



# Patient safety and hospital visiting at the end of life during COVID-19 restrictions in Aotearoa New Zealand: a qualitative study

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## ABSTRACT

**Background** Visiting restrictions were enacted in Aotearoa New Zealand to reduce transmission of COVID-19 and protect the healthcare system. This research aimed to investigate the experiences of families and clinicians of hospital visiting for people with palliative and end-of-life care needs during restrictions.

**Methods** Semistructured interviews were completed between March and October 2021 with family members and clinicians who had personally experienced enactment of visiting restrictions during pandemic restrictions. A critical realist ontology was used to approach data analysis, sorting and coding to generate themes.

**Results** Twenty-seven participants were interviewed, 13 being families who had experienced bereavement of a family member during the restrictions: seven nurses or physicians and seven being non-bereaved family members. Four themes were generated: patient safety—(re)defining the ‘Visitor’; the primacy of SARS-CoV-2—patient safety and negotiating risk; dying alone: enduring harms; and agency, strategies and workarounds.

**Conclusion** Visitor rights and visitor policy at the end of life require greater protection during a pandemic. Transparent, coherent, publicly available evidence-based guidelines that key stakeholders, including patients, families and ethicists, are included in producing, are urgently required. We want to avert a legacy of disenfranchised grief in future pandemics.

## INTRODUCTION

The first case of COVID-19 was reported in Aotearoa New Zealand (NZ) on 28 February 2020 resulting in public health orders and new laws issued by the government turning lives upside down.<sup>1</sup> Strict border restrictions and a four-level alert system, including a stay-at-home order ([figure 1](#)), were introduced to minimise community transmission, eliminate the virus and protect the vulnerable. These were some of the most restrictive in the world.<sup>2</sup> While initially

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Understanding competing safety risks of ‘visitors’ to hospitals is critical to providing equitable, safe, high-quality palliative and end-of-life care (EOLC). There are few data exploring the experiences of visiting restrictions during the COVID-19 pandemic from the perspectives of patients, families and clinicians.

## WHAT THIS STUDY ADDS

⇒ This study has highlighted the paradox of patient safety for people receiving palliative and EOLC in hospital. That is, patient safety measures put in place to prevent harm inadvertently caused harm from the perspectives of families and clinicians. Family members play a central role in patient safety. Sociopolitical structures put in place as a result of the pandemic resulted in the marginalisation of family members from the care of people in hospital even at the end of life.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Key stakeholders including patients, families, clinicians, cultural leaders and ethicists must be involved in producing transparent, consistent, publicly available, evidence-based visiting guidelines. There is a need for ethical legitimacy in public health measures. The notion of ‘visitor’ in hospital spaces needs to be redefined.

contributing to a low spread and low mortality, they were seen as restrictive and oppressive by many.

As part of its response to the COVID-19 pandemic, WHO recommended ‘*numbers of visitors and visiting periods in hospitals should be highly restricted*’<sup>3</sup> (p 10) to reduce the impact of the disease and maintain essential health services. On 24 March 2020, the NZ COVID-19 National Hospital and Clinic Visitor Policy was distributed with advice to district health boards on how to manage visitors to healthcare facilities.<sup>4</sup> At that time, the recommendation was that visitors with no suspicion of COVID-19 be allowed to enter; visitors be allowed entry on compassionate grounds and that a maximum of one visitor was allowed for one visit per day to high-risk areas such as the intensive care unit (ICU) or emergency department and two visitors for other areas.<sup>4</sup> However, specific visiting policies were left to the discretion of individual district health boards, other health entities and individual clinicians, and subsequently were interpreted across the country in numerous ways, depending on context, and were often ambiguous. Every hospital/healthcare facility in NZ instituted either a ‘no visiting’ or, at least, a very restrictive visiting policy.

