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Research paper

## Family experiences and perceptions of intensive care unit care and communication during the COVID-19 pandemic

R. Digby, PhD, RN <sup>a, b, \*</sup>, E. Manias, PhD, MN, MPharm <sup>a</sup>, K.J. Haines, PhD, BHSc (Physiotherapy) <sup>c, d</sup>, J. Orosz, MD, MPH <sup>e, f</sup>, J. Ihle, BMed, FRACP, FCICM <sup>e, f</sup>, T.K. Bucknall, PhD, BN <sup>a, b</sup>

<sup>a</sup> Deakin University, School of Nursing and Midwifery, Centre for Quality and Patient Safety, Research, Institute for Health Transformation, Faculty of Health, Geelong, VIC, 3220, Australia; <sup>b</sup> Alfred Health, 55 Commercial Rd, Melbourne, VIC, 3004, Australia; <sup>c</sup> Department of Physiotherapy, Western Health, Melbourne, Victoria, Australia; <sup>d</sup> Department of Critical Care, School of Medicine, The University of Melbourne, Melbourne, Victoria, Australia; <sup>e</sup> Department of Intensive Care, The Alfred Hospital, Melbourne, Australia; <sup>f</sup> Department of Epidemiology and Preventative Medicine, Monash University, Melbourne, Australia

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### ABSTRACT

**Introduction:** In 2020, during the first wave of the COVID-19 pandemic in Melbourne, visitor access to acute hospitals including intensive care units (ICUs) was initially barred, followed by a limit of one person per patient for one hour per day. This study explores the care and communication experienced by family members of ICU patients during this time.

**Methods:** This qualitative descriptive study was conducted at an Australian quaternary hospital. Semi-structured phone interviews were conducted using an aide-memoire designed to understand participants' experiences as family of a patient during this time. Interviews were recorded, transcribed, and thematically analysed.

**Findings:** Twenty family members of patients in the ICU participated. Three major themes were identified: 'impact of restricting visiting procedures', 'family experiences of communication', and 'care and support'. Inflexible visiting restrictions had a momentous impact on families. Participants objected to having to nominate only two people to visit during the admission and the short visiting time limit. Some family members suffered extreme stress and anxiety during their absence from the bedside. Additional challenges were experienced by rural families, visitors with disabilities, and the young children of patients who were excluded. Communication with clinicians varied. Telehealth was valued by some but not universally embraced. The relationship between staff members and families and involvement in decision-making were unaffected.

**Conclusion:** Families experienced significant psychological distress from being separated from their critically ill relatives. Patient care and involvement in decision-making appeared to be unchanged, but communication with staff felt to be lacking. Better alternatives to face-to-face communication must be sought to limit the impact of family separation on mental health. Families are a key link between the patient and clinicians and often play a major role in patient support and recovery after discharge. There is an urgent need to support them and facilitate meaningful engagement despite the obstacles.

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## 1. Introduction

COVID-19 disease caused by the severe acute respiratory syndrome coronavirus 2 has had widespread devastating effects on health, society, and the economy globally, being declared a pandemic in March 2020.<sup>1</sup> Hospital visiting was severely curtailed to limit the spread of infection between patients, families, and staff members. These visiting restrictions have challenged the role of the family in patient care and recovery and have had a distressing

\* Corresponding author at: Deakin University, School of Nursing and Midwifery, Centre for Quality and Patient Safety, Research, Institute for Health Transformation, Faculty of Health, Geelong, VIC 3220, Australia.

E-mail addresses: [r.digby@deakin.edu.au](mailto:r.digby@deakin.edu.au) (R. Digby), [emancias@deakin.edu.au](mailto:emancias@deakin.edu.au) (E. Manias), [kimberley.haines@wh.org.au](mailto:kimberley.haines@wh.org.au) (K.J. Haines), [j.orosz@alfred.org.au](mailto:j.orosz@alfred.org.au) (J. Orosz), [j.ihle@alfred.org.au](mailto:j.ihle@alfred.org.au) (J. Ihle), [tracey.bucknall@deakin.edu.au](mailto:tracey.bucknall@deakin.edu.au) (T.K. Bucknall).

impact on many families.<sup>2</sup> Families normally play a pivotal role in the care of patients in the intensive care unit (ICU), providing emotional support, surrogate decision-making, and patient advocacy.<sup>3</sup> Visiting restrictions have kept families and patients apart, causing additional trauma to many.<sup>4</sup>

Psychological consequences for patients and families resulting from critical illness and ICU admission have been the subject of considerable previous research.<sup>5–14</sup> The attendance and inclusion of family members in the ICU has been identified as an important factor in providing patient- and family-centred care,<sup>15–17</sup> decreasing the risk of delirium,<sup>18,19</sup> and improving patient psychological recovery.<sup>19</sup> Additionally, family presence at the bedside has well-documented benefits for the family who are often extremely anxious and may be in danger of developing an acute stress disorder leading to post-intensive care syndrome<sup>5,7,20</sup> or complicated grief.<sup>21</sup>

ICUs in different parts of the world have widely diverse visiting practices, with many following policies of restricted visiting during nonpandemic times, despite evidence that open visitation reduces anxiety in family and improves patient outcomes.<sup>22–29</sup> However, globally the trend is towards increased accessibility for families.<sup>30–32</sup> In Australia, visitation during nonpandemic times is quite liberal, with many units open to visitors 20–24 h per day.<sup>33</sup> The Australian National Safety and Quality Health Service Standards recognise that the presence and participation of a support person in hospital can reduce patient anxiety and confusion and increase family satisfaction with care.<sup>34</sup> There has been extensive previous research on the effects on families of ICU patients during nonpandemic times.<sup>5,7,10,13,35</sup> The additional visiting restrictions introduced during the pandemic added another element to the ICU experience that requires further investigation.

This study explored the experiences of family members of ICU patients during the COVID-19 pandemic outbreak when visiting was severely restricted. The objectives were to understand (i) the perceived psychological, physical, and social impacts on families and patients, (ii) family experiences and satisfaction with communication, (iii) family roles in decision-making, and (iv) family participation in care.

