A bad time to die? Exploring bereaved families/whānau experiences of end-of-life care under COVID-19 restrictions: a qualitative interview study

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Abstract

Background: There have been international concerns raised that, during the COVID-19 pandemic, there was an absence of good palliative care resulting in poor end-of-life care experiences. To date, there have been few studies considering the pandemic's impact on people dying from non-COVID-19 causes and their families and friends. In particular, there has been very less empirical research in relation to end-of-life care for Indigenous, migrant and minoritised ethnic communities.

Objectives: To explore bereaved next-of-kin's views and experiences of end-of-life care under COVID-19 pandemic regulations.

Design: This qualitative study involved in-depth one-off interviews with 30 ethnically diverse next-of-kin who had a family member die in the first year of the pandemic in Aotearoa, New Zealand.

Methods: Interviews were conducted by ethnically matched interviewers/interviewees. A reflexive thematic analysis was used to explore and conceptualise their accounts.

Results: A key finding was that dying alone and contracting COVID-19 were seen as equally significant risks by bereaved families. Through this analysis, we identified five key themes: (1) compromised connection; (2) uncertain communication; (3) cultural safety; (4) supported grieving and (5) silver linings.

Conclusion: This article emphasises the importance of enabling safe and supported access for family/whanau to be with their family/whānau member at end-of-life. We identify a need for wider provision of bereavement support. We recommend that policy makers increase resourcing of palliative care services to ensure that patients and their families receive high-quality end-of-life care, both during and post this pandemic. Policy makers could also promote a culturally-diverse end-of-life care work force and the embedding of culturally-safety practices across a range of institutions where people die.

Keywords: bereavement, COVID-19, cultural safety, family caregiving, grief, holistic health care, palliative

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Introduction

The global COVID-19 pandemic has been identified as 'a bad time to die'[1] with concerns raised that this period has witnessed a 'stark departure from a palliative care approach'.[2,3] Visiting restrictions, though necessary to protect patients with palliative care needs who are susceptible to virus transmission,[4] have been identified as a major

factor in the increase of patients dying alone.[5,6] Concerns have also been raised about the availability of specialist palliative care services during the pandemic period.[7] A systematic review of international evidence reveals that attempts to reduce infection risk have resulted in the reduction of community nursing and hospice involvement.[8] Evidence has also been found that patient and families' perceptions of health care systems as being under-resourced and sites of virus transmission have led to a reduction in their contact with services[9,10] and perceptions of poor clinician communication in this period.[11] This situation has resulted in the intensification of family caregiving responsibilities in terms of both hours provided[12,13] and an increase in the number and complexity of tasks, such as decision-making and medication administration.[14,15] Early evidence indicates that increased pressures on families to provide care have been bad for their health, exacerbating family caregivers' levels of anxiety, depression, fatigue, sleep disturbance and social isolation and loneliness.[13,16,17] The pandemic has also been found to have impacted family caregivers' financial well-being.[17] Other evidence suggests that patients and their families have not received sufficient spiritual or emotional support in their final days of life.[6] Further qualitative research is required to deepen understanding of the pandemic from the perspectives of patients approaching their end-of-life and their families and friends.[18,19]

Researchers have also begun to consider outcomes following a loved one's death, with concerns raised that the pandemic has precipitated the rise of complex and prolonged grief.[19] Evidence suggests that complex grief is associated with negative perceptions about the quality of the dying experience and lack of preparedness for death.[20] Complex grief is a public health concern linked to a range of adverse health outcomes such as major depressive disorder, post-traumatic stress disorder and substance abuse disorder, and other negative mental health outcomes, such as suicidality, reduced quality of life and overall functional impairment.[21,22] Lack of access to and availability of specialist bereavement care have been identified as barriers in a number of countries.[8] Particular concerns have been raised regarding the increased risk of complex grief among minoritised ethnic communities who have died at higher rates from COVID-19.[23,24]