Visiting restrictions presume patient safety is achieved by protecting the healthcare system as a whole—patients, employees and visitors. Hospitals play an important role in palliative care with research showing hospitals can feel much safer than home for patients/families.<sup>5</sup>

Before the pandemic, families were increasingly recognised as collaborators in the safety and quality of care for people in hospital.<sup>6,7</sup> In NZ, the Health Quality and Safety Commission highlights that ‘*consumers should be actively involved in decision making about health and disability services at every level – including governance, planning, policy, setting priorities, and highlighting quality issues*’.<sup>8</sup> Family members are not passive bystanders in hospital,<sup>9</sup> assuming roles including companion, assistant, representative, translator, informant, navigator and planner.<sup>10</sup> People

requiring palliative and/or end-of-life care (EOLC) in hospital can feel safe when connection with family/friends is maintained.<sup>11</sup>

Inpatient visitor policies during COVID-19 varied. A recent US study analysed visitor policies of 13 hospitals during the COVID-19 outbreak.<sup>12</sup> Authors reported that policies differed in EOLC and critical care situations with five sites having no restrictions, four having the number of visitors assessed on a case-by-case basis, three allowing unlimited visitors and one allowing a single visitor.<sup>12</sup>

Understanding competing safety risks of ‘visitors’ to hospitals along with the most effective strategies and opportunities to counter these is critical to providing equitable, safe, high-quality palliative and EOLC. There are few data exploring experiences of visiting restrictions during the pandemic<sup>13</sup> from the perspectives of patients, families and clinicians. This research aimed to investigate the experiences of any person—for example, patients, families and clinicians of restrictions to hospital visits for people with palliative and EOLC needs during COVID-19 restrictions in NZ.

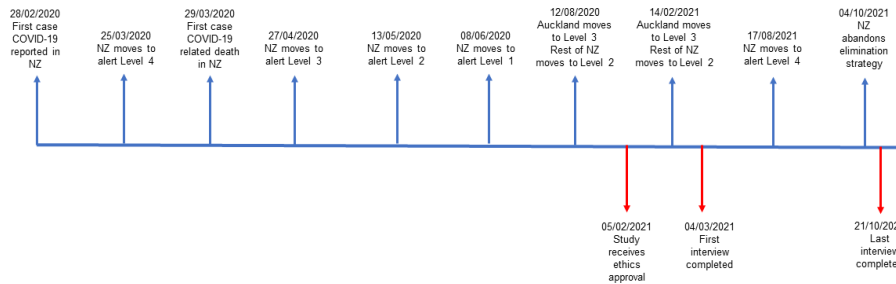
## METHODS

### Design, setting and participants

Intending to be as inclusive as possible we set out to recruit adults who received palliative care as a hospital inpatient and/or anyone who self-identified as a ‘visitor’ and who had an experience with hospital ‘visiting’ policies during COVID-19 restrictions. Recruited participants self-selected as being significant persons to the person visited—we now refer to these participants as family participants for simplicity. We also recruited hospital clinicians. We recruited people using purposive and snowball sampling: a poster and invitation to participate were distributed via the research team’s clinical, research and national professional networks including palliative and intensive care. Posters were placed around the hospital and via social media (Facebook, Twitter), newsletters and the University’s research recruitment platform.

Level	Range of measures
Level 4 – Eliminate	Stay-at-home orders; closure of schools and businesses except essential services e.g. supermarkets, pharmacies; travel restrictions; reprioritisation of healthcare services; rationing of supplies and requisitioning of facilities; all gatherings cancelled and public venues closed.
Level 3 – Restrict	Stay at home; travel limited; closure of public venues and schools; no mass gatherings; non-essential businesses close – work-from-home orders; elective procedures in hospitals deferred; gatherings up to 10 people allowed for weddings, funerals. Physical distancing of 2 metres.
Level 2 – Reduce	Restrictions on mass gatherings – limited to 100 people; limitations on non-essential travel in NZ; high-risk people advised to stay at home; physical distancing of 2 metres; health and disability services can operate as normal; schools reopen
Level 1 – Prepare	Self-isolation and quarantine; intensive COVID-19 testing; physical distancing encouraged; mass gatherings restricted to 500 people; stay at home if sick.

