

ORIGINAL ARTICLE

COVID-19 pandemic: end-of-life experience in Australian residential aged care facilities

Emma Hack ¹, Barbara Hayes ^{2,3}, Nicholas Radcliffe ¹, Sally Monda ¹ and Paul Yates ^{1,4}

¹Department of Geriatric Medicine, Austin Health, ²Department of Cancer Services, Northern Health, ³Northern Clinical School, University of Melbourne, and ⁴University of Melbourne, Department of Medicine, Austin Health, Melbourne, Victoria, Australia

Key words

residential aged care facility, end-of-life care, palliative care, COVID-19, bereavement support.

Correspondence

Emma Hack, Austin Health, 145 Studley Road, Heidelberg, Vic. 3084, Australia.
Email: emma.hack@austin.org.au

Received 12 July 2021; accepted
10 November 2021.

Abstract

Background: The COVID-19 pandemic has significantly impacted those in residential aged care facilities (RACF). This research was undertaken to explore and better understand the effects of the pandemic on the experience of next-of-kin and carers who encountered the death of a loved one who resided within a RACF during the pandemic.

Aims: To explore end-of-life experiences for residents who die in RACF and their next-of-kin/carers during the COVID-19 pandemic, to identify areas of concern and areas for improvement.

Methods: Prospective single-centre mixed methods research was undertaken involving telephone interview with next-of-kin or carers of residents who died within 30 days of being referred to Austin Health Residential InReach Service during the 'second wave' of COVID-19 in Melbourne, Australia, in 2020. Qualitative and quantitative data were collected. Qualitative description and aspects of grounded theory were used for analysing qualitative data. Thematic analysis of the interview transcripts used open and axial coding to identify initial themes and then to group these under major themes.

Results: Forty-one telephone interviews were analysed. Major themes identified included: COVID-19 pandemic, communication and technology, death and dying experience, bereavement and grief, and social supports and external systems.

Conclusions: Findings identify the many COVID-19 pandemic-related challenges faced by participants and their dying loved one in RACF. Access to palliative care and bereavement support is crucial for dying residents and for grieving that has been made more difficult by the pandemic.

Introduction

COVID-19 and aged care

The COVID-19 pandemic¹ is an ongoing global catastrophe, with the unrelenting death toll described as an 'acute convergence of loss'.² At the time of writing in Australia, 400 residential aged care facilities (RACF) have experienced COVID-19 outbreaks, with most cases in Victoria.^{3,4} Older people have a higher risk of infection and mortality from COVID-19⁵ and of 2398 cases in Victorian RACF, 696 (29%) have died.⁴

Following a surge in COVID-19 cases known as the 'second wave', metropolitan Melbourne was placed into

'lockdown' for 112 days between June and October 2020.⁶ Restrictions implemented included an embargo on visitation, activities and movement within RACF.

Those living in RACF who required medical and end-of-life care (EOLC) were managed by hospital-based Residential InReach (RIR) teams, Community Palliative Care (CPC) services and general practitioners (GP). Hospital admission including for those requiring EOLC was considered depending on the residents and next-of-kin/carers preferences, clinical need and for public health reasons.^{5,7}

EOLC, bereavement and grief

Grief is heightened by unexpected⁸ and traumatic deaths^{9,10} and observing distress at end-of-life.¹¹ Economic,

Funding: None.
Conflict of interest: None.

financial or occupational hardship – each of concern during the COVID-19 era – also augment grief.¹²

Bereavement has a cost to the health economy¹³ and grief has an association with physical^{2,9,14} and mental health disorders. It is unsurprising that the reports of mental distress¹⁵ and depressive symptoms^{16,17} are widely prevalent since the onset of the COVID-19 pandemic and concerns exist for a surge of bereaved people developing prolonged grief disorder.^{10,18}

Following death, a sense of control over rituals is important,¹⁹ while the funeral itself provides social support,²⁰ acceptance and closure²¹ and helps give meaning to bereavement.^{20,22} The loss of usual post-death rituals in the COVID-19 era has negatively impacted mourning and bereavement.²³

There are currently few studies on the experience of relatives and carers bereaved by death of a loved one during the COVID-19 pandemic.^{24,25} While not all those who are bereaved require formal psychological support, the availability of services and risk evaluation helps to assess grief and if further input might be needed.^{8,9,26}

This study was conceived to understand better the impact of the COVID-19 pandemic on the experience of EOLC for RACF residents and their next-of-kin or carers.

Methods

Participants and recruitment

Participants were next-of-kin or carers for residents referred to RIR between 1 June and 31 August 2020, and who died within 30 days of referral. RIR is a Department of Health Victoria programme that offers an alternative to Emergency Department transfer by providing timely specialist medical support (including geriatrics and palliative care) to residents in RACF.²⁷

Purposive sampling was used to recruit a sample of 40 participants, anticipating this would provide a wide range of experiences and achieve saturation of themes. Next-of-kin/carer was identified from RACF records as the primary contact person (PCP) for the resident. PCP was excluded from invitation to interview if there was an inability to establish contact, lack of conversational English or inappropriateness to engage (e.g. little/no RIR involvement).