Indeed, while there has been a widespread acknowledgment that the pandemic has exacerbated inequities around health care for Indigenous, migrant and ethnically minoritised communities,[25] very less empirical research relates to end-of-life care. A few notable exceptions have shown how restrictions on funerals and delays in returning family members' bodies to their ancestorial land have been perceived as cultural breaches for a range of indigenous groups, in Aotearoa, New Zealand (NZ), Fiji and South Africa.[26–28] Palliative care service providers have also noted the disproportionate impact of service changes on minoritised ethnic groups.[29] For example, one UK study noted that the decreased availability of translators coupled with clinician's use of personal protective equipment, impeded communication between service providers and patients and their families where English was not their first language.[29] Scholars have raised concerns that COVID-19 regulations centre a Western worldview, exacerbating the existing tendency of health services to prioritise an individual's physical health over community connection and spiritual well-being.[30] Some evidence from Aotearoa suggests Māori reported receiving culturally-safe end-of-life care in hospitals despite pandemic regulations, but only because staff were already deemed culturally competent.[31] However, further research from the perspective of Indigenous, migrant and minoritised ethnic populations is urgently needed to deepen understanding of culturally-safe end-of-life care under pandemic regulations. This is particularly urgent in the NZ context throughout the pandemic; Māori and Pacific people living in NZ have been at greater likelihood of COVID-19 hospitalisation and death due to the virus.[32]

This study focuses specifically on NZ as it has been described by some as an exemplar of pandemic control.[5] The NZ government's 'go hard and go early' approach resulted in significant changes to health care delivery in order to minimise the spread of the virus.[33] The four-level COVID-19 alert system (see Table 1) was considered among the most stringent responses to the pandemic globally.[34] Very strict visiting policies were put in place for residential aged care facilities, hospices, hospitals and palliative care units.[35] Policies initially prohibited any visitations and then for a substantial period limited visiting to only one person.[31] Home visiting services, including hospice nursing, were radically reduced

Table 1. New Zealand's four-level COVID-19 alert system.

NZ COVID-19 alert levels	Work/businesses	Public transport	Social gatherings	Public venues/ educational facilities	Travel
Level 4 – Eliminate Virus is not contained in community	Essential services only, that is health, borders, supermarkets	Severely limited to essential workers only and maximum number of patrons	All social gatherings banned	All public venues and educational facilities closed. Distance/online learning only	Only essential personal movement and doing essential work
Level 3 – Restrict Heightened risk that virus is not contained	Businesses can open, with contactless precautions	Severely limited with physical distancing and maximum number of patrons	Gatherings of up to 10 allowed only for weddings, funerals and tangihanga (Māori funeral)	Early learning centres for essential workers children, open with a maximum of 10 per 'bubble'. Distance/ online learning available	Limited to your local area only
Level 2 – Reduce Disease is contained, but risks of community transmission growing	Businesses open with physical distancing precautions and maximum number of patrons	Limited with physical distancing	Gatherings of up to 100 in indoor and outdoor spaces allowed	All learning services open with public health control measures	Travel across boundaries permitted with safety measures
Level 1 – Prepare Disease is contained	No restrictions	No restrictions	No restrictions	No restrictions	No restrictions
NZ, New Zealand.					

and limited to people with high needs.[36] National lockdowns prohibited funerals and tangihanga (traditional Māori funeral customs) entirely with restrictions remaining until level 1.[37] Unlike other countries, there was very less virus transmission in NZ during the first year of the pandemic and only 21 deaths. The country also never experienced the intense rationing of hospital or intensive care beds seen internationally.[38] The country therefore makes for an interesting case study for exploring the impact of pandemic regulations on end-of-life care, where people were not dying of COVID-19.

Aim

To explore bereaved next-of-kin's views and experiences of end-of-life care under COVID-19 pandemic regulations.

Materials and methods

This article presents a qualitative semi-structured interview study drawn from a wider mixed-methods study about bereaved next-of-kin experiences during the COVID-19 pandemic in Aotearoa, NZ. We adopted a qualitative approach that provides an in-depth understanding of human behaviour, emotion, attitudes and experiences[39] and is particularly suited to picking up nuances of emotionally sensitive topics such as end-of-life and bereavement.[18] This study gained ethical approval from the University of Auckland's Ethical Committee (ref: 22084). To ensure transparency and rigour, our methodology conforms to the 32-point qualitative research reporting guidelines set out in the consolidated criteria for reporting qualitative research (COREQ) checklist.[40]

Data collection

The research team conducted a modified version of the Views of Informal Caregivers Experiences (VOICES) survey,[41] for next-of-kin who experienced bereavement during the pandemic. Individuals were considered eligible if they were officially documented as next-of-kin on a hospital registry for an adult (over 18) who died between 1 March and 31 December 2020 and resided in Aotearoa, a large metropolitan city. Of the 194 survey responses received (response rate of 12.8%), 90% indicated they would be happy to be re-contacted. We purposively sampled this

sub-section of participants to ensure maximum variation, in terms of place of death (home, hospital and residential care facility), gender and ethnicity. We also sought a diversity of relationship statuses to the deceased, recognising that next-of-kin included not only relatives (wives, daughters, sons and siblings) but also non-related friends and neighbours.