**Figure 1** COVID-19 New Zealand (NZ) alert levels summary.



**Figure 2** Timeline of pandemic restrictions and study enrolment in Aotearoa New Zealand (NZ).

Participants contacted the researchers by email or via a QR code on the recruitment poster.

### Data collection

Following written consent, author DB, trained in qualitative methods, conducted audio-recorded semi-structured interviews from March to October 2021 (figure 2). Depending on participant preference and COVID-19 restrictions, interviews were face to face, by telephone or via video (Zoom).

An interview guide was used—figure 3. (See online supplemental appendix for full interview guide.)

### Data analysis

Recordings were transcribed by a professional transcriber after signing a confidentiality agreement. Participants were offered the opportunity to receive copies of their transcripts. Two participants requested to review their transcripts—neither requested changes. Data analysis proceeded alongside data collection. A critical realism epistemology underpinned data analysis.<sup>14</sup> Further, we analysed data through a sociocultural lens of patient safety. Rather than a narrow clinical technical view of patient safety and a ‘measure and manage’ approach focused on reduction of adverse events, we instead conceptualised patient safety as including understanding of patient safety from the healthcare ‘user’ perspective and as something that is produced and reproduced dynamically in practice as part of complex organisations.<sup>15</sup> NVivo 2020 software<sup>16</sup> was used to organise and code data. RP, DB and AC met fortnightly to discuss, revise and interpret coding in light of patterns and tendencies (‘demi-regularities’) in the data, consistent with critical realist

#### Family participants

- Describe their experiences of visiting or wanting to visit someone in hospital and/or
- Discuss perspectives of their role as visitor
- Describe the risks in visiting during restrictions
- Tell us about any advice you received from healthcare providers/others about visiting.

#### Clinician participants

- reflect on the visiting policy for their work area during COVID-19 restrictions
- Were you involved in the formulation of the policies;
- How did you feel about visitors in the clinical area during COVID-19 restrictions
- Describe any challenging situations during that time.
- Tell us about who should decide who is able to visit a patient;
- the role of the visitor;
- potential risks to patients from restricted visiting

**Figure 3** Interview guide.

ontology and epistemology in a process of abduction (we had a set of general ideas or concepts of patient safety) and retroduction (coding was reconnected back to structural mechanisms and conditions of the visiting experience).<sup>17</sup> We approached our analysis by asking the question of how visiting policies, as causal forces at a global, national and organisational level, produced sociocultural safety ‘events’, that is, people’s experiences of how ‘realities’ unfolded and were enacted locally.

## RESULTS

There were a total of 27 participants from across the North Island of NZ (table 1). No patient participants were recruited. Thirteen family visitors were bereaved as a result of an expected adult death, and one an infant death, while seven visited during an acute event. The remaining seven family participants, while not bereaved, spoke of personal experiences of visiting a family member in an acute or critical condition in a healthcare facility. Most participants were a son, daughter or partner of the person they visited. Two family participants were also clinicians. Seven clinicians reflected on personal experiences of enforcing visitor policies within the clinical space. Interviews ranged in length from 22 to 69 min (average 40 min).

**Table 1** Study participant characteristics (n=27)

Age (years)	Range	21–90
	Median	50
Gender (n)	Male	4
	Female	22
	Gender diverse	1
Ethnicity (n)	NZ European	20
	Māori	3
	European (other)	3
	Pacific Islands	1
Interviews (n)	Family members	20
	Clinicians (nurses or physicians)	7
Four themes were generated: patient safety—(re)defining the ‘visitor’; the primacy of SARS-CoV-2—patient safety and negotiating risk; dying alone—enduring harms; and agency, strategies and workarounds. NZ, New Zealand.		