## 2. Method

### 2.1. Design

This qualitative descriptive study<sup>36</sup> used interviews conducted in May–December 2020 with key family members of patients in the ICU during the severe visiting restrictions. The study is reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ).<sup>37</sup>

### 2.2. Setting

The study was set in the ICU of a major quaternary, teaching hospital in metropolitan Melbourne in Victoria, Australia. The ICU normally has a 56-bed capacity with some additional beds at the peak of COVID-19 waves. Each year, this ICU has approximately 3000 admissions. Apart from serving the local community, the ICU also provides state-wide services for patients with trauma, patients with burns, patients undergoing heart and lung transplantation, patients requiring artificial heart technology, patients requiring extracorporeal membrane oxygenation, patients requiring hyperbaric medicine, patients undergoing bone marrow transplantation, and HIV patients. The unit is staffed according to Australian standards with 1:1 or 1:2 nursing ratios depending on patient acuity. While a dedicated COVID area was used during the pandemic for patients admitted with COVID pneumonia, there was ongoing need

for maintaining state services and the majority of ICU patients were still admitted with non-COVID-related issues.

In March 2020, visitor access to the ICU was prohibited, with some limited exceptions for patients at the end of life.<sup>38,39</sup> Once the number of cases in the community decreased, visitors were again allowed with certain restrictions based on the enhanced standard infection prevention and control practices recommended by the World Health Organization (WHO) during previous management of infections of Middle East respiratory syndrome in 2012 and severe acute respiratory syndrome in 2003.<sup>40</sup> For example, one visitor per patient could attend each day for a maximum of 1 h at a pre-arranged time.<sup>41</sup>

Visiting guidelines at major metropolitan acute hospitals in Melbourne, Victoria, Australia, were adapted as the situation evolved. Initially in March 2020, no visitors were permitted except those with special permission when their relative was at the end of life. In April 2020, the number of cases decreased and visiting restrictions were eased, although there were minor differences in implementation between hospitals. In the study hospital, visitors were screened on entry, and they were restricted to one person per day for 1 h at an agreed time.

### 2.3. Participants

A purposive sample of family members of patients who were in the ICU during the COVID-19 visiting restrictions were recruited. In this study, a ‘family member’ was defined as any person with a close familial, social, or emotional relationship to the patient, not necessarily related to the patient by blood.<sup>42</sup> Eligible family members were older than 18 years and able to have a conversation in English. Family members of patients who were dying were not approached.

### 2.4. Data collection

Participants were recruited with the help of the ICU family liaison nurses, a role established during the pandemic to facilitate communication. They identified families who would be eligible to participate and asked their permission to be approached by a researcher. A researcher then contacted them, explained the study, and sent them information via email or post. Participants gave verbal audio-recorded consent before interview. Some patients had been discharged to a general ward before their family member was interviewed.

Interviews were conducted via phone and audio-recorded by an experienced female postdoctoral researcher/nurse (RD) who was previously unknown to the participants. The interviews were open-ended and semistructured starting with general questions. Participants were encouraged to expand on issues that were important to them. Before commencing the interview, participants were reassured that they were not obliged to discuss anything that they would prefer not to and that they were free to terminate the interview at any time; however, none did. If participants appeared upset, they were asked if they wanted to discontinue the interview or be referred to the ICU social worker for support. All chose to resume the interview after a short break, and none took the option of further support. An interview guide (aide-memoire) was developed by the researchers with reference to previous literature in this area and clinical experience and focused questions on understanding the effect that very limited access to patients has had on family members (Box 1).

Rigour was demonstrated by the consistent application of method and the appropriateness of the methodology to address the research aims. Consistency, reliability, and transferability were supported by using an interview guide to ensure that the

**Box 1**

## Aide-memoire

Due to the COVID-19 pandemic, you were restricted from visiting your relative or loved one in ICU.

- Have you had a relative or loved one in ICU previously?
- Were the restrictions imposed upon you because of the pandemic vastly different from your previous experience?
- How do you feel about the restrictions on visiting your relative in ICU? Were they reasonable/unreasonable?
- How does your family who have been restricted from visiting feel?
- How has it affected your relative who was the patient?
- How have the staff been communicating with you during this time? (In person/phone/facetime/ Telehealth?).
  - What has worked well with this way of communicating?
  - What are the challenges you have experienced?
  - How informed did you feel about your relative's progress?
  - What opportunities did you have in contributing information about your relative/their health goals/ wishes?
  - How were you able to participate in decision-making on behalf of your relative?
- How did the reduced access affect your relationship with the staff?
  - In what way?
- Besides communication with staff about your relative, what other aspects of your relative's stay in ICU were you involved in?
- Do you have any suggestions how we could improve the experience for families while maintaining the required restrictions?
- Is there anything else you wish to share with us on this topic?

participants were given the opportunity to comment on the same issues. The interviewer had extensive experience in qualitative interviewing, enhancing credibility and truthfulness. All members of the research team participated in reviewing the data, contributing to reflexivity, and ensuring that the themes faithfully reflected the content of the interviews. Interview transcripts were not returned to participants for review as the advantages of this technique are generally minimal.<sup>43</sup>

### 2.5. Ethical considerations

The Human Research Ethics Committee of the health service granted ethics approval (AH/314/20). Participants were given

written information about the study and gave recorded verbal consent before being interviewed.

### 2.6. Data analysis

Phone interviews were audio-recorded and transcribed verbatim. Analysis of the data was conducted using thematic analysis<sup>44</sup> and NVivo software (QSR International) for data management.<sup>45</sup> Themes were developed inductively as patterns in the data were identified using an approach described by Braun and Clarke.<sup>44</sup>

### 2.7. Findings

Twenty family members of patients who were in the ICU during the COVID-19 visiting restrictions were interviewed. Interviews were 28- to 55-min long. Three participants were male. The relationship to the patient included daughters (n = 4), wives (n = 6), husbands (n = 2), sisters (n = 4), mothers (n = 2), and a brother (n = 1). Demographic data other than relationship to the patient were not collected.

Data were analysed and arranged into three major themes with several subthemes underpinning them: inflexible visiting rules, family experiences of communication, and care and support (Table 1).

The themes are discussed with extracts from interviews included in Table 2.

## 3. Theme 1: Impact of restricting visiting

The inflexible visiting restrictions had a momentous impact on the family of patients in the ICU during the pandemic. Most could understand the rationale for restricted visiting but had an overwhelming need to be with their critically ill relative. Participants reported heartbreaking stories of family separation during an extremely traumatic time.