Data collection took place between February and June 2022. All participants were a minimum of 6 months post-bereavement and provided informed, written consent prior to the interview. The interview guide was informed by the questions asked in the VOICES survey which has been previously modified for the NZ context,[41] existing literature, the clinical experiences of working under pandemic conditions of some of our team and priorities identified by our Te Ārai Palliative and End-of-Life Care Kahui Kaumātua (Advisory group of Māori Elders). A member of this advisory group (JN) subsequently became the lead Māori interviewer for the study. Interview question topics included end-of-life circumstances, including the caregiving context and final moments; views on health service use and post-death circumstances including funeral/ tangihanga and bereavement (Appendix 1).

Interviews were conducted by seven researchers from different ethnic backgrounds including Māori, Samoan, Chinese, Indonesian and New Zealand European (NZE). Three interviewers experienced a family bereavement during the pandemic which made them particularly attuned to participants' experiences. Interviews were ethnically matched between interviewer and interviewee where possible.

Potential participants who had provided consent to be re-contacted were telephoned or emailed and invited to take part in an in-depth interview to expand on what they had shared in their surveys. Four NZE and two Pacific participants declined as they felt they were too distressed by their experience to discuss it further. Interviewers and interviewees did not personally know each other prior to the interview. One-off interviews were conducted in the participant's preferred language and in the medium of their choice–telephone, zoom or face-to-face (only under level 1 COVID-19 restrictions). Interviews were recorded and transcribed verbatim. Where interviews were not originally conducted in English, they were translated into English by the interviewer and then anonymised. Transcripts were not returned to the participants but were reviewed by each interviewer for accuracy. Interviews ranged from 16 min to 2 h and averaged 45 min in length. Data saturation was determined at the point when we had enough information power, and patterns of meaning were beginning to crystallise.[42]

Analysis

Our analysis drew on a reflexive thematic analysis approach which emphasises the researcher's active role in knowledge production.[39] This aligned with our multi-ethnic research teams approach to end-of-life care being a culturally contingent concept shaped by the worldviews of both families/ whanau and ourselves as researchers. The goal of this research approach was to identify 'patterns of shared meaning, cohering around a central concept'.

Analysis began inductively, with each interviewer selecting one or two transcripts to read and re-read together with an experienced lead analyst (TM, of NZE ethnicity). This process enabled the team to compare different cultural understandings of end-of-life care and grieving processes through asking questions about each other's interpretations. This close reading of transcripts also helped to centre participants' descriptions and perspectives of their end-of-life caring experience. This iterative process was designed to ensure rigour, credibility and trustworthiness, as well as the cultural sensitivity of the analysis.[43]

Following line-by-line scrutiny of the transcripts, four descriptive codes were created, each with four to six sub-categories. TM, with close support from a second analyst (KM) used NVIVO-12 data management software to code each transcript into this provisional framework. Through subset team discussion, we refined and clustered data into five themes. Each theme addresses outlining cases as one of the key findings was the heterogeneity of family/whānau experiences. To support themes, participants' quotes are presented below and described using the following information: relationship to the deceased, age, ethnicity and unique interview number.

Results

In total, we conducted 30 interviews. Seventeen were conducted over zoom, eight over the telephone

Table 2. Characteristics table next-of-kin.

Relationship to deceased	Number of participants
Spouse	11
Child	12
Sibling	6
Neighbour	1
Ethnicity of next-of-kin	
New Zealand European	16
Māori	8
Samaon	1
Chinese	1
Indonesian	1
Malaysian	1
Indian	1
Gender of next-of-kin	
Female	22
Male	8
Age of next-of-kin	
40s	2
50s	9
60s	9
70s	8
80s	2

and five in person. Participant's demographic details and demographics of the deceased are presented in Tables 2 and 3, respectively. Sixteen participants were NZE, eight Māori, one Samoan, one Chinese, one Malaysian, one Indonesian, and one Indian (see Table 2). A thematic analysis of the interview data identified five key themes: (1) compromised connection; (2) uncertain communication; (3) cultural safety; (4) supported grieving and (5) silver linings.

Compromised connection

Most participants discussed the importance of being connected with family and whānau (Māori term describing family) as they approached their end-of-life. Many were frustrated and worried about how visiting restrictions impacted their ability to be with their dying relative, despite recognising the importance of these restrictions to prevent the spread of the virus. The following participant described pleading with hospital staff every day to see her dying husband:

> The fact that neither [daughter] nor I were allowed to be with him for nine days when it was nothing to do with COVID at all just seems stupid quite frankly. I mean I would have slept [there], I would have done anything to have been with him. Yeah. And I had no support because I was on my own. (Wife, 70s, E1)

In this case, her husband died alone, a fear expressed by almost all participants.