PCP were contacted consecutively based on the known date of death. Initial telephone contact to introduce the study was made approximately 2 weeks after resident death, and verbal consent was obtained to continue the contact and to send written information and a consent form through email or mail. Telephone interviews took place 6–8 weeks after death using a combination of structured and semi-structured questions

(Supporting Information Appendix S1). Interviews were conducted by EH and with permission all were audio-recorded. Participants were advised that the research did not provide formal psychological support and to seek help through their GP for referral to appropriate services if required. Those identified with potential need for further support were provided with grief and bereavement information and services (Appendix S2).

Analysis

Mixed methods analysis was conducted. Qualitative description²⁸ and aspects of grounded theory²⁹ were used to explore the experiences reported in interviews. Transcription of the interviews was verbatim with the removal of identifying information. Transcripts were then analysed using NVivo 12 software, identifying individual themes (open coding) and subsequently arranging these into related groups (axial coding). EH, BH and PY independently reviewed samples of transcripts to ensure consistency in identified themes and discussed findings to reach a consensus on final themes. Quantitative data including COVID-19 status and aspects of management were sourced from RACF and hospital records and reported using descriptive statistics. Ethics approval was obtained from Austin Health Human Research Ethics Committee (Approval COVID/13).

Results

Quantitative

RIR received 502 referrals between 1 June and 31 August 2020 across 53 RACF, of which 110 residents died within 30 days (Table 1). Recruitment and details of the 41 participants interviewed are illustrated (Fig. 1, Table 2). Interviews ranged between 18 and 54 min (median 37.25 min).

Community COVID-19 case numbers and restrictions during this period illustrate the research context, which includes Victoria's 'second wave' (Fig. 2).

Qualitative

Five major themes were identified: (i) COVID-19 pandemic; (ii) communication and technology; (iii) death and dying; (iv) bereavement and grief; and (v) social supports and external systems. Comparable themes were described for both residents with and without COVID-19.

Table 1 Residential InReach referrals

	All referral episodes	Death within 30 days	Participants interviewed
Referral episodes, <i>n</i>	526		
Excluded lacking essential information (RACF name, documented RIR encounter), <i>n</i>	24		
Total referral episodes included, <i>n</i> (%)	502	110 (22)	41
No. RACF	53	34	19 (3 COVID-19 outbreaks)
Resident age, median (range) (years)	88 (52–103)	88 (52–103)	88 (52–103)
Resident sex, <i>n</i> (%)			
Female	312 (62)	66 (60)	25 (61)
Male	190 (38)	44 (40)	16 (39)
Primary contact person, <i>n</i> (%)			
Relative (family member)	470 (94)	102 (93)	38 (93)
Non-relative (friend, guardian, other)	23 (4)	8 (7)	3 (7)
Not listed/unidentified	9 (2)	0 (0)	0 (0)
RIR resident review, <i>n</i> (%)			
Direct face-to-face	308 (61)	75 (68)	32 (78)
Telephone consultation	194 (39)	35 (32)	9 (22)
COVID-19 positive	149 (30)	36 (33)	17 (41)
Dexamethasone used	10 (7)	5 (50)	3 (30)
Community Palliative Care (CPC) referral, <i>n</i> (%)			
Yes	84 (17)	41 (37)	19 (46)
No	418 (83)	69 (63)	22 (54)
Palliative care medications charted, <i>n</i> (%)			
Yes	181 (36)	78 (71)	31 (76)
No	321 (64)	32 (29)	10 (24)
Use of oxygen, <i>n</i> (%)			
No	453 (90)	87 (79)	34 (83)
Yes – new	36 (7)	20 (18)	7 (17)
Yes – long term	13 (3)	3 (3)	0 (0)
If death within 30 days			
Time from RIR referral to death, median (range) (days)		9 (1–30)	8 (1–30)
Use of continuous subcutaneous infuser device in RACF, <i>n</i> (%)			
Yes		10 (9)	1 (2)
No		100 (91)	40 (98)
Place of death, <i>n</i> (%)			
RACF		80 (73)	34 (83)
Hospital		30 (27)	7 (17)

PCP, primary contact person; RACF, residential aged care facility; RIR, Residential InReach.