**Patient safety: (re)defining the 'Visitor'**

The term 'hospital visitor' referred to any individual not employed in the hospital, who was visiting an inpatient under any circumstances, meaning a person who was a close care partner of a patient with a long-term condition was treated the same as a casual friend. The exclusion of hospital visitors during the pandemic aligned with the assumption this would mean hospitals would be safe places. Our data show, however, that this brought to the fore other realities of patient safety, in the way it was enacted. Clinicians expressed these realities in terms of the effects on them as well as patients and family members. The seeming retrograde step of what we refer to as (re)defining family members to 'visitor' was particularly perturbing for one clinician:

I understand why we call people visitors, but it kind of makes it sound like they're curious bystanders visiting the zoo or visiting the museum. You know, that they're passive. .... and they're not, they're not there as bystanders. They're there as deeply engaged and interested family members and partners and sons and daughters. (P024 Clinician)

Clinicians also questioned administrative decisions in the wider context of who encountered a person and who did not. While a no-visitor policy was a major change, other normative clinical practices continued. One clinician expressed how the modus operandi of the ward round remained unchanged and how this was inconsistent with the no-visiting policy:

What they found really hard was that there'd be a doctors' round and there'd be ten doctors and nurses standing outside the room talking about their child who was an oncology child ... But, they weren't allowed their family members in so they found that a bit hypocritical really, .... I felt uncomfortable and I completely agreed with them but there was nothing I could do. (P015 Clinician)

Moreover, the assumption that having no visitors meant hospital patients would be safe did not fully account for the role family members have in patient safety. Family participants saw their role as fundamental and critical to the safety and care of the dying person. Here, safety was not solely technical clinical safety or the absence of adverse events, rather safety included attending to fundamentals of patient care such as eating and drinking and attending to hygiene and dignity:

I came in one morning after breakfast and she was absolutely covered in cornflakes and milk and yoghurt... consequence of her not having someone to help her. (P10 Family)

Family participants saw themselves as having several patient safety roles including as a support person, an information gatherer and a communicator and

advocate especially if their family member had a cognitive impairment.

I have a husband with dementia... My role is the support person ... I attend all of his health visits to the doctors or the hospitals.... I do the communication; I collect the information. (P011 Family)

Likewise, many clinicians felt unable to provide safe, high-quality person-centred care without the presence of a care partner who knew the patient as a person. One clinician conveyed how having a care partner present grounded them:

[Visitors] are humanising because they help us see this kind of vulnerable naked sick person on the bed. This is who they matter to, this is who they like, this is what their life is like. You know, it humanises our patients which I think helps us provide better care. (P024 Clinician)

Clinicians also saw family members as a clinical resource and instrumental in a calming influence:

Relatives are incredibly useful to nursing and medical clinicians and really help ... whether they're confused patients or ... buoying people up or just ... as a useful resource. So you actually ... missed the help that they bring .... relatives are often extremely useful for ... calming anxious people. (P016 Clinician)

**The primacy of SARS-CoV-2: patient safety and negotiating risk**

Our data show that families and clinician participants had agency often adopting their own risk evaluations. One family member described how this was contrary to blanket policies:

Our mother had had a COVID test that was clear and had come from a facility with no COVID so why the lockdown when she shifted facilities? (P013 Family)

Family members who had evaluated the risk for themselves often enacted mitigating strategies of their own, describing how they would go to extraordinary lengths to accompany their dying relative and/or suggesting enabling strategies to be able to do so:

I was a single bubble here.... I was a risk, but, you know, to put a bracelet or something you know like around your ankle, like a prisoner I would have been quite happy to do that. (P022 Family)

Participants' evaluation of risks at an individual level meant that SARS-CoV-2 safety structures in place at a macro level were questioned. Some participants experienced the enactment of these structures as strict sociopolitical rules which were seen to be disproportionate to the context and the associated risks:

She (mother) was not allowed in the hospital at all because she was over the age of 60 and that was, ... deemed high risk! ... I just thought there's a tremendous overreach here, you know ... but a grieving family



that's been in isolation of [sic] a deceased person who had two COVID tests that came back negative I thought we were pretty low risk. (P06 Family)

Interestingly, clinicians considered the risk of transmission at multiple levels, weighing risks to themselves, their family/household members as well as patients and visitors. Some clinicians positioned visitors as 'outsiders' who presented heightened risk to those already 'inside' the hospital:

Having that one stranger coming into the hospital, where who knows where they have been and who they've been exposed to. (P026 Clinician)

Clinician participants often questioned how risk was weighted both at an individual patient level and for the whole hospital population. Just as family members did, clinicians tended to contextualise risk and question generic policy:

And if someone is being nursed in a side room, ... but, you know what really is the risk? What is the risk to people coming in, agreeing to wear their PPE [personal protective equipment] and masks through a corridor and then sitting in a side room with the door shut? I.....it did seem there was a bit of a lack of common sense you know that we were actually just making yeah sort of sacrificing a group of people for the possibility of what might be occurring with another group. (P016 Clinician)

#### **Dying alone: enduring harms**

Mostly, participants regarded being physically present with a person at the end of life as a societal norm and human right that should supersede any other policy.

When someone is dying I think we as humans have a right to have someone with us... And the closest person to that person has a right to be there and that right should surmount anything else. (P022 Family)

Moreover, as a sociocultural event—not being with a family member at the end of life held enormous cultural significance for some participants.

For me culturally it was hard. Yeah, I was quite pissed off actually. (P02 Family)

Families most often conveyed the effects of distress as having a direct and significant impact on their longer term physical health:

It all but killed me... I was very sick afterwards. I think if my husband had just died under normal circumstances ... but it's the way he died. (P022 Family)

Family participants, for the most part, conveyed their distress and grief, alongside cultural, psychological and physical sequelae associated with not being able to accompany a person as they died. One participant expressed this in patient safety terms:

The thing that was raging in my head because at that point the anger starts to build in I'm thinking,

well what's the first rule of medicine? First rule of medicine, do no harm. And all I could think about was, well you're certainly not helping our situation. (P06 Family)

The impact of feeling they had abandoned their dying family member despite circumstances beyond their control could be long lasting:

She would have died alone ..... That would be something that I would have to live with ... that's really difficult to feel like you've deserted your mother when she's dying. (P015 Family)

The grief associated with the death of a family member was exacerbated in the context of other losses, grief and adaptations associated with the pandemic:

And at that point I just felt something really snap ... From the time that dad went into hospital and right until that point all I'd had were people barking orders at me... I've lost a lot of faith in the compassion of our health system. And particularly aspects of the nursing because the doctors were immune to all of this, they just carried on. (P06 Family)

Clinician participants who witnessed the aforementioned distress and its manifestations spoke of their concern for making a difficult situation more difficult and painful, people not having the ability to grieve as they would normally, abuse from relatives, abnormal grief reactions, disenfranchised grief and of the impact of a 'bad' death.

I really think that the aftermath of this pandemic isn't going to be long COVID and it isn't going to be you know respiratory cripples. It's going to be deeply wounded people with grief that they have nowhere to grow into. (P024 Clinician)

For clinicians, balancing individual needs of patients and families with wider risks and associated policies could result in moral conflict and distress. As 'enforcers' of visiting restrictions, clinicians and other hospital staff were often faced with family member's ensuing distress and anger when enacting visiting:

Our receptionist was not physically assaulted, but, intimidated to the point where she was really quite shaken because of someone who wanted to come in and wasn't able. (P019 Clinician)

#### **Agency, strategies and workarounds**

Where they had agency, clinicians and family members enacted a variety of strategies and 'work arounds' to circumvent structural limitations of policies. Family participants, often mobilised by anger and frustration, strongly advocated for patients and themselves:

They said well we know, we understand how you feel, and I said 'no you don't understand how I feel because this is not your mother that's dying, it's mine.' And so we argued backwards and forwards. (P021 Family)

Family participants shared experiences of the local strategies and clinical adaptations in place to support their visiting, and they frequently reflected on these in relation to wider structural barriers. As part of their reflections, family participants described visiting procedures in detail and highlighted the potential to evade such procedures:

Make us sign forms and fill out things ... And the form's the easiest thing in the world to manipulate. (P05 Family)

Having seemingly exhausted all other avenues, some family participants also sought legal routes as a means to gain access:

He came back from [overseas] to see his dying father ... So after 11 days of battling and getting nowhere, ... he went to \*\*\*\* Court and won. (P014 Family)

Mainstream media and social media were further mechanisms of advocacy and agency employed to advocate for access:

So I ended up posting it (on social media) ... with a picture of me holding my granddad's hand. And actually quite a few people shared it and liked it and everything, so it got out there. (P07 Family)

Where they felt able to, clinicians also found creative ways of enacting hospital policy, juggling the 'rules' with the needs of patients and families:

Did we enforce twohours? Yeah not really. I wasn't going to put a timer on it like 'right you entered the unit at 10.45 and you will be leaving at 12.45.' (P017 Clinician)

## DISCUSSION

This study highlights that restrictive hospital visiting policies instituted during COVID-19 lockdowns in NZ, produced significant unintended consequences and harm for families and staff by the way they were enacted. Our data also give voice to family participants who consider patient safety to include physical care and psychological, emotional, spiritual, and social support and care.<sup>11 18</sup>

In keeping with previous research our findings show that family members play a pivotal role in patient safety in hospital.<sup>19</sup> Our study also found that the family role in patient safety extends beyond error prevention to include person-centred care; supporting mobility and activities of daily living; providing emotional support, and a crucial link to the healthcare team as patient safety.<sup>9</sup> Notwithstanding that, not all patients or families wish or can be present in hospital when a person is critically ill or dying. Despite the rhetoric of family-centred care, our findings show how visiting policies became a sociopolitical structural mechanism to exclude family members from hospitals. In so doing, family members became 'risk generating' 'visitor outsiders' rather than care partners who contribute to

patient safety, the role of visitor returned to that seen in days long past. We also found that some clinicians and family members in our study responded by using 'workarounds' to gain access to patients with life-limiting illnesses and/or dying. This is consistent with previous reports,<sup>20 21</sup> and could be seen as innovative and empowering for families who felt they were left little choice when not content to follow the party line and rules dictated to them at a time of high emotional stress.

Our data raised questions around human rights and freedoms. In NZ, the rights of patients and families are supported through the Code of Health and Disability Services Consumers' Rights (the Code).<sup>22</sup> Right 8 of the Code is the '*Right to support*'—*every consumer has the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed.*<sup>22</sup> However, participants in this study clearly described that this did not happen. During a pandemic and threat to public health and safety, the ethics surrounding visiting rights need to be discussed with high degrees of transparency and clarity.<sup>23</sup> Restrictions on hospital visits may over-ride the protection of individual freedom and autonomy.<sup>24</sup> A balance between the rights and interests of the wider community and those of individuals is required, however. Our findings support the need for ethical legitimacy in public health measures<sup>25</sup> as well as careful attention to wider evidence as it becomes available. For example, a systematic review and meta-analysis concluded that flexible ICU visitation policies did not increase the rate of acquired infections, septic complications, ICU mortality or length of stay when compared with restrictive visiting policies. The same study also highlighted reductions in frequency of delirium and severity of anxiety among ICU patients.<sup>26</sup> Early in the pandemic, nosocomial infections were found to be as high as 44% with most of those nurses and medical staff.<sup>27</sup> A recent study found that the potential for nosocomial transmission of SARS-CoV-2 from hospital visitors was, in fact, extremely low (0.01%).<sup>28</sup> The most likely route of nosocomial transmission of SARS-CoV-2 to patients was via healthcare workers or patient-to-patient transmission.<sup>29</sup> It is therefore vital that visiting policies be reviewed frequently during a pandemic so as to be based on current levels of risk and most importantly be proportionate to that level of risk.