Missing a shared presence

Participants across cultural groups stressed how their inability to be present placed an emotional and psychological toll on their dying family member. For Māori family members, visiting restrictions and restrictions on tangihanga undermined whānau kotahitanga (togetherness) and were viewed as 'a real breach of our tikanga' (traditional customs) (Daughter, 40s, Māori4). Illustrating this, a pair of Māori daughters shared their initial distress at being separated from their mother in the hospital under level 3 conditions:

> she had been crying. And all she said was, take me home, when am I going home? Are you coming to pick me up now, I'm ready to go home. That was her constant korero (discussion) every time we went in to see her. (Daughter, 40s, Māori4)

Community stay-at-home measures also impacted family and close friends' ability to be with one another. As one person explained under level 4 requirements: 'my daughter couldn't come over, or you know, if she'd come over we had to meet at the door' (Wife, 70s, NZE1). Not all participants followed these regulations, however, and instead weighed up the risk of contracting COVID-19 *versus* missing their family member's last moments. As one mother implored her son, an essential worker: 'It doesn't matter, you know, it's more important that you see your dad . . . if you bring COVID in well, so be it' (Wife, 70s, NZE11). Another 80-year-old participant convinced an ambulance driver to let her travel with

Table 3. Characteristics table deceased.

Cause of death	Number of participants
Cancer	14
Lung	3
Dementia	4
Heart	6
Bowel	1
Kidney	1
Accident	1
Ethnicity of deceased	
New Zealand European	17
Māori	6
Samaon	1
Chinese	1
Indonesian	1
Malaysian	1
Indian	1
Australian	1
British	1
Gender of deceased	
Female	14
Male	16
Age of deceased	
40s	2
60s	11
70s	9
80s	5
90s	3

her partner who had dementia in the ambulance, despite restrictions forbidding it, through stressing that it would be in the best interests of his safety:

> I said please be aware he's a strong man and he'll lash out. Because he's alone and he's lost, and he's got dementia, and if he hears a friendly voice he knows he's safe. (Female partner, 80s, Māori6)

Others were more hesitant of spreading the virus, recognising that social connection was potentially contaminating. A Pacific participant described how many of her family were too nervous to visit her father-in-law in the hospital for fear of accidentally spreading the virus. She visited her father-in-law but strictly followed pandemic rules, as she explains: 'I follow the protocols in terms of the protecting, keeping the patients on the ward safe by me not going from one ward to the other' (Step-daughter, 50s, Samoan1). In another case, the family priest visited and remained outside the house, delivering supplies and emotional support from the footpath.

Digital work-arounds

Some participants used digital work-arounds to remain connected despite their physical separation. Families often relied on health care professionals to support this. One participant described how the Aged Residential Care (ARC) staff would hold the phone to her husband, who had dementia, and she felt that 'as long as he heard my voice, he was happy' (Wife, 60s, Māori1). Another participant described how she quickly taught her 82-year-old mother to use an iPad once they heard that visiting restrictions were about to be put in place in the hospital, though she remained reliant on staff to support her:

> And the nurses were very good, they'd set it up, like a couple of times she, like she'd have to hook up on the wi-fi and things, stuff like that, that she'd never in a million years had to think about, you know? (Daughter, 50s, NZE7)

Digital connection was important to family members who sought emotional support despite being physically apart. Participants talked about how comforting text messages and phone calls were in this period: 'Most people knew we were in end-of-life care and I'd get texts and things, saying you know, thinking of you and that' (Wife, 70s, NZE11). Almost all participants described using technology to connect with family members overseas while borders were closed. Six families applied for travel exemptions from the ban on international visitors so that they could travel to be with their dying relative; only one of these applications was successful.

Uncertain communication

Participants felt a double-whammy of uncertainty in this period relating to both the impending death of their family member and the rapidly changing pandemic conditions.

Many participants felt that the lack of consistent communication with health care professionals deepened their insecurity. Multiple participants expressed deep distress that their family member delivered their end-of-life diagnosis without any support person present. This was poignantly captured through this husband's reaction:

> But I just wish they would have actually got me up there to comfort her. Because there'd be nothing worse than saying to, you know, patients sorry we can't do anything, well we're shipping you off to the hospice and they're on their own. I was really gutted by that. Yeah absolutely. You know, I know COVID was the issue, but, geez they need to work around it somehow. (Husband, 60s, NZE5)

Communication breakdowns

As only one person was allowed to visit in hospitals during level 4 and 3 COVID-19 restrictions, this often resulted in the duty of communication falling to this family member, often compounding their stress and resulting in miscommunication. One participant felt she was actively restricted from receiving information about the next steps following her neighbour's death because she was not biological family, despite her being his primary carer and being listed formally as his next-of-kin.