COVID-19 pandemic

Emotional response to COVID-19 and outbreaks, lockdowns and restrictions. Participants described a wide range of emotional responses, including shock on learning of RACF COVID-19 outbreaks. Some had hoped their loved one would survive COVID-19 infection, while others expressed denial and despondency:

‘Surely he’s a strong man, he’ll be fine, but obviously he wasn’t’ (participant 31)

‘I thought perhaps they’ve got it wrong’ (participant 39)

‘[I] knew that if she’d catch the COVID she’d be a goner’ (participant 15)

Some participants had hope, while others expressed anger. Participants feared for their loved one and also for themselves from contagion:

‘You get so scared now the minute... you have a runny nose’ (participant 11)

Residents reported distress and isolation from visitation restrictions and ‘lockdowns’ as routine contact with family and friends was lost:

‘He was really getting quite down about being stuck in a room’ (participant 40)

‘For two and a half months I had to speak to her outside the window... it was... terrible, I can’t even talk about it now... just to see the distress on her face... her close friends... couldn’t come because of...’

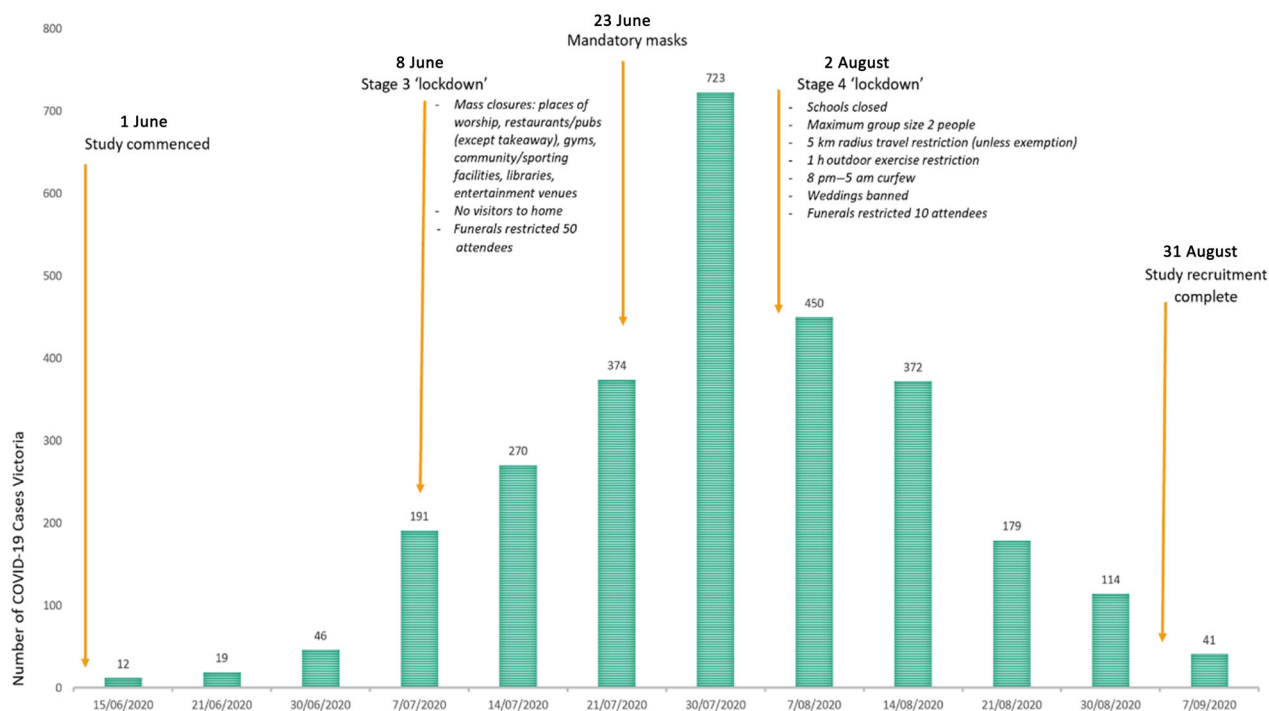


Figure 1 Restrictions in metropolitan Melbourne during the ‘second wave’ in 2020.

COVID, they were in lockdown in Aged Care facilities themselves’ (participant 8)

Many residents had previously relied on visitors for care needs and enforced absences during lockdowns led to perceived compromise in care:

‘Sometimes... [if] dad [was] refusing or not eating I went and helped him... with feeding... unfortunately when the COVID-19 started... they said “no” because of these restrictions... I’m not a visitor but also a helper’ (participant 21)

Perception of RACF response. Many participants expected high-quality care and had trust in the RACF:

‘You wanna be pretty sure where your mum is going to be that she’s gonna be well cared for... the people that work there were just fabulous’ (participant 14)

Others expressed emotions consistent with anger and loss of trust, or described the management of RACF as having financial rather than humanistic and healthcare priorities:

‘You’ve [the RACF] given COVID to my father’ (participant 41)

‘See how business runs, no thoughts... about a human’ (participant 23)

Concern was expressed over loss of regular staff and changes to the operational structure of RACF during outbreaks. Details and plans were often said to be scant and disarray was prevalent:

‘We’d speak to two different people and get two different answers’ (participant 41)

‘Nobody seems to know what they’re doing’ (participant 23)