The very policies intended to promote patient safety had unintended consequences and, for some, resulted in iatrogenic harm including omission of fundamental care, poor communication and emotional and social harm. This is consistent with patients and families' previous descriptions of harm at the end of life.<sup>11</sup> Our findings resonate with previous research that shows COVID-19 visiting restrictions were negatively associated with poor health and care provision.<sup>13</sup> Moreover, restrictive visiting is associated with increased rates of

delirium and hasty end-of-life decisions.<sup>13</sup> Previous work has also highlighted how important the presence of family members is in a ‘good’ death.<sup>30</sup> Restricting people from accompanying their family members at the end of life has been associated with prolonged grief disorder, post-traumatic stress, poor bereavement outcomes, mental health and quality of life and well-being.<sup>9 31</sup> This study demonstrates that all efforts should be made to facilitate in-person visiting to mitigate harm and to promote safety.

The finding of the primacy of SARS-CoV-2—patient safety and negotiating risk aligns with other NZ work in the aged care setting.<sup>21</sup> Researchers have reported poor communication, inconsistencies, delays in visitor screening processes and concerns about the patient being alone at the time of death. It should be possible to develop options for future pandemics such as providing areas within a hospital or ward where a family can be with a dying patient without fearing harm to other patients; also, developing support worker roles to educate families in donning and doffing of PPE so they can visit safely.

Our data also highlight serious workforce issues for clinicians who described both ethical and moral distress. Future planning and policies must extend to providing support mechanisms for staff to alleviate the distress caused by having to play the role of both the carer and enforcer.

### Limitations

That data were collected solely in Aotearoa NZ in the context of NZ restrictions means that findings may not be wholly transferable to other jurisdictions. Despite our aim, we were unable to recruit patient participants. This was in part a result of our recruitment strategy, which was limited by not being able to access the hospital to recruit patients due to COVID-19 restrictions. A further limitation is that the findings may represent those for whom the visiting restrictions were particularly problematic. Nevertheless, our participants had experiences in several North Island hospitals and clinical settings. Data included a range of family participants. In addition, we extended our sample to include clinicians when we realised their voices would make an important contribution to the study. Finally, the significant and multiple competing demands of the Māori researcher on our team, exacerbated by the pandemic, meant that they were unable to contribute to data collection or analysis.

### Implications for practice, policy and research

Our findings highlight the need for policy formulation and enactment to weigh risks of harm with patient safety, balancing compassionate care and human rights with public health principles. We propose that key stakeholders including patients, families, clinicians, cultural leaders and ethicists are included in producing transparent, consistent, publicly available evidence-based

visiting guidelines. The Australian and New Zealand Society for Palliative Medicine COVID-19 Special Interest Group has led the development of a scientifically based, ethically informed framework to improve equity and consistency for inpatients receiving palliative care during the pandemic.<sup>32</sup>

Further, our findings reinforce the need for consistent, clear and timely communication for clinicians and families. Previous work identified that ad hoc applications for visiting on compassionate grounds may undermine just approaches to decision-making and lead to these circumstances being seen as ‘exceptional’ rather than ‘expected’.<sup>32</sup>

The long-term effects of visiting restrictions on families including long-term mental health effects of delayed and complicated grief are not yet fully known. Further work in this area would identify areas of concern and relationship to visiting restrictions.

We would propose follow-up interviewing of families and clinicians in this study to determine ongoing impacts of their experiences and how this might have affected them physically and psychologically and how it may also have impacted their trust of healthcare and healthcare personnel.