### 3.1. The visiting process

The 1-h visiting time commenced when the visitor came through the hospital entrance to be screened, and time was allocated for departure, leaving 30–40 min at the bedside. Some participants described feeling cheated of time with their relative by hospital administrators and suggested they should have a full hour by the bedside, "It doesn't take me 10 min to walk back out", and be permitted to visit both during the morning and afternoon instead of once per day. Other participants objected to the call reminding them that their visit was nearly over, as it intruded on time with their relative.

Difficulties were experienced by families that would usually have two people visiting, with one being the support person to the other visitor. There was no allowance for different needs of visiting individuals. A man with intellectual disability was accompanied by his brother to the door of the ICU where he was then handed over to staff members. His brother was very concerned about his disabled brother visiting their father without

**Table 1**  
Themes and subthemes.

Impact of restricting visiting	Family experiences of communication	Care and support
<ul style="list-style-type: none"> <li>• The visiting process</li> <li>• Separating families</li> <li>• Restrictions were distressing to children</li> <li>• Unique challenges for rural families</li> <li>• Family and staff relationship</li> </ul>	<ul style="list-style-type: none"> <li>• Staying in the loop</li> <li>• Opportunities to connect</li> <li>• Teleconferencing with families</li> <li>• Family involvement in decision-making</li> </ul>	<ul style="list-style-type: none"> <li>• Enhanced care and support for patients</li> <li>• Compensatory care and support for families</li> <li>• Suggestions for improvement</li> </ul>

**Table 2**  
Participant quotes.

	Quotes
<b>Theme 1: Impact of restricted visiting</b>	
• The visiting process	<p>1. But by the time I get up to level 1 they are going to screen me again and ask 101 questions ... exactly the same questions as the front, and when I'm at ICU I'm like no, I haven't been in contact, I haven't been in contact ... no we have to ask you the questions. Like the people at the front just asked ... (P.7).</p> <p>2. I think maybe it was 25 min, so even though it was 1 h, that was from the minute I put my foot in the door at the front ... until I got up to ICU. They estimated that it took me 'x' amount of time to get up there and then ... (P.4).</p> <p>3. There was one time they cut my visiting down by 15 min because they were going to take him in for a scan and nobody told me and I said can I make up this 15 min tomorrow? She goes 'no! (P.12).</p> <p>4. I just felt that one a day you know they had two visiting times, lunchtime and afternoon. If I came in at lunchtime, why couldn't somebody else drop in in the afternoon? But they didn't allow that at all. Once a day only (P.19).</p> <p>5. They call the bedside nurse to give you a 10-min bell to say that you've got 10 min left. That's my least favourite part to be honest. I think we are all aware that we have 40 min in there ... but it doesn't take me 10 min to walk back out of the hospital. It probably takes me a minute and a half ... it is quite frustrating when I think you know it just feels like such minimal time ... it's just dehumanising. (P.1)</p> <p>6. I think that they (visiting restrictions) were reasonable. I think we have to be careful with the pandemic and follow whatever restrictions that are in place. It's a matter of public health and being safe and respecting other people. Especially in hospitals where other people have their health conditions ... through a pandemic there has to be some rules put down that we have to follow. (P.10).</p> <p>7. I understand why they are so restricted. I mean it's COVID ... but at the same time it's depressing ... but I understand why they're doing it at the same time. (P.3)</p> <p>8. They check your temperature and ask who you are going to see and so forth and that's quite straight forward. Go straight to the lifts and then you're checked on the list for the appointment time ... If you're ahead of time you've got to wait well that's understandable and it's just one of those things (P.11).</p>
• Separating families	<p>1. Why should I not be able to sit there and hold her hand? If I was there for 16 h a day and went home to have some sleep, how do I pose to anymore risk that just being there holding her hand? I just can't come at these restrictions, it's not right. (P.13).</p> <p>2. The operation finished at 1:30 in the morning and the next morning I was there at about 8 o'clock and I couldn't go in because I had no appointment you see so I waited until about 11 before they contacted me and let me in ... it was hard for me because you know she just had a major operation open chest surgery (P.17).</p> <p>3. We asked for a catholic priest to anoint [patient]. A pastoral worker rang, and he shared that that the priest wasn't allowed in the day before ... So that was a bit distressing for us because we knew for sure and certain that [patient] would want a priest ... and so the pastoral worker gave [patient] the last rights. Now, part of those giving of the last rights you do need a priest ... so he did talk about maybe doing it via telehealth ... that was upsetting because that was something really important to us and we know important to [patient] .... [Patient] has joked since "well that's why I didn't die, I wasn't going to go out via telehealth" (P.4)</p> <p>4. They said you can take one kid in ... how do you pick a kid? I had to do that, and they said to me, but your daughter is 18. It doesn't matter that she is 18 you know she has high level anxiety, she is on the spectrum she doesn't deal with normal life ... I really felt that that was one place where families were really let down. (P.14).</p> <p>5. We have 3 children, so the other 2 children ... [name] our 2nd child and myself we alternated going in but [father] and [brother] sort of sacrificed themselves for us to be able to go in ... The 4 of us sat down and talked about it and they said that really [daughter] and I should go in ... [Father] would drive us in and then he would go and sit across the road in the park or go for a walk. That was the closest he could be to [patient]. (P.4).</p> <p>5. Having to get special permission to escort him up and then he had to stay there on his own ... I don't know if really if he was like shocked from all the machines and everything. He seemed to be ok, but he's mentally challenged ... although he is 48 it's like talking to a small child. (P.10).</p> <p>6. It's really hard that only two of us can go in there and only one at a time, because you haven't got each other for support. You get in there and the doctor tells you bad news and you're in there crying on your own. It's so awful! (P.5)</p>
• Effect on patients	<p>1. Dad to be honest was a little bit lost so he wasn't really ... especially the first few days in ICU... He hasn't really got 100% what's happening. (P.1).</p> <p>2. He was upset but I think he was more upset that they were upset ... he got upset because the kids were upset that they couldn't see him ... he would have liked to have been able to reassure them (P.14).</p> <p>3. I saw her for the first time yesterday where she was conscious. She didn't want me to go, she was just clinging on to my hand, looked frightened. (She said) I'm really sick, I'm so scared, I want you here. (P.5)</p> <p>4. He just wants me there .... he is always saying, can you come back?...umm it's hard on everyone (sounding upset) ... sorry (P.6).</p>
• Restrictions were distressing to children	<p>1. My kids are absolutely distraught. Like my 9-year-old was the one that pulled her to the edge of the swimming pool which she dived in and broke her neck. (P.13).</p> <p>2. I guess the child restrictions are hard too ... He's crying, he's distressed, he wants his mum. And he's angry ... he waved her off in the ambulance and he hasn't seen her for over a week now ... what's wrong with my mum? Why can't she come home? (P.5).</p> <p>3. if I can go in and my kids live with me why can't just one at a time? ... Just take one child to visit their father ... you know it's been almost over 2 weeks since they have seen their dad ... They're 12, 15, 17, 19. (P.12).</p>
• Unique challenges for rural families	<p>1. ... because the restrictions are only 20 min a day visiting, only one person a day. I didn't actually go down there because they had him in a coma, an induced coma ... so I thought that was pointless, but the staff were fantastic ... (P.18)</p> <p>2. Someone has to sit in the car with the four-year-old as well which makes it hard, because my mum's blind so she can't actually get herself into the hospital to see her, and that's another issue ... I think it's different if you live in Melbourne and you're local ... It's a lot of money and a lot of time. And tiredness on top of the stress and the emotional exhaustion ... logically you get it, but your heart doesn't get it ... we're sort of a family who'd be in holding her hand every day, all day if we could. (P.5)</p> <p>3. I've been trying to keep the kids as normal as possible so they can be around their friends, we've just been taking it day by day. I've been travelling up and down ... I am able to drop the kids at school and get down there and do the visitation and get back in time to pick them up ... so we were up at 7 o'clock to get the kids ready for school, dropped the kids off to school did the 2.5-h trip down drove back 2.5 h. I fell asleep for an hour and half on the couch and the kids woke me up saying "dad, can you cook us dinner?" (P.13).</p>