Communication and technology

Technology and barriers to communication. Communication emerged as a central theme and varied in quality:

‘Sometimes I didn’t hear back for a couple of days and a couple of days in COVID is... you know things can happen in 48 hours’ (participant 39)

Residents with non-English speaking backgrounds were distinctly disadvantaged during ‘lockdown’ as

many relied on visiting family for interpreting. While technology was largely endorsed as essential for contact, the effectiveness was limited by auditory, visual or cognitive impairment. Many struggled with the lack of physical touch or presence, particularly at end of life:

‘She was saying... why are they coming into my room and wearing masks... I don’t understand’ (participant 36)

‘How can you say goodbye over the telephone, that’s not a normal situation’ (participant 29)

Planning ahead. Although the pandemic had been ongoing for several months, anticipatory planning for COVID-19 was uncommon. Decision-making during outbreaks was uncertain or reactive.

While many wished to stay in the RACF, several residents were ultimately transferred to hospital. For RACF affected by COVID-19 outbreaks, urgent conversations regarding goals and place of management were frequently led by RIR:

‘[They] rang me and... explained... about being in hospital and being where she is in the nursing home... we changed our mind... [about] sending her to hospital and to keep her where she knows... familiar faces... and that was her home’ (participant 32)

Dying and death

Anticipation of death. Anticipation of death was associated with emotional pain and longing to be with the loved one. For those afflicted with COVID-19, there was fear of the unknown and trajectory of illness. Many were shocked at the course of COVID-19 from initial diagnosis, to becoming symptomatic, to subsequent rapid decline and death:

‘He didn’t have any outward signs of any great illness... [he said] I’ve felt worse with a common cold’ (participant 25)

‘I wish that I was with her, it hurts knowing she was on her own when she went’ (participant 12)

Alleviation of suffering was described as important and many felt residents were kept more comfortable with medications, such as morphine. Compassionate but limited visitation was sometimes offered at end-of-life in RACF and hospital settings, although the availability of this varied depending on context:

Table 2 Primary contact person interviewed

Total		41
Age		Median 61 years (Range 42–83)
Sex	Female	26 (63%)
	Male	15 (37%)
Relation	Relative	38 (93%)
	Non-relative	3 (7%)
Information and consent sent through	Email	37 (90%)
	Mail	4 (10%)
Resident length of stay at RACF	<1 month	5
	1 month to <12 months	11
	12 months to 3 years	11
	>3–10 years	6
	10 years +	1
	Unknown/incomplete	7
Time from death to initial telephone call (2 weeks)		Median 16 days Range 5–32 days
Time from death to interview (6–8 weeks)		Median 44 days Range 39–57 days
Bereavement/grief document sent	Yes	5
	No	36
Has funeral occurred	Yes	34 (83%)
	No, cremation only	4 (10%)
	No, planned for future date	3 (7%)
If funeral occurred (n = 34)	PCP attendance at funeral	
	Yes attended	33
	No did not attend	1
	Number of attendees at funeral	
	5 or less	2
	6–10	22
	11–30	4
	31–50	6
	Funeral what PCP ‘hoped for’	
	Yes	18 (53%)
No	12 (35%)	
Unsure/unclear	4 (12%)	
Live/video technology used to record/stream funeral	Yes	20 (59%)
	No	14 (41%)

PCP, primary contact person; RACF, residential aged care facilities.

‘I was extremely grateful I was given that opportunity to go and see him for that half hour’ (participant 24)

Guilt, abandonment and acceptance. There were concerns for dignity and a sense that residents deserved better. There were feelings of guilt and abandonment:

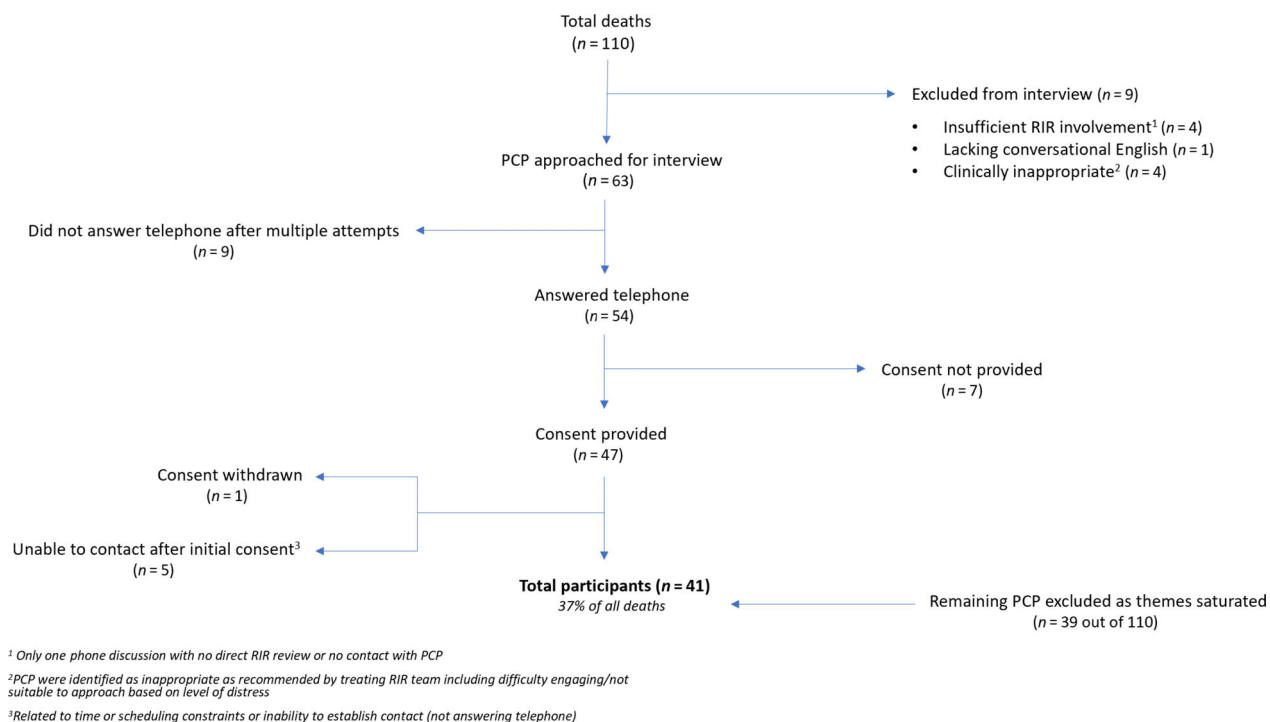


Figure 2 Interviews and exclusion criteria. PCP, primary contact person; RIR, Residential InReach.

‘We put her in that home... so I have a sense of guilt’ (participant 29)

Some had witnessed the effects of significant comorbidities, such as dementia over years. Several participants expressed acceptance and a sense of relief that death and suffering were not prolonged:

‘It’s... a blessing that he’s gone because his quality of life wasn’t really that good’ (participant 34)

Bereavement and grief

Bereavement and loss of carer role. Acknowledging bereavement and expressions of compassion were welcomed. Disappointment ensued when these gestures were absent:

‘There wasn’t a card, there wasn’t a phone call, something to say she was a valued member of [the RACF] ... there was nothing... I found that really distressing and really hurtful’ (participant 36)

Some did not obtain important sentimental belongings post-death, such as photographs or clothing related to fear of contagion.

Particular note was made of the loss of carer role. Some were used to visiting the resident daily and had

continued to be significantly involved in their care. Many reported a sense of loss from usual RACF staff relationships:

‘I benefited from the interaction with the staff...you looked forward to seeing them...it’s a funny sort of feeling, you share such intimate moments with people and then all of a sudden you don’t see them again’ (participant 6)

Many participants felt their grieving had been delayed as a result of restrictions:

‘I feel I haven’t grieved’ (participant 32)

The investigator provided five participants bereavement and grief support information (Appendix S2) as they were particularly distressed or were seeking direction to services. Others had already sought formal psychological support. The act of taking part in the study meant participants were heard, which many found salutary. Some cried during discussions, though these and other participants expressed gratitude at taking part in the project:

‘Thank you for the opportunity to be involved, that in itself is therapeutic’ (participant 36)

RIR and CPC were well-received. Residents who were referred to CPC received follow-up contact after death, but this applied to less than half of participants:

‘They did ring to see how I was going which was nice... I did receive a letter from them as well’ (participant 31)

Those not referred to CPC did not receive any formal follow-up support, with some feeling disregarded. Many did not know how to seek bereavement support.

Post-death rituals, religious and cultural practices. Most funerals were limited to 10 attendees. Most reported these restrictions as distressing. Some participants found the smaller service a positive experience.

Social distancing and masks at the service blunted the ability to perceive and express emotion:

‘Sometimes you just need that physical touch’ (participant 41)

‘You can’t show emotional support... covered up by a mask’ (participant 39)

It was reported some people did not attend funerals due to fear while others delayed the event, planning for a memorial at a time when restrictions were relaxed.

Most funerals for those of Catholic religion were unable to have Offertory or Holy Communion. At least one resident was unable to receive the Last Rites before death. One participant whose family were Afghan immigrants of Muslim religion arranged a funeral 1 day after death to avoid looming attendance restrictions, but in keeping with Islamic tradition for a quick burial post-death. Another participant whose family were Greek Orthodox was unable to have an open casket as was customary:

‘It’s an opportunity to see their face... we didn’t have that... my image of my mother was just being double bagged in two black bags’ (participant 36)

Live streaming of funerals was widely utilised. Most reported this as effective though some reported technical difficulties. Those who declined live streaming felt it was impersonal, that others would struggle to access the technology or that it was too expensive.