### CONCLUSION

The findings of this study point to the iatrogenic harm and distress caused to both families and clinicians caring for those at the end of life during COVID-19 visiting restrictions in Aotearoa NZ. The ongoing legacy of these experiences is unknown and future research should be undertaken to elucidate the long-term effects on both families and clinicians and to demonstrate how thoughtful, evidence-based, code-signed visiting policies might address the ethical and moral issues highlighted in this study.

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# Supplemental Material

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## Interview Guide for Participants - Relatives

### Semi-structured Interview Guide for Participants

- Introductions
  - Answer any questions participants have
  - Explain the purpose of the interviews
  - Take consent
  - Highlight the use of the recording function
1. What hospital, hospice or other care facility did you visit, or try to visit, during the COVID-19 restrictions?
  2. Was it as a patient or as someone visiting a patient or resident??
  3. Were there any obstacles/hurdles to you visiting?
  4. Can you share that visiting experience?

#### ***Experience as a patient?***

1. Can you tell us about the circumstances that led to you going into hospital? Were there any limitations to who could come and see you and/or be with you? Did you know what they were?
2. How did you feel about the visiting 'rules'?
3. How did it feel not to have visitors?
4. Should you be able to decide who is able to visit you and for how long?
5. Who should have a say in visiting 'rules' – who should visit and when?
6. What do you think the role of 'visitors' are when you are seriously unwell?

#### ***Experience as a 'visitor'?***

7. Can you describe your experiences of visiting someone in hospital, or not visiting but wanting to visit?
  - a. How did it feel not to be allowed to visit?
  - b. What was the procedure for being allowed to visit? Did you understand/were you told what to do? Was it the same each time you visited
  - c. What happened when you actually arrived at the hospital? What did the staff do to help you visit your relative/friend/whanau member?
  - d. What type of relationship do/did you have with the person you were visiting? Family/whanau?
  - e. Who do you think should decide whether or not you are able to visit and who should be able to visit?
  - f. What do you think your role is as a visitor. Can you tell us when, how often people should have visitors when someone has a serious illness? What kind of support did you/do you provide when you visit the hospital– companionship? Advocate or helper? What do you think the expectation of health care staff was/is when you visit?

- b) Do you think there were/are any risks to you or the person or other people in hospital when you visit the hospital? How were those risks managed by the hospital? Did anyone talk to you about these risks before you visited?
- c) What advice would you give to hospitals, nurses/doctors, decision-makers about people visiting hospital when the person you cared for /are caring for has a serious illness?

**About you**

What is your age?

What is your ethnicity?

What is your gender?

## Interview Guide for Participants – Clinicians

### Semi-structured Interview Guide for Participants

- Introductions
- Answer any questions participants have
- Explain the purpose of the interviews
- Take consent
- Highlight the use of the recording function

### **Experience as a Clinician**

1. Where were you working, during the COVID-19 restrictions and what was your role at the time?
2. Can you recall what the visiting policy was for your work area during COVID Level 4 & 3 last year? Please describe it.
3. Were you involved in any of the decision-making around the visiting rules/policy and if so how?
4. Who do you think should design the visiting policy for your area?
5. How did you feel about having or not having visitors in your clinical area during the COVID restrictions?
6. Do you think there should be specific rules/policy for different groups of people?
7. Did the visiting policy create any challenging situations for you with patients/relatives/friends/whanau members? Describe those situations.
  - a). Did you do anything 'creative' to allow visitors to visit? Or mitigate the impact of visitors not being able to visit?
8. Who should decide who is able to visit a patient and the length of the visit (during COVID restrictions)?
9. What do you think the role of 'visitors' are when a patient is seriously unwell?
10. Can you describe any risks you saw to people in hospital by allowing or disallowing visitors during COVID restrictions
11. Did you encounter any situations when managing visiting during COVID restrictions which created dissonance for you as a clinical professional? If so, can you tell us more about that situation.



12. Knowing what you know now, would you support the same policy in any future Level 4 Lockdown and subsequent visiting restrictions?

**About you**

What is your age?

What is your ethnicity?

What is your gender?