Table 2 (continued)

	Quotes
<ul style="list-style-type: none"> <li>• Family and staff relationship</li> </ul>	<p>4. We are down here from Queensland and are both from the country and sitting in a city apartment with not a lot to do ... we just have to find ways to fill in our days pretty much because we only get to see her for 1 h every two days (P.15).</p> <p>1. They have a job to do and they were doing their job ... and following the procedure but I didn't talk to them about it (P.19).</p> <p>2. Look I couldn't fault them that was as good as seeing them face to face they totally have everything there ready. If you were going to ask a question almost pre-empting you and giving the answers before you've even asked it. They are very, very good at their jobs. Excellent at their jobs. (P.18).</p> <p>3. They were all a great bunch of nurses, very compassionate ... they had such a happy nature about them like ... they just made you feel welcome and comfortable and always greeting you and let you know how mum was going ... and if I asked a question they were happy to answer it. They give you a bit of space and any moment you needed them to be there they were there ... just very accommodating (P.15).</p>
<b>Theme 2: Family experiences of communication</b>	
<ul style="list-style-type: none"> <li>• Staying in the loop</li> </ul>	<p>1. '... they were giving us an update every day, a nursing update, but they haven't done it (since Sunday). The doctor's rung us a couple of times but the communication's a lot less now than it was in the beginning ... they're only going to ring you if there's major changes.' (P.5).</p> <p>2. 'The staff have been calling me once or twice a day. The communication is excellent. I haven't been having to chase any information. When I come into the hospital someone approaches me and tells me what has been going on'. (P.13).</p> <p>3. A couple of times I have requested an update from the doctors that are taking care of my dad but ... there is a little bit of difficulty get through the doctors ... and I can understand that ... I am trying not to whinge about it (P.10).</p> <p>4. Usually, a doctor is visiting and asks you questions about things that happen at home or how procedures are at home ... my husband is a bit different to most because he has been permanently ill for 12 years. This time round I didn't get a phone call or asked any questions at all .... The doctor I only spoke to once .... as soon as he came out of surgery was the only time I spoke to the doctors (P.14).</p> <p>5. Every time I came in to visit him the doctors were doing their rounds and they personally spoke to me one on one when I was there. The timing I came was perfect ... (P.12).</p> <p>6. The only thing I didn't particularly like was when the registrar would come in and speak over [patient] ... I then just started to ask if we could step outside the room and speak as opposed to speaking over her. You felt that they were talking about her as this subject rather than ... because it is all very matter of fact (P.4)</p> <p>7. When doctors or consultants or registrars came and asked if I would like an update I would put them off and say "I only have this short time with [patient], can I talk to you after my 40 min?" Otherwise it was impinging on the time I have with [patient] which is short enough already (P.4).</p> <p>8. 'The doctors have been very good. I had a report probably, on an average of, every 3 days.'</p> <p>9. 'The staff were great ... his individual nurses would ring me morning, noon and night' (P.18)</p> <p>10. I called. I kept calling, I'd call in the morning and then I'd call during the day, and I'd call in the evening. Sometimes I would call at midnight just to touch base if he has had a bad day. (P.12)</p> <p>11. '... there's a lot of things that happen in there that you don't necessarily hear about. Not that you need to hear about everything, but it's only sometimes later when you listen to a nurse talking to somebody else ...' (P.9).</p> <p>12. I was listening to the nurses talking to each other because I didn't know anything ... Yeah, so you kind of fill in the information. (P.6).</p> <p>13. '... when my husband went in for the operation, they rang me and said, "he is going into the operating room now" and then they rang me again later, "the operation has started. We will inform you when the operation ends". They didn't! So, 10 h later I am worried sick thinking ... I did ring them and the operation went fine and finished at 2 o'clock, so it was a 6 and half hour operation ... and I didn't know that ... They didn't ring to say "he survived the operation" and because there was no information I actually thought the worst' (P.19)</p> <p>14. Look communication is huge, or lack thereof so more and better communication. It would be great to know that, for example at 4 o'clock each day that I am going to get a call and just a bit of an update about what happens during the day. (P.6)</p> <p>15. It was a bit of a mess because I didn't understand how critically unwell she was when she was in [country town] because she went off by ambulance and no-one contacted me till the next day. I was so angry and upset. It was horrible. (P.5)</p> <p>16. You know sitting around waiting for a phone call is just torture. I have got past that stage of thinking "I might be interrupting them". I have got to that stage where I think he doesn't have the capacity to ask to speak to us himself, so I need to advocate for him. (P.1)</p> <p>17. You'd rather talk to them face to face. It's a bit impersonal when you're on the phone, you sort of would like to put a name to the face ... I haven't seen the surgeon, the main surgeon. It's harder on the phone. (P.3).</p>
<ul style="list-style-type: none"> <li>• Opportunities to connect</li> </ul>	<p>1. There were long periods where he was ... there were medicines he had to take, and he was hallucinating and ... we just couldn't talk to him (P.14.)</p> <p>2. Once he was able to talk, he had his own phone down there we spoke a few times a day, but you know within 5 min that's it. He would want to get off the phone (P.18)</p> <p>3. The day before dad had started to wake up and manage a few words with me. Mum was super excited to get in to see him the next day to see his progress. She had her appointment time for the afternoon but then he had been sedated 5 min before mum's appointment time for a bronchoscopy ... that was quite tough on her. (P.1).</p>
<ul style="list-style-type: none"> <li>• Teleconferencing with families</li> </ul>	<p>1. He came out of surgery Monday morning and Monday night we had telehealth. The nurse hooked it up for us and next thing I know my phone was ringing 'please except this telehealth' and we managed to see him, and the kids managed to see him oh, it was amazing ... beautiful. Very nice. It was a good surprise. (P.12)</p> <p>2. ... we did video hook-up ... they're great but you want to hold your mum ... and see her in person rather than staring at a screen (P.15)</p> <p>3. I just want to sit there and hold her hand and say I love you. You didn't feel that you could with the nurse there on telehealth. (P.5)</p> <p>4. I didn't think we needed to do that (telehealth) because he doesn't have the facilities. ... They don't have the internet on at home, so that would be a bit of a nightmare to do it that way. So, we just rang him on a daily basis just to let him know what was going on ... (P.2)</p> <p>5. I was given that as an option but my husband when I spoke to him said he didn't want to do that just because he had a lot of wires and tubes and he felt that would be upsetting and traumatising for the kids so he decided we would just talk on the phone. (P.14)</p>
<ul style="list-style-type: none"> <li>• Family involvement in decision-making</li> </ul>	