Social supports and external systems

Social supports. Expressions of anxiety and disempowerment were common. Some were working from home while assisting their children to undertake remote learning. There were multiple challenges to well-being, including loss of social support networks and community, travel and leisure activities:

‘A lot has been taken out of our hands’ (participant 41)

Technology and Internet access was key to maintaining contact. Regular contact with family and friends appeared to confer more positive coping. Some had lost employment and were reliant on government welfare. Financial hardship and legal difficulties were encountered.

System response, accountability and the future. Some felt let-down by the government and events unfolding with many expressing expectation of a more prepared and effective response:

‘We thought... there would be... lessons learnt from... New South Wales [where the first RACF COVID-19 outbreak occurred in Australia] and we were naïve’ (participant 24)

There were reports of mixed advice from authorities and information could be difficult to obtain:

‘I’ve rung police stations about whether I’m allowed to travel and they don’t even know the answer’ (participant 37)

There were expressions of anger and frustration around a perceived lack of accountability, although there were statements of hope for improvement.

‘It’s really important... we use this horrid opportunity to learn something... to improve things’ (participant 36)

‘Most people who work in Aged Care work there for very good reasons, but they work with limited pay and limited resources... the imperative is not just for my parents’ generation but the generations that follow’ (participant 24)

Discussion

The voices and stories of those interviewed illustrate the multiple effects the pandemic and restrictions had on the relationship with their loved ones leading up to and following their death. To our knowledge, this is the first qualitative study on end-of-life experiences in Australian RACF during the COVID-19 pandemic. Themes identified are similar to existing international qualitative studies on next-of-kin/carer bereavement, although our study is unique in that it is specific to the RACF setting and had a superior sample size.^{24,25}

The importance of technology for communication at end-of-life during the COVID-19 pandemic has been

reported^{30,31} though this was no substitute for physical human presence and contact. Future planning pertaining to COVID-19 had often not occurred, as described previously.³² The mix of positive and negative funeral experiences by those bereaved in the COVID-19 era has also been reported.¹⁹

While grief varied between participants, those more impacted by social isolation and lacking support reported particular distress.³ While the future discourse of this disenfranchised grief is not yet known, longer-term studies are taking place.³³ Routine bereavement follow up was only available to PCP of residents who had been referred to CPC,³⁴ highlighting the importance of access to palliative care in RACF^{35,36} not only for symptom management for residents, but also to provide support to next-of-kin.³⁷ Limitations of this research are that experiences are subjective from a limited number of participants and are not generalisable and there is potential for selection bias.

Humanitarian crises, including the COVID-19 pandemic, affirm the need for integrated palliative care.^{38–41} While grief is a normal response to loss, support should be accessible if needed. The importance of bereavement is recognised by governments worldwide, with supported leave available,² including in Australia⁴² though there is no homogenous model of care providing bereavement support to next-of-kin/carers of those in RACF.

Since the study period concluded, additional supports have become available, including resources from the Australian Centre for Grief and Bereavement, the Australian COVID-19 Palliative Care Working Group, Dementia Support Australia and Phoenix Australia, as

well as increased funding for clinical psychology consultations. Whether bereaved people know how to access these supports is less clear.

Conclusions

Findings identify the personal cost of both the pandemic and visiting restrictions on residents and their broader supports and families. It is important when planning for pandemics that these individual burdens are fully considered when making plans aimed at the greater good of the community. The critical caring role of many next of kin and carers needs recognition, and if not permitted, will need to be compensated for by increased staffing during a pandemic, recognising that this is not equivalent to visits from a loved one.

Since the conclusion of the study, metropolitan Melbourne has exited 'lockdown' and re-entered 'lockdown' at least four times. On 1 March 2021, findings from the Aged Care Royal Commission were released, highlighting inadequacies in palliative and EOLC in RACF. The importance of providing high quality, trusted palliative care and bereavement support, identified in the present study, has confirmed the recommendation that all RACF workers should undertake regular palliative care training, and that palliative care should be considered 'core business' of RACF.⁴³ It is a moral and future imperative to ensure high-quality care in RACF, including for public health policy and response to future infection outbreaks. This should include support for those who are bereaved.

