

Original Article

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



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Abstract

Background. Australian COVID-19 public health measures reduced opportunities for people to communicate with health-care 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

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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* 2024;67:147–156. © 2023 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

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 pre-pandemic 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 home¹⁵ 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 studies¹⁶ 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-Revised¹⁷ 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 9¹⁸ 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 7¹⁹ 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 Scale²⁰ 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 40²⁰ (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 V26²¹. 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 n (%)	Home Death	PValue
	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.

^aBonferroni 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
	<i>n</i> (%)			^b Sig
	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

^aFisher's exact test.

^bBonferroni 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) $\times$ 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

^aBonferroni 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 findings⁴ 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	Home Death	P-Value
	Mean (SD)	Mean (SD)		
	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.

^aFrequency includes only participants 12 or more months bereaved.

^bIndependent sample t-test.

^cFisher 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 Standards¹ 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 psychosocial 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.

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Supplementary materials

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