Two extreme cases attested to a complete breakdown in communication whereby their family member died in hospital and it took them hours (in one case multiple days) to be informed. As one participant describes,

> She died alone and then it was just a disaster. They didn't know what to do . . . I said 'you have to ring her daughter, you have to ring her daughter'. They said 'we can't'. And I said 'why not?' And they said 'we can't; the doctor has to see her . . .' I asked why the doctor wasn't there and they said 'it wasn't an urgent case obviously anymore'. (Sister, 50s, Māori2)

Participants often felt that communication was not a priority for busy health care professionals, which made them feel disregarded: 'I think with the whole COVID going on, they were all so, oh just so like "oh we're so busy, we're so busy"' (Daughter, 50s, NZE10). Other participants believed that it was a result of 'our whole health system is disintegrating' (Sister, 60s, NZE3) prior to COVID-19. This meant, as another participant put it, that patients and staff bore the 'brunt' of the stretched health care system (Wife, 70s Chinese1). Participants were nonetheless forgiving of health care professionals, summarised clearly by one participant: 'They probably were restricted, yes, and trying to do what they could in the circumstances. I understood that at the time' (Wife, 60s, NZE15).

Good communication

Our analysis also identified examples of good communication, particularly when patients were involved with the hospice service, described by one participant as ' just great. . .through the pandemic it was just amazing the service' (Sister, 50s, NZE14). Furthermore, a Malaysian participant described feeling proactively looked after by their hospital team following the death of her brother:

> Oh, they were fantastic. I remember a couple of staff they were really concerned about me. They were just making sure that I am okay. And even after he passed away, they asked me if I want to stay at the hospice for one or two more days. (Sister, 60s, Malaysian1)

Another participant expressed her gratitude for the daily check-ins by hospice about the syringe driver and medical supplies, as well as their instant response by phone following her father's death to arrange the death certificate 'even though it was a Sunday' (Daughter, 50s, NZE7).

Participants expressed ambivalence around how the pandemic made them explicitly discuss end-of-life planning. Some families felt it was good that the circumstances provided an opportunity to speak plainly about death. Others felt let down when these discussions were not actioned, especially in the case of preferred place of death and burial wishes. Such complexity is captured in this daughter's description of her conversation with her father which resolved in her unexpectedly caring for him at home:

> Having that conversation with him, because of the COVID, he had concerns. He had concerns that, you know, and he would say it to me, he would say,

if I go [to hospital], I won't be coming back. And so, he obviously, you know, he had this fear that if he went, us as his whānau (family) couldn't visit him or be in there with him. And his other fear was if he went in there, he might catch COVID from those that have COVID that are in hospital. And he knew how vulnerable he was to catching it. So, and I knew that he would prefer to die at home than die alone in hospital. (Sister, 50s, Māori3)

Cultural safety
Participants deemed the cultural safety of care at the end-of-life, particularly relational and spiritual components, very important. Our analysis identifies some variance in the quality of culturally-safe care.

Culturally-safe care
Instances of culturally-safe care tended to reflect processes already in place and the knowledge of particular health care providers, rather than relating to anything COVID-19 specific. For example, two Māori sisters described how they arranged for the kaumātua (support from Māori Elders) service in the hospital to perform their mother's spiritual rites, as one sister explained 'we had them come through. And, yeah, she was doing karakia (prayers, incantations, chants) with Mummy' (Daughter, 50s, Māori5). These participants also described feeling aroha (care/compassion) from the wider health care team who came to acknowledge their mother's death through respectful silence:

> Oh wow. I s'pose in the reality of being in hospital that your whānau (family), you know, have passed, I know when Mummy passed, you know, the cleaner came through. She stood there and she just nodded her head. Then the doctors came through and they just, yeah. (crying) That was quite a moment for me. Mmm, ae . . . It was that grieving, it was like, 'oh Mummy, you know, these people cared for you and they're acknowledging, you know, they're acknowledging you passing'. (Daughter, 50s, Māori4)

In another instance, a devoted Christian participant described how he was impressed that staff in the hospital knew how to handle and prepare his wife's body in line with their customs:

> So, the two nurses they pull off the cloth again, wrap her again, everything with a kind of like white sheet

like that (white linen), white linen full and give me all of her stuff and then they said 'okay we are going to bring her to the morgue; you need to contact funeral home to arrange the pick-up and prepare for the burial'. So, yeah that was what happen right before four o'clock. (Husband, 60s, Indonesian1)

Participants felt acknowledged and supported by health care professionals who shared a similar cultural background. A Māori participant viewed the outstanding support she and her husband received from his ARC manager on account of him being Māori too. She described how the ARC manager performed karakia (prayers, incantations and chants) immediately after death and let her enter the facility, despite strict no-visitor policies, so she could be with her husband's body overnight.