References

- World Health Organization (WHO) WHO Announces COVID-19 a Pandemic. Geneva, Switzerland: WHO; 2020 [cited 2020 Apr 20]. Available from URL: <http://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-COVID-19/news/news/2020/3/who-announces-COVID-19-outbreak-a-pandemic>
- Petry SE, Hughes D, Galanos A. Grief: the epidemic within an epidemic. *Am J Hosp Palliat Care* 2021; **38**: 419–22.
- Australian Government: Department of Health. COVID-19 outbreaks in Australian residential aged care facilities. Canberra: Commonwealth of Australia; 2021 [cited 2021 Oct 28]. Available from URL: https://www.health.gov.au/sites/default/files/documents/2021/10/covid-19-outbreaks-in-australian-residential-aged-care-facilities-22-october-2021_0.pdf
- Australian Government: Department of Health COVID-19 cases in aged care services – residential care. Canberra: Commonwealth of Australia; 2021 [cited 2021 Oct 28]. Available from URL: <https://www.health.gov.au/resources/covid-19-cases-in-aged-care-services-residential-care>
- Roland K, Markus M. COVID-19 pandemic: palliative care for elderly and frail patients at home and in residential and nursing homes. *Swiss Med Wkly* 2020; **150**: w20235.
- Tsirtsakis A, RACGP News GP. Ending the second wave: how did Victoria get to zero active cases?. The Royal Australian College of General Practitioners; 2020 [cited 2021 Mar 15]. Available from URL: <https://www1.racgp.org.au/newsgp/clinical/ending-the-second-wave-how-did-victoria-get-to-zero>
- Hack E, Yates P. Unmet needs: COVID-19 and the 'wandering' patient. *MJA InSight*; 2020 [cited 2021 Mar 15]. Available from URL: https://insightplus.mja.com.au/2020/47/covid-19-and-the-wandering-patient/?utm_source=InSight%2B
- Hawton K. Complicated grief after bereavement. *BMJ* 2007; **334**: 962–3.
- Stroebe M, Schut H, Stroebe W. Health outcomes of bereavement. *Lancet* 2007; **370**: 8–14.
- Eisma MC, Boelen P, Lenferink L. Prolonged grief disorder following the coronavirus (COVID-19) pandemic. *Psychiatry Res* 2020; **288**: 113031.
- Prigerson HG, Cherlin E, Chen JH, Kasl SV, Hurlzeler R, Bradley EH. The stressful caregiving adult reactions to experiences of dying [SCARED] scale: a measure for assessing caregiver exposure to distress in terminal care. *Am J Geriatr Psychiatry* 2003; **11**: 309–19.