(continued on next page)

Table 2 (continued)

	Quotes
	<p>1. So early on when he was first transferred to the Alfred it was more like "So what would your dad want out of this situation? ... he will hopefully be a candidate for a heart transplant, there were a few discussions yesterday whether we think he would be happy with that, and they have had little chats about that with dad now that he has more of a capacity to make those decisions. We definitely feel we have been involved in all the decision making (P.1).</p> <p>2. When they put him in ICU, they rang during that time for the breathing tube to be placed in. I think that was the first consent and then the trache was the second one. It's a matter of life I'd say there. You go along with what the doctors explain to you and its part of it (P.11).</p> <p>3. I didn't get to make a decision but she was in just a very dark place not knowing information and feeling sorry for herself thinking she is never going to walk again or move so ... she was telling the nurses that she wanted to sign a do not resuscitate ... and I said well that's horseshit, that's not happening and like where do I stand as her husband that she can't do that ... I just told her and excuse the language to shut the f**k up she's being a dickhead (P.13).</p> <p>4. The doctors sort of gave us the option if we wanted to do surgery or she would die, and we said we'll give her a go. The quality of life may be reduced. They were very honest in what they said but we felt even though it's probably not what mum wanted to do we felt we had to give her a bit of a fighting chance (P. 15).</p>
<b>Theme 3: Care and support</b>	
• Enhanced care and support for patients	<p>1. I have so much praise for both teams, here and at the [hospital 1]. They were able to get him onto the ECMO and have him actually wake and neurologically unaffected is pretty much incredible. We are just so thankful for all the care (P.1).</p> <p>2. I was absolutely thoroughly pleased with the care and attention that [patient] got. I felt he was looked after very well ... how lucky are we that this sort of thing happens in Australia? If you have an accident and you can go to a place like this? You know it is awesome (P.7).</p> <p>3. I just have great admiration, seriously just great admiration for all that has been done for [patient] in the ICU. I was really overwhelmed how caring and professional ... everything was. It's been a pretty emotional experience and they have been really supportive through that too ... I think my husband feels that way too (P.8).</p> <p>4. I am quite happy with the care given to her though ... for so long was a real big stress for me ICU have so many casual nurses ... some of these casual nurses are the younger ones. I understand that there are a lot of old experienced casual nurses but some of the younger ones but I think it's definitely a risk factor</p> <p>5. Pretty much giving him a little bath. I've always done it for him the last few years and he has been happy with me doing it. He always says, 'nah nah nah when my wife comes, she'll do it' ... it's something I have always done. I changed his bedsheets when he would get up into the chair ... get his bed all ready. Sometimes get him off the chair, put him on the bed. Whatever food he's got, which is what mainly what I bring with me from home. Help him eat it, pack it all up and get his ice ready for the night. He likes his ice in his esky bottle. (P.12)</p> <p>6. For somebody especially with delirium, I thought I was useful and helpful. So, at one point I offered to feed [patient] which he required, and it actually happened to be mealtime for the staff so one nurse had to go and relieve another nurse. I was able to feed [patient] while she went and did that, and I was able to stay a little bit longer ... but that was very carefully checked. (P.7).</p> <p>7. I massaged her feet with nice hand cream ... I read her a card from a colleague, a work colleague it was a very long card, and it brought a tear to her eye (P.4).</p> <p>8. Just holding her hand and talking to her. She wasn't very active then so ... pretty much just letting her know we were there. (P.15).</p>
Compensatory care and support for families	<p>1. I just spoke to her a couple of times, and she just ran through what we can and can't do, how to do everything, giving me numbers for different places to call, making sure that we were doing ok and just generally being a bit of a sounding board. They picked the right person for the job because she was very personable ... and caring (P.14)</p> <p>2. I'm a pretty proactive person anyway so I had already found out a lot of that information from just going through the website and that sort of thing and calling. I called ahead to find out but definitely I can see how to someone who didn't have access to all that stuff it is totally necessary. (P.1)</p> <p>3. She has rung a couple of times, but I don't really understand what the roles is. She always says 'we are here to support you, anytime you need more information you can ring here or da da da da da and then they go off along their way....it all really seems a bit superficial (P.6).</p> <p>4. I have a very close-knit family ... I work with my sister and mum and dad and friends. We all live within 800m of each other so (laughs) from that point of view we have done alright (P.14).</p> <p>5. I am pretty independent, and I can priorities fairly well and I don't sweat the small things. I think I probably do but I am trying not to ... yes, I have got a very good personal circle (P.7)</p> <p>6. The staff really made me comfortable. I was really nervous about going into the ward and they put me at ease and if it wasn't really for the staff I wouldn't have anyone else that really backed me up during that time. Even though you have people who say they support you and everything ... just the anxiety and not knowing what you are going to see or if she has taken a turn for the worst or anything the staff really helped with that ... The reception staff probably made the most positive impact ... They personalised the experience and they always made sure they used your name and the patient's name and followed up on everything. (P.16)</p> <p>7. The social worker was excellent. She kept in contact, she always returned the phone calls, she offered support for everyone ... for [son] and [husband] also for the girl who [patient] shared a unit with who started CPR on [patient] ... they offered support for her. (P.4).</p>
• Suggestions for improvement	<p>1. The Alfred admission process for family and friends is very lacking. They need more staff or better equip their staff to deal with people who are going through the worst times of their life. The Alfred needs more people at the front, and they probably need two people maybe three people. Like I think if they even had 5 people answering their phones they'd still be on the phone (P.13)</p> <p>2. If they let me in and my child lives with me, they're not going to school they are not doing anything else, yet I am allowed in. To me what difference is it to let a child who lives in that home that's not got contact with anybody ... that would be my number one thing, using their common sense in the fact that you've got people living in the same house, if I can come in what does it matter that they come in as well? (P.14).</p> <p>3. If you have the two people screened to be able to come in for the duration of their stay but we can have the option of the third if one can't make it because that was a very fixed rule. Even if we couldn't go in together even if we could have a backup so say if I couldn't go in or my brother couldn't go in at least someone could be there (P.16).</p> <p>4. We were given an hour but then given 25 min ... if you are there for an hour, why can't you be there for 2 h? (P.4)</p>