Similarly, a Samoan participant described in detail how impressed she was by a Samoan nurse they encountered in the hospital who 'practiced the understanding of the culture' by 'providing for the dignity of the person who was preparing to go' (Step-daughter, 50s Samoan1):

> And that nurse, that Samoan one from the palliative team was there as well. She came early in the morning and said 'have you prepared yourself, because I think that it'll be around afternoon that he'll go?' And she was right . . . she scolded the nurses because the nurses didn't come to wipe him down and when they know that it's towards his final moments they should've come and done that . . . So she asked the nurses on the ward to get the basin and flannels and soap and everything. (Step-daughter, 50s Samoan1)

Culturally unsafe care
Not all participants felt supported by the cultural support team. A Māori participant felt 'really disappointed in that [kaumātua] service actually, really disappointed' (Sister, 50s, Māori2) because they did not visit with her sister during her hospital stay. The same Samoan participant mentioned above felt let down by the formal cultural adviser who could not speak Samoan adequately enough to converse with her father-in-law.

Aspects of institutional space also enabled cultural safety. Multiple participants described how the whānau room in hospital – a separate larger family room off a hospital ward – allowed families to grieve in their own way, 'cry as loud as you

want' and 'spend as long as possible in the room' (Husband, 60s, Indonesian1). Families were only offered access to the whānau room once level 3 COVID-19 restrictions were lifted.

Burial practices

Another very important cultural element related to burial practices. Families went to great lengths to ensure that their family members were laid to rest in the appropriate manner. Māori expressed the importance of returning and being buried on their kāinga tupu (ancestoral home). Travel restrictions made this difficult, yet families went to extreme lengths to make it so. In one case, a Māori participant petitioned the Government for a managed isolation and quarantine facility spot for her sister to enable her to enter the country so that she could be buried in at her whānau's urupā (burial site). A Samoan participant successfully arranged for her father-in-law's body to be returned to Samoa, though she felt that there were 'too many strings to be pulled' to do so. Māori whānau frequently paid out of pocket for the expensive long-term embalming to ensure that they could transport their family member's body home once restrictions were lifted:

> It costs more money, I think it cost us an extra $800 [NZD] or something like that. But we thought we would go with that because that gave us that option. Otherwise we would've probably had to bury him up here at a, you know, the [city name], you know, the local cemetery and that's not what we wanted to do. (Sister, 50s, Māori3)

Funeral restrictions remained in place through this period which meant that not everyone could pay their respects which was really upsetting to wider whānau:

> the tangi (shortened word for funeral) was really sad. People couldn't come from Auckland, Auckland was in lockdown. And three of her children watched it on Zoom and her boy was desperate to see her in the casket, but, our kaumātua wouldn't let it happen. (Sister, 50s, Māori2)

Grieving alone

COVID-19 lockdown restrictions were challenging for many participants as they impacted their typical coping strategies. Not being with their family member when they died and not being able to see their body made processing the death particularly difficult. Under level 4 COVID-19 restrictions, families were not able to view the deceased. An NZE wife described this separation as 'cruel' given she was in the same 'bubble' (define) as her husband. She felt that 'there was absolutely no reason that I couldn't have been there with him' (Wife, 70s, NZE1). Similarly, a Malaysian participant, sobbing throughout her interview, described her parents 'pain' from not being able to be with their 'youngest baby' due to border restrictions when he died.

Seeing no one

Another key concern raised by many participants, including half of NZE participants, was the suspension of the chaplaincy service in hospitals under pandemic regulations. Participants were baffled by this decision, exemplified by a participant's description of shock following a phone call with someone from her church: 'She said none of us can [come into the hospital]. The Bishop has told us. There was absolutely no care at all really' (Wife, 70s, NZE1). Families sought work-arounds including asking their own pastor to administer last rites over the phone and in one instance rallying other families in the hospital to support them in prayer when it was apparent their family member was about to die.