- 12 Martikainen P, Valkonen T. DO education and income buffer the effects of death of spouse on mortality? *Epidemiology* 1998; **9**: 530–4.
- 13 Stephen AI, Macduff C, Petrie DJ, Tseng F, Schut H, Skår S *et al.* The economic cost of bereavement in Scotland. *Death Stud* 2015; **39**: 151–7.
- 14 Zhang B, El-Jawahri A, Prigerson HG. Update on bereavement research: evidence-based guidelines for the diagnosis and treatment of complicated bereavement. *J Palliat Med* 2006; **9**: 1188–293.
- 15 Botha F, Butterworth P, Wilkins R Heightened mental distress: can addressing financial stress help? In: Broadway B, Payne AA, Salamanca N, eds. *Coping with COVID-19: Rethinking Australia. Taking the Pulse of the Nation 2020*. Melbourne: The University of Melbourne, Melbourne Institute: Applied Economic and Social Research; 2020 [cited 2021 Mar 15]. https://melbourneinstitute.unimelb.edu.au/___data/assets/pdf_file/0004/3562906/Coping-with-COVID-19-Rethinking-Australia.pdf
- 16 Ettman CK, Abdalla SM, Cohen GH, Sampson L, Vivier PM, Galea S. Prevalence of depression symptoms in US adults before and during the COVID-19 pandemic. *JAMA Netw Open* 2020; **3**: e2019686.
- 17 Bertuccio RF, Runion MC. Considering grief in mental health outcomes of COVID-19. *Psychol Trauma* 2020; **12**: S87–9.
- 18 Goveas J, Shear K. Grief and the COVID-19 pandemic in older adults. *Am J Geriatr Psychiatry* 2020; **28**: 1119–25.
- 19 Burrell A, Selman LE. How do funeral practices impact bereaved relatives' mental health, grief and bereavement? A mixed methods review with implications for COVID-19. *Omega* 2020. <https://doi.org/10.1177/0030222820941296>.
- 20 Pang TH, Lam C. The widowers' bereavement process and death rituals: Hong Kong experiences. *Illness Crisis Loss* 2002; **10**: 294–303.
- 21 Mitima-Verloop HB, TTM M, Boelen PA. Facilitating grief: an exploration of the function of funerals and rituals in relation to grief reactions. *Death Stud* 2019; **11**: 1–11.
- 22 Chan CL, Chow AY, Ho SM, Tsui YK, Tin AF, Koo BW *et al.* The experience of Chinese bereaved persons: a preliminary study of meaning making and continuing bonds. *Death Stud* 2005; **29**: 923–47.
- 23 Cardoso ÉAO, Silva BCAD, Santos JHD, Lotério LDS, Accoroni AG, Santos MAD. The effect of suppressing funeral rituals during the COVID-19 pandemic on bereaved families. *Rev Lat Am Enfermagem* 2020; **28**: e3361.
- 24 Hanna JR, Rapa E, Dalton LJ, Hughes R, McGlinchey T, Bennett KM *et al.* A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. *Palliat Med* 2021; **35**: 843–51.
- 25 Hamid W, Jahangir MS. Dying, death and mourning amid COVID-19 pandemic in Kashmir: a qualitative study. *Omega* 2020. <https://doi.org/10.1177/0030222820953708>.
- 26 Selman LE, Chao D, Sowden R, Marshall S, Chamberlain C, Koffman J. Bereavement support on the frontline of COVID-19: recommendations for hospital clinicians. *J Pain Symptom Manage* 2020; **60**: e81–6.
- 27 Kwa JM, Storer M, Ma R, Yates P. Integration of inpatient and residential care in-reach service model and hospital resource utilization: a retrospective audit. *J Am Med Dir Assoc* 2021; **22**: 670–5.
- 28 Sandelowski M. Focus on research methods: whatever happened to qualitative description? *Res Nurs Health* 2000; **23**: 334–40.
- 29 Corbin J, Strauss A. Grounded theory research: procedures, canons, and evaluative criteria. *Qual Sociol* 1990; **13**: 3–21.
- 30 Vargo D, Zhu L, Yan Z. Digital technology using during COVID-19 pandemic: a rapid review. *Hum Behav Emerg Technol* 2021; **3**: 13–24.
- 31 Feder S, Smith D, Griffin H, Shreve ST, Kinder D, Kutney-Lee A *et al.* "Why couldn't I go in to see him?" Bereaved families' perceptions of end-of-life communication during COVID-19. *J Am Geriatr Soc* 2020; **69**: 587–92.
- 32 Moora KJ, Sampson EL, Kupeli N, Davies N. Supporting families in end-of-life care and bereavement in the COVID-19 era. *Int Psychogeriatr* 2020; **32**: 1245–8.
- 33 Harrop E, Selman L. Supporting people bereaved during COVID-19: a mixed methods study of bereaved people's experiences and the bereavement services supporting them. 2020 [cited 2021 Mar 15]. Available from URL: https://www.cardiff.ac.uk/___data/assets/pdf_file/0019/2434033/Website-Summary_BereavementCovid19-1.pdf
- 34 O'Connor M, Wilson B. Managing bereavement when a family member dies in an aged care home: the impact of COVID-19. *Med J Aust* 2021; **214**: 333–333e1.
- 35 Broad JB, Gott M, Kim H, Boyd M, Chen H, Connolly MJ. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *Int J Public Health* 2013; **58**: 257–67.
- 36 Borbasi JAL, Tong A, Ritchie A, Poulos CJ, Clayton JM. "A good death but there was all this tension around" – perspectives of residential managers on the experience of delivering end of life care for people living with dementia. *BMC Geriatr* 2021; **21**: 306.
- 37 Palliative Care Australia: The Economic Benefits of Palliative Care and End-of-Life Care in Residential Aged Care. Economic Research Note 4, July 2017. Palliative Care Australia; 2017 [cited 2021 Mar 15]. Available from URL: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/07/PCA019_Economic-Research-Sheet_4a_RACFs.pdf
- 38 Coghlan R Centre for Humanitarian Leadership: Working Paper 002. Palliative Care in Humanitarian Crises. The Centre for Humanitarian Leadership Deakin University; 2019 [cited 2021 Mar 15]. Available from URL: <https://centreforhumanitarianleadership.org/wp-content/uploads/2019/09/002-R-Coghlan-Palliative-care-in-humanitarian-crises.pdf>
- 39 Mayland CR, Harding AJE, Preston N, Payne S. Supporting adults bereaved through COVID-19: a rapid review of the impact of previous pandemics on grief and bereavement. *J Pain Symptom Manage* 2020; **60**: e33–9.
- 40 Etkind S, Bone AE, Lovell N, Cripps RL, Harding R, Higginson IJ *et al.* The role and response of palliative care and hospice services in epidemics and pandemics: a rapid review to inform practice during the

- COVID-19 pandemic. *J Pain Symptom Manage* 2020; **60**: e31–40.
- 41 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 Symptom Manage* 2020; **60**: e70–4.
- 42 Australian Government: Fair Work Ombudsman. Compassionate and bereavement leave. The Fair Work Ombudsman and Registered Organisations Commission Entity; 2021 [cited 2021 Mar 15]. Available from URL: <https://www.fairwork.gov.au/leave/compassionate-and-bereavement-leave>
- 43 Australian Government Royal Commission into Aged Care Quality and Safety Final Report: Care, Dignity and Respect. Volume 1 Summary and recommendations. Canberra: Commonwealth of Australia; 2021 [cited 2021 Mar 15]. Available from URL: <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1.pdf>

Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web-site:

Appendix S1. Quantitative Experiences Questionnaire (QEQ).

Appendix S2. Grief – support services.