Table 2 (continued)

Quotes
5. So maybe update every day ... look, the nurses were all helpful when I spoke to them but there wasn't any other communication. (P.3).
6. Regular communication. It would be great to know that, for example at 4 o'clock each day that I am going to get a call and just a bit of an update about what happens during the day (P.6).
7. My first main suggestion would be for nursing staff to be proactive with calling families and I know that it takes time but even just 2 min to say "look he has been stable overnight, he is doing really well, would you like to have a chat with him or would you like to say hello?". Even if he is not in the capacity to talk back I just think it was really important to me for dad to be able to hear my voice. (P.1)
8. I do not know what the hospital's operational procedures and all that but it is a fair point that ICU have so many casual nurses. I understand that there is a shortage of nurses, but for an ICU ... (P.17).
9. It's probably one thing that I have been disappointed in that he doesn't have consistency in the terms of nursing staff... there is only once that I have had the same person on twice in a row. You just get a relationship and then they are gone again, and you never see them again (P.6).

ECMO, extracorporeal membrane oxygenation; ICU, intensive care unit.

support. Other examples including the visually impaired mother of a patient and an 18-year-old girl with autism visiting her father were denied the family support they needed when visiting. An older participant with a heart condition found that walking from the hospital entrance to the ICU combined with the stress of her husband being unwell was extremely taxing. Participants described the situation as "daunting", "disgusting", "rigid", and "unfair".

However, some participants without additional needs found the restrictions reasonable and were happy to comply for the greater good. One remarked, "We have to take care of public health".

### 3.2. Separating families

Restricted visiting caused intense distress for some participants. They described the traumatic situation which led to their relative being admitted to the ICU and the subsequent anguish of being excluded from visiting. The loss of control which was associated with separation was very difficult for some to accept. Some participants were very angry about the restrictions, using strong language when describing their situation. One participant said that family presence to maintain patient mental health was more important than any risk of infection. Hearing bad news without the presence of other family members was especially difficult, reporting "It's so awful!" The permitted visitor was alone when discussing the patient's condition with the doctor and had no family support when the news was grim.

Seeing the patient in person was reassuring to family. One older man whose wife was admitted with an aortic aneurysm at 8 pm returned by hour-long tram ride at 8 am the following morning and was turned away because he did not know about the visiting restrictions, and it was too early for visitors. He spent the next 3 h sitting alone in the park opposite the hospital waiting to see her to be reassured that she was still alive. He found this experience deeply distressing.

The mother from a family with a strong Catholic faith requested a priest to administer the last rites to her daughter when her daughter's condition became perilous. However, the request to have a Catholic priest enter the ICU was denied and the last rites were delivered by a pastoral care worker with a priest present via telehealth. The mother felt that this was not a valid substitute and that it was "really important" for them.

Families could nominate two visitors, but many found this difficult, describing it as "not right", "dehumanising", and "really let down". A close family of two parents and three adult children was upset that they had to choose only two people to visit for the duration of the patient's stay. They chose the patient's mother and sister which meant that the father and brother did not see the patient in person at all during her lengthy admission. They

believed they should have been permitted to rotate visiting between them.

Some patients were unconscious and not aware of their family visiting, so the effect of the restrictions on them was minimal. Other patients were very aware of their families and did not want them to leave, which was very difficult for both parties. One tearfully reported, "She was clinging on to my hand". Several participants became tearful when recounting parting scenes with their sick relatives who wanted them to stay.

### 3.3. Restrictions were distressing to children

Children younger than 16 years were barred from visiting unless granted an exemption under exceptional circumstances such as end-of-life care. Some participants were very distressed by this limitation because of the effect on the mental health of both child and sick parent. One 9-year-old boy who helped rescue his mother after an accident was not allowed to visit her in hospital. His father felt strongly that this was having a detrimental effect on his son's ability to come to terms with the situation as evidenced by the child's anxiety. Parents described their children as being "distracted", "distressed", and "crying".