Participants also discussed the difficulties of not being able to see anyone immediately after their family member's death and funeral service. This left them feeling acutely lonely and separated from other people. This was particularly pronounced where people lived by themselves, or only with the person who had just passed away:

> I let myself in and I came in and poured myself a drink of brandy. Sat down, I had nothing, I was completely on my own. It was dreadful, it was absolutely unreal. (Wife, 70s, NZE1)

Bereavement support

Issues were compounded when participants wanted bereavement support and were unable to access it leaving families feeling 'ripped off' (Daughter, 50s, NZE4). Most participants in this situation actively sought out formal support services. These included telephone helplines, as well as general mental health support offered through their general practitioner. In one case, a participant found a community-organised grief therapy group which she found hugely beneficial, despite

it only lasting eight sessions and having to pay for it herself.

A third of participants were formally offered bereavement support, most commonly from either someone associated with hospice or their funeral director. Not everyone felt they needed this support but all appreciated receiving the offer:

> Even though you don't take it, that's still a nice sign. I had no idea that would be done. I just thought it's the last you ever hear from them, the people at the hospital. But, no it was some like, you know, a case manager that would ring me every few weeks to begin with. And a couple of months later I got a letter, a nice letter from them, you know. I was bloody impressed by the fact that they would even do that. **(**Husband, 60s, NZE5**)**

Participants who did not want external bereavement support described how they received sufficient support from their family and friends.

Silver linings

Most participants sought some 'silver lining' from their experience. Some pointed to how stay-at-home measures meant that people had time and space to be with their families. Multiple participants described how remote working was a positive feature of the restrictions and meant they could spend more time with their family:

> in a weird way we were probably lucky because as I said we were, you know, we were all in lockdown so we were all at home. So probably it helped get through, it was probably easier, especially for my mother. (Son, 50s, Indian1)

Some participants commented on the unexpected benefits of restrictions. For example, a participant described how a last-minute change to keep her husband at home rather than send him to hospice as he has originally wanted resulted in 'a positive' as they were able to spend extensive time together. She noted, however, that she would have liked more support in doing so: 'it would have been nice if the caregivers could have stayed say for an hour and let me go for a walk' (Wife, 70s, NZE11). Changes to funerals were also positively experienced by a handful of participants who explained that size restrictions on funerals took stress off families: 'you don't need huge crowds

around the place. It was, you know, stressful enough in itself' (Husband, 60s, NZE5).

Participants also positively spoke about the uptake of online video streaming services for funerals. They enabled family members and friends living overseas – especially older people – to attend the funeral when they would not have been able to in pre-COVID situations. One daughter described of her 93-year-old mother's streamed funeral: 'there was all Mum's friends in Scotland, a lot of friends she'*d* made in Australia. So actually, there was a whole lot of people watched it that I just wouldn't have even imagined' (Daughter, 50s NZE10).

Discussion

This study provides novel insights into end-of-life caring and bereavement from the perspectives of family/whānau bereaved during COVID-19 regulations in Aotearoa, NZ. Participants shared varied accounts of end-of-life care during this period, with most confirming that there was indeed a stark departure from good end-of-life and palliative care principles.[2] However, we also identified instances of effective improvisations to accommodate COVID restrictions resulting in good end-of-life care and 'silver linings'.

A key finding from this study was how rigid public health regulations effective in stopping virus transmission, impacted family members and health care professionals' ability to provide responsive care. Participants repeatedly reported dissatisfaction with visiting restrictions; a barrier spotlighted in other national contexts.[5,6] To provide good end-of-life care, families did not necessarily adhere firmly to COVID-19 regulations in all cases but rather balanced the risk of virus infection (for themselves and others) with the risk of their family member dying alone, something also observed in Fiji.[27]

Dying alone and contracting COVID-19 were seen as equally significant risks by bereaved families. This highlights a need for policy makers to consider the public health risk associated with poor end-of-life care when designing pandemic policy and not just focus on virus transmission. This finding also supports calls made internationally[5,18] for discretionary visiting regulations which allow at least one family member to be present with the dying patient in any health care

institution. We would go further to contend that, rather than merely framing family/whānau as visitors, it would be useful to conceptualise them as part of the caregiving team.[44] Enabling safe and supported access for family/whānau would both mitigate the stress of the patient and improve grief outcomes for family members.[45]

Technology was rarely seen as a sufficient substitution for face-to-face visits which is in line with previous observations,[30] although families used it if it was their only option. Our findings indicate that health care professionals need to prioritise supporting digital connection and communication between patient and their families. A hospital-based study has shown how this can be successfully achieved through Whatsapp which enables real-time updates about a patient's conditions and the ability for families to provide feedback.[3] Telehealth solutions with components like these ought to be explored further.[46]

