pre- and post-death information on grief and bereavement; ensure supports are available for those managing end-of-life at home and that such supports are in place prior to as well as at the time of the death.

## Author Contributions

EAL and FM conceived the study. MA, JP, LB, TL, JP, MD, JT, AH, JH, IG, IK, CG, NG, AD, and CR contributed to the development of the protocol. SC, SI, and FM contributed to statistical analysis. All authors contributed to drafting the paper, revised the paper and approved the final versions.

## Disclosures and Acknowledgments

This research received Medical Research Future Fund (MRFF)—Coronavirus Research Response—2020 COVID-19 Mental Health Research Grant Opportunity (MRF2005576). The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article. All participants provided written informed consent prior to participation. The study protocol was approved by the University of Technology, Sydney Research & Ethics Committee. Ref ETH20-5447.

## Acknowledgments

The authors would like to thank the bereaved participants who completed our survey.

## Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.jpainsymman.2023.10.025.

## References

1. Palliative Care Australia. National Palliative Care Standards. 5th ed. PCA: Canberra; 2018.

2. Runacres F, Steele P, Hudson P, Bills M, et al. "We couldn't have managed without your team": a collaborative palliative care response to the COVID-19 pandemic in residential aged care. Aust J Ageing 2022;41(1):147–152.

3. Morris SE, Moment A, Thomas JD. Caring for bereaved family members during the COVID-19 pandemic: before and after the death of a patient. J Pain Sym Man 2020;60(2):e70–e74.

4. Selman LE, Farnell D, Longo M, et al. Risk factors associated with poorer experiences of end-of-life care and challenges in early bereavement: results of a national online survey of people bereaved during the COVID-19 pandemic. Palliat Med 2022:2692163221074876.

5. Wallace CL, Wladkowski SP, Gibson A, White P. Grief during the COVID-19 panademic: considerations for palliative care providers. 60: e70-e76. doi:10.1016/j.jpainsymman.2020.04.012

6. Hart JL, Turnbull AE, Oppenheim IM, Courtright KR. Family-centered care during the COVID-19 era. Pain Sym Man 2020;60(2):e93–e97.

7. Hanna JR, Rapa E, Dalton LJ, et al. A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. Palliat Med 2021;35(5):843–851.

8. Lee SA, Neimeyer RA, Mancini VO, Breen LJ. Unfinished business and self-blaming emotions among those bereaved by a COVID-19 death. Death Studies 2022: 1–10.

9. Lobb EA, Bindley K, Sanderson C, et al. Navigating the path to care and death at home—it is not always smooth: a qualitative examination of the experiences of bereaved family caregivers in palliative care. J Psych Onc Res and Pract 2019;1(1):e3.

10. World Health Organisation. World Health Organisation coronavirus (COVID-19) dashboard. World Health Organisation; 2019 https://covid19.who.int/.

11. Australian Bureau of Statistics. Provisional mortality statistics: provisional deaths data for measuring changes in patterns of mortality during the COVID-19 pandemic and recovery period. 2021.

12. Siette J, Seaman K, Dodds L, et al. A national survey on COVID-19 second-wave lockdowns on older adults' mental

wellbeing, health-seeking behaviours and social outcomes across Australia. BMC Geriatrics 2021;21(1):400.

13. Tangcharoensathien V, Bassett MT, Meng Q, Mills A. Are overwhelmed health systems an inevitable consequence of COVID-19? Experiences from China, Thailand, and New York state. BMJ 2021;372:n83.

14. Maccallum F, Breen L, Phillips J, et al. The mental health of Australians bereaved during the first two years of the COVID-19 pandemic: a latent class analysis. Psych Med (In Press) 2023.

15. Swerissen H, Duckett S. Dying Well. Grattan Institute; 2014. ISBN: 978-1-925015-61-4.

16. Selman LE, Chamberlain C, Sowden R, et al. Sadness, despair and anger when a patient dies alone from COVID-19: a thematic content analysis of Twitter data from bereaved family members and friends. Palliat Med 2021;35(7):1267–1276.

17. Prigerson HG, Boelen PA, Xu JH, et al. Validation of the new DSM-5-TR criteria for prolonged grief disorder and the PG-13-Revised (PG-13-R) scale. World Psychiatry 2021;20(1):96–106.

18. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001;16(9):606–613.

19. Spitzer RL, Kroenke K, Williams JBW, Low BA. A brief measure for assessing generalized anxiety disorder. Arc Int Med 2006;166:1092–1097.

20. Mundt JC, Marks IM, Shear MK, Greist JH. The work and social adjustment scale: a simple measure of impairment in functioning. Br J Psychiatry 2002;180:461–464.

21. IBM and Corp IBM SPSS. *Statistics for Windows*. [Version 26.0]. IBM SPSS Corp: Armonk, NY; 2019.

22. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Inernet Res 2004;6(3):e132.

23. Schloesser K, Simon ST, Pauli B, et al. “Saying goodbye all alone with no close support was difficult”: dying during the COVID-19 pandemic: an online survey among bereaved relatives about end-of-life care for patients with or without SARS-CoV2 infection. BMC Hlth Serv Res 2021;21(1):998.

24. Yildiz B, Korfage IJ, Witkamp EF, et al. Dying in times of COVID-19: Experiences in different care settings: an online questionnaire study among bereaved relatives (the CO-LIVE study). Palliat Med 2022;36(4):751–761.

25. Fisher J, Tran T, Hammarberg K, et al. Quantifying the mental health burden of the most severe covid-19 restrictions: a natural experiment. J Affect Dis 2021;293:406–414.

26. Fisher JR, TD Tran, Hammarberg K, et al. Mental health of people in Australia in the first month of COVID-19 restrictions: a national survey. Med J Aust 2020;213(10):458–464.

27. Harrop E, Mann M, Semedo L, et al. What elements of a systems’ approach to bereavement are most effective in times of mass bereavement? A narrative systematic review with lessons for COVID-19. Palliat Med 2020;34(9):1165–1181.

28. Aoun SM, Rumbold B, Howting D, Bolleter A, Breen LJ. Bereavement support for family caregivers: the gap between guidelines and practice in palliative care. PloS One 2017;12(10). e0184750-e.

29. Luckett T, Donkor A, Phillips J, et al. Australian specialist palliative care’s response to COVID-19: an anonymous online survey of service providers. Ann Palliat Med 2021;10(3):2747–2757.

30. Tucci A, Doka K. A call to action: facing the shadow pandemic of complicated forms of grief OMEGA. J Death and Dying 2021;83(1):164–169.

31. Aoun SM, Breen LJ, Howting DA, et al. Who needs bereavement support? A population based survey of bereavement risk and support need. PLoS One 2015;10(3):e0121101.

32. Australian Bureau of Statistics. Household use of information technology Available at: www.abs.gov.au/statistics/industry/technology-and-innovation/household-useinformation-technology/latest-release. Reference period 2016-2017. Accessed March 28, 2018.

33. Hunt KJ, Shlomo N, Addington-Hall J. Participant recruitment in sensitive surveys: a comparative trial of ‘opt in’ versus ‘opt out’ approaches. BMC Med Res Method 2013;13(1):3.

34. Chapman M, Russell B, Philip J. Systems of care in crisis: the changing nature of palliative care during COVID-19. J Bioeth Inq 2020;17(4):761–765.

35. Selman LE, Chao D, Sowden R, et al. Bereavement Support on the Frontline of COVID-19: recommendations for Hospital Clinicians. J Pain Symptom Manag 2020;60(2):e81–e86.