### 3.4. Unique challenges for rural families

The restricted visiting time was especially difficult for rural and regional families who drove for hours to get to the hospital for a very short visit. Families had their own challenges in addition to the stress of having their relative in the ICU and the long distance from the hospital, including caring for children and managing employment or farms. One described the added trauma of distance as "a lot of money and time on top of emotional exhaustion", "a struggle", and "very challenging". One participant was juggling visiting her critically ill sister while caring for her mother and her sister's 4-year-old child. Another participant from a country town, that was a 7-h drive from the hospital, felt that the distance and expense were too great for such a short visiting time and relied on phone communication instead. Two daughters of a patient lived in rural Queensland and were staying in a nearby hotel while their mother was in the ICU. As each daughter was only permitted to visit for a short time every second day, they found the time between visits went very slowly. They believed they were wasting valuable time which could be spent with their mother or at home with their children and businesses.

### 3.5. Family and staff relationship

None of the participants felt that the visiting restrictions affected their relationship with staff members who they believed



were following government directives and not responsible for the decision to limit access to families, many describing the staff as “very compassionate”.

#### 4. Theme 2: Family experiences of communication

##### 4.1. Staying in the loop

Families felt that by not being present at the bedside, they were missing vital information and communication about their relatives. Communication with staff was very important to them but was variable and dependent on the staff on duty. Participants variably described their experiences as “disappointing”, “excellent”, and “impersonal”. Communication with nurses was generally more consistent than with doctors. Phone calls from staff were most frequent when their relative was first admitted and staff required information from the family but often decreased after a few days. Some family members took the opportunity to be updated about their relative’s progress during incidental face-to-face contact with doctors although one participant thought it took valuable time from being with the patient and preferred to speak to the doctor on the phone.

Expectations of communication frequency varied, with some satisfied with a phone call every few days, whereas others expected more frequent updates, preferably at least once per shift. There did not appear to be a standard process for staff communication with families. Some family members rang the unit several times each day to speak to the nurse at the bedside, but others waited for staff to phone them and reported feeling left out of the loop at times. Anxiety was particularly high when waiting to hear news after surgery. One participant in the study described waiting for a call from the hospital as “torture”.

Some families found telehealth (videoconferencing) a good way to connect, mainly when the patient was conscious, but others were reluctant to engage in this way because they thought it would be too distressing. One participant reported that seeing her husband via telehealth was “amazing”, but others considered it “upsetting” and “traumatising”. Notably, not all families had access to an appropriate device at home. Communicating with staff on the phone rather than face-to-face had limitations. It could sometimes be difficult for family members to know which clinician they were talking to without the visual clues that come with face-to-face encounters. Telehealth was rarely used for short communication between staff members and families.

##### 4.2. Opportunities to connect

Every contact with their unwell relative was valued by family members. Many patients were unconscious and unable to communicate; however, conscious patients could sometimes participate in phone calls or talk to visitors. Arriving in the unit to find that the patient had been taken for a test was much more disappointing than during non-COVID times because the opportunities to see each other were so limited. If a visit was cut short for clinical reasons, there was no flexibility to extend the visiting time to compensate.

Telehealth was used in the ICU for communication between patients, staff members, and families, connecting with the family at home on an electronic tablet or computer. If the patient was unconscious, the nurse might talk directly to the family and explain the patient’s condition and the care they were receiving, with the family able to see the patient. Participants had mixed reactions to telehealth. It was agreed that it had a role to play for some, but it was by no means a replacement for visiting in person. “I just want to sit there and hold her hand”. Not everyone had technical skill and

an appropriate device at home. Others found that seeing their relative in the ICU environment without being able to touch them was too distressing.

##### 4.3. Family involvement in decision-making

Decision-making appeared unaffected by the restrictions. Family members who would ordinarily be involved were still consulted, sometimes by phone and other times in person when they were visiting. Examples of decisions that would involve families included consent for surgery, commencement of end-of-life care, or intubation.

A participant whose wife had requested not to be resuscitated felt compelled to step in because he believed she was not making a sound decision because of her mental health. One family was involved in decision-making on behalf of their mother who had suffered a brain haemorrhage. Despite believing that they were going against her wishes, they decided to consent for surgery. None of the participants mentioned family meetings as a time when decisions were made.

#### 5. Theme 3: Care and support

##### 5.1. Care and support for patients

All participants reported satisfaction with care in the ICU. Some were particularly grateful for the expert treatment that their relative had received and were impressed by the professionalism of the staff members describing them as “awesome”, “supportive”, and “incredible”. Only one participant reported contributing significantly to patient care. Most participants would perform minor care tasks such as adjusting pillows or assisting with feeding if the situation arose, but none said that they had any desire to be more involved with care. “I just sat and held her hand”. The familiarity of close family could be comforting to patients, especially those with delirium. Most participants chose to maximise the emotional connection with their relative rather than contribute to physical care.

##### 5.2. Care and support for families

The family liaison nurses routinely contacted family members by phone once or twice to explain the visiting process, answer their questions, and direct them to appropriate support if needed. The liaison nurses were an important resource for some families with limited personal support, but others who were more independent had less need of their help. Participant responses varied from “They put me at ease” to “I don’t really understand what the role is”. A close network of family and friends provided all the support many needed. However, one participant, despite having a strong personal network, found reassurance from the ICU staff, which could not otherwise be provided by people outside of the ICU realm. Referrals to social work for family support were rare.

Most participant suggestions were about changing the visiting restrictions to allow more access and flexibility. Improving the admission process for visitors at the hospital entrance where there could be a queue for screening, minimised bureaucracy on admission and departure, and maximised time at the bedside. Participants described the process as “lacking”, “frustrating”, and “thorough”. Two people older than 16 years could be nominated as visitors for each patient. Several participants suggested that the hospital should be less rigid about who could visit, especially allowing an accompanied child to come in to see a sick parent. Greater leeway to nominate more than two visitors would give

families better opportunity to both spread the load and allow other close family members to visit.

Communication with staff needed greater frequency and quality of information transmitted. It would be reassuring to families if nurses called them for an update each shift even if there was no significant change. Continuity of care by familiar staff was suggested to improve the relationship between staff and family and provide more consistent care.