Improving communication with family and friends has the potential to mitigate other barriers to patient's end-of-life care observed during COVID restrictions. Poor communication from health care professionals around prognosis was described by many participants in this study and has been identified in the international literature as a barrier to good end-of-life care.[11] Interestingly, participants in this study did not view poor communication as pandemic-specific but rather related it to under-staffing and poor resourcing and, as such, endemic to a health care system already under strain. These findings suggest the need for increased resourcing of palliative care services to ensure patients and their families receive high-quality end-of-life care, both during and post this pandemic. The added responsibilities on families during the pandemic were enhanced by a feeling of unwillingness to strain the already pressured health care system, something observed in other countries.[10] In addition, findings from this study show that existing wrap-around care models such as hospice did support some families well and therefore need to be better resourced to improve accessibility to a wider number of people.[8]

Another key finding from this study was people's experiences of culturally-safe palliative and end-of-life care during the pandemic. We identified that pandemic policies, such as visiting restrictions to institutional care settings, travel restrictions across borders and regions and limitations on attendance of funeral/tangihanga restrictions, disproportionately impacted Indigenous and families from minoritised ethnic groups. Interestingly, this finding has been observed both in Aotearoa, NZ, and internationally.[47] Indeed, it has been argued that such disparities emerged because pandemic regulations operated from a Western ontology emphasising the role of the individual and virus transmission over the relational nature of end-of-life care and the importance of family, community and spiritual connection to the homeland.[26] These systemic cultural blind spots left some families unable to conduct their religious and cultural rites and responsibilities at end-of-life or having to opt for costly options such as long-term embalming in order to wait for restrictions to be lifted.

Given the impact of pandemic restrictions on some cultural groups, it is imperative that cultural leaders be included in the consultation and planning process around end-of-life care during future pandemics.[48–50] At the very least, universal adoption of pandemic policies must contain sufficient safeguards and flexibility built into the system.[29] Notably, instances of culturally-safe care were evident in the study findings. These were often a result of institutionally-embedded cultural safe practice that was present prior to the pandemic, such as employment of cultural advisors, having translators available and a whānau space in hospital. As observed in another hospital-based study focusing on Māori,[31] culturally-safe care resulted from individual health care providers having shared cultural background with the patient and or whānau. This attests to the benefit of having a culturally-diverse end-of-life care work force and embedding culturally-safety practices across a range of institutions where people die.

This study adds empirical weight to initial fears around the rise of complex grief in this period.[19] Participants connected their difficult grief with not being allowed to see the deceased's body or farewell them appropriately and with lack of bereavement support.

As identified in other national contexts,[8] there needs to be improved resourcing and prioritisation of bereavement services and increased bereavement training of the range of health and social care professionals. Bereaved family's emotional and psychological needs should be integrated into palliative care provision, and that

bereavement support needs to be woven into pandemic planning around end-of-life care.[8]

Conclusion

This article explores bereaved family/whānau members' experiences of end-of-life care during the COVID-19 pandemic in Aotearoa, NZ. During any future pandemic, this article emphasises the importance of enabling safe and supported access for family/whanau to be with their family/whānau member at end-of-life. We also identify a need for wider provision of bereavement support as many families fell through the gaps. We recommend that policy makers increase resourcing of palliative care services to ensure patients and their families receive high-quality end-of-life care, both during and post this pandemic. Policy makers could also promote a culturally-diverse end-of-life care work force and the embedding of culturally-safety practices across a range of institutions where people die.

Declarations

Ethics approval and consent to participate
This study gained ethical approval from the University of Auckland's Ethical Committee (ref: 22084).

Consent for publication
All participants provided written consent for this study. The consent form explicitly outlined that participants' anonymised transcripts would contribute to an academic publication.

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Appendix 1

Interview schedule for bereaved next-of-kin's experiences of end-of-life care under COVID-19 restrictions

1. End-of-life care
   (a) Preparing for death
   (b) Place and circumstances of death
   (c) Decision making
2. Health service use and experiences of end-of-life care
   (a) Supports received from NGOs
   (b) Participants' wider community
3. Post-death
   (a) Caring for the body/tūpāpaku
   (b) Caring for family/whānau
   (c) Disposing of the body/tūpāpaku
   (d) Post-death rituals
   (e) Funerals/tangihanga
4. Bereavement experience
5. Strategies family and whānau adopted to mitigate negative impacts
6. For Māori, how they adapted tikanga and kawa for the situation

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