## 6. Discussion

This study explored the experiences of family members of ICU patients during the COVID-19 pandemic when visiting was severely restricted and communication was mostly limited to phone calls and telehealth. Restricting access to patients in the ICU was one of many strategies used to prevent the spread of COVID-19 in the hospital; however, in some instances, it caused significant trauma to families and patients. Psychological harm was evident in some participants. Communication with all clinicians became even more vital to maintain the connection between families and patients; however, modes of delivery were inconsistent. Compassion for families with extenuating circumstances including those based in rural Victoria did not always manifest.

The study demonstrates that separation of families and patients caused considerable harm. Family members reported suffering intensely from being separated from their critically ill relatives at a time when family connection was most needed. This separation and limited ability to develop a relationship with staff led some families to feel disconnected and anxious. It is well established that close family members of patients in the ICU are at risk of anxiety, depression, post-traumatic stress, and complicated grief,<sup>10,21,46,47</sup> often taking longer to recover from the critical care experience than the patients themselves.<sup>47,48</sup> In this study, the separation sometimes resulted in a lack of confidence in care, a finding which has been reported previously.<sup>47,49</sup> Increasingly, it is accepted that critical illness has an effect on the whole family,<sup>5,13,50,51</sup> causing acute physiologic shock and anxiety in some cases.<sup>52</sup> The children of patients in our study (aged 4–17 years) were reported to be confused and upset and had difficulty comprehending the reason for separation from their unwell parent, regardless of their developmental age. Children can be particularly affected when a parent is admitted, and it is known that allowing children to visit increases the child's awareness of their parent's condition and reduces feelings of separation, fear, guilt, and helplessness.<sup>53–55</sup>

In the absence of in-person visiting, communication with the clinical team was of paramount importance,<sup>56</sup> but not always done well. Consistent with recent research, both families and clinicians found that speaking on the phone or by telehealth was inferior to face-to-face communication.<sup>57,58</sup> Using a structured communication tool or bundle to prompt clinicians to address specific issues can reduce misunderstanding and improve clinician–family relationships.<sup>8,59–61</sup> Our study also validated previous findings that clear, effective communication with staff and respect and compassion to patients and families were key determinants of family satisfaction.<sup>3,62</sup>

Telehealth was used to connect with some families; however, as previously reported, it was found that there was some resistance from staff members who felt that they were too busy, the system was not user-friendly, or devices were not readily available.<sup>57,63,64</sup> Innovative technology such as the Virtual Intensive Care Unit which electronically connects families and patients via smart phones and has the potential to improve communication between patient, clinician, and the family is being developed<sup>2,63,65,66</sup> and may be more available in the future. Communication via phone and

telehealth is valuable, but the trauma inherent in having a close family member critically unwell is overwhelming, making any substitute for personal contact inadequate.<sup>67</sup> During phone calls, information is communicated to family, but empathy and connection can be difficult to convey.

Extreme distress requires a compassionate response; however, during the pandemic when infection control measures used to limit the spread of infection take precedence, person-centred care came under threat. Compassion or placing the good of others first must be the motivating force within the health system.<sup>68,69</sup> This study found that visiting rules during the pandemic were strictly followed, despite many families having very difficult extenuating circumstances. Adhering rigidly to these rules caused harm and considerable trauma to some families as evidenced by emotional discussions during interview. Sitting by the bedside of a relative battling a life-threatening illness is an instinctive demonstration of human connection and is difficult to replace.<sup>35</sup> Relationships are fundamental to person-centred care<sup>70</sup> but hard to maintain effectively during such restrictions. Imposing relationship restrictions may arguably be necessary to guard public health, but support of family and friends is a necessity to mitigate the trauma connected with the ICU.

There is an urgent need during this pandemic to support the family of patients in the ICU and facilitate meaningful engagement despite the obstacles. Families are a key link between the patient and clinicians and often play a major role in patient support and recovery after discharge.<sup>47</sup> However, some families in this study reported struggling to find a meaningful connection with clinicians and understand the practical implications of their relative's situation. The difficulty of building a relationship with staff over the phone led some to struggle maintaining trust. Local as well as rural families could feel distanced because of not being present in the ICU. When prevented from being with their relative, family members imagine the worst.<sup>11,49</sup>

### 6.1. Strengths and limitations

The main strength of this study is that it extends the currently limited body of literature by presenting an in-depth understanding of the effect of patient and family separation in the ICU to comply with COVID-19 restrictions. Families were recruited during the time that restrictions were in place; hence, recall of information was not generally impaired. This study used a small sample of family participants from one ICU in Melbourne, Australia. The inclusion of families from other facilities may reveal a more varied experience. Only family members who were able to speak fluent English were recruited; hence, we did not explore the perspectives of those from more diverse backgrounds.

## 7. Conclusion

The severe visiting restrictions introduced in the ICU during the pandemic to limit the spread of infection and protect patients and staff members have been reported to cause significant psychological and social impacts on families. In some instances, family members described suffering extreme stress when prevented from being with their unwell relative. Alternatives to face-to-face communication such as telehealth and regular phone calls had limitations. The rigidity of the visiting rules was a source of frustration to many. Alternative compassionate solutions which are more flexible and take account of individual circumstances must be introduced to limit the impact of family separation on mental health. Illogical rules related to visiting, such as preventing family from seeing the patient for the allotted time if the patient is taken for a test, need to be reviewed. Developing technological

innovations may improve communication and connection between patients, families, and staff members.

### 7.1. Significance and implications

This study explored the experiences of family members of ICU patients during the COVID-19 pandemic outbreak to determine the effect that severely restricted visiting has had on their experience. The primary reason for restricting visitors was to limit the spread of the virus to vulnerable patients and essential staff members; however, there were unintended consequences for family and patients which must be addressed. Individual circumstances must be considered in order to maintain family-centred care.

### Conflict of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

### CRedit authorship contribution statement

**Robin Digby:** Investigation, formal analysis, writing – original draft, writing – review and editing, project administration. **Elizabeth Manias:** Conceptualisation, methodology, formal analysis, writing – review and editing. **Kimberley Haines:** Conceptualisation, methodology, formal analysis, writing – review and editing. **Judit Orosz:** Conceptualisation, formal analysis, writing – review and editing. **Joshua Ihle:** Conceptualisation, formal analysis, writing – review and editing. **Tracey Bucknall:** Conceptualisation, methodology, formal analysis, writing – review and editing, supervision

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