

## ORIGINAL ARTICLE

# Parental perceptions on the impact of visiting restrictions during COVID-19 in a tertiary neonatal intensive care unit

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**Aim:** During the first wave of coronavirus disease 2019 (COVID-19), visiting guidelines in neonatal units changed to maintain the health and safety of staff, neonates, and families. In the neonatal intensive care unit/special care nursery (NICU/SCN), restrictions were placed on parental contact and extended family excluded. Our team was interested in evaluating the effect of these restrictions on parental stress and discharge confidence.

**Methods:** A prospective descriptive study utilising survey methodology was undertaken. The survey was developed and previously used by the NICU research group to evaluate parental knowledge and understanding, parental role, communication, and parental stress (admission/discharge). We have also included a section regarding COVID19 visiting restrictions (ETH.2020.LRE.00124). The survey used a five-level Likert scale. Statistical analysis was completed using SPSS version 21.

**Results:** Notably, 33 surveys were returned. Results showed visiting restrictions reduced social contact between partners 26/33 (84%), with their other children 14/16 (87.5%) and extended family 28/33 (84.8%). Parents indicated that they had high levels of confidence in understanding their babies' medical needs (78–93%) and gaining hands-on experience caring for their baby (87–100%). However, 11/33 (33%) of parents reported concerns with discharge processes and gaining consistent information as challenges during their baby's admission. Notably, 17/33 (51.5) stated their NICU/SCN experience had been very to extremely stressful. Parents openly described how the restrictions had affected their mental/emotional health identifying the need to treat parents as one unit, and a gap in the psychological support available for families.

**Conclusion:** Support services and consistency of communication with NICU/SCN families need to be enhanced and prioritised during periods of restrictions, especially peri-discharge.

**Key words:** COVID-19; developmental; intensive care; neonatology; parent.

## What is already known on this topic

- 1 Family centred care is a core tenant of a neonatal intensive care units' philosophy.
- 2 Including families in the care of their baby has increased their confidence in caring for their baby.
- 3 Social isolation and visiting restrictions in place due to COVID19 reduced family contact with neonates admitted to a NICU.

## What this paper adds

- 1 COVID-19 has impacted on neonatal intensive care units' capacity to implement family centred care.
- 2 Social isolation and visiting restrictions have increased parental stress during their baby's admission to NICU.
- 3 Parents' reported restrictions limited time with their baby, as well as with other children and their partners.

Since March 2020, the world has been facing the global public health crisis caused by coronavirus disease 2019 (COVID-19). Physical distancing and social isolation have been introduced to try to control rising numbers of cases and reduce fatalities.<sup>1</sup> To prevent transmission from unknown cases within the hospital, there have been significant changes in guidelines outlining how

and which family members are able to spend time with a baby admitted to a neonatal unit.<sup>2,3</sup>

Evidence has shown having a baby admitted to a neonatal intensive care unit (NICU) is a highly stressful experience for parents.<sup>4</sup> One of the most important aspects of a parent's NICU experience is the need to gain skills and confidence in preparation for their baby's discharge.<sup>5</sup> NICU parents are accustomed to high levels of support and guidance while caring for their baby during hospitalisation.<sup>5</sup> Family-centred programmes and peer support groups have also been shown to assist parents throughout their baby's admission and discharge home.<sup>6</sup> Family-integrated care decreases parental stress and has a positive impact on parental confidence and parental

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Conflict of interest: None declared.

Accepted for publication 6 June 2022.

role attainment.<sup>7–9</sup> The basic tenants of FIC include parents spending 6–12 h a day with their baby, increased period of kangaroo (skin to skin) care, parental involvement in all aspects of their baby's care as well as providing an education and support package for families including facilities for refreshment, rest and peer interaction.<sup>7,8</sup> It is well documented that parents gain a great deal of emotional support, guidance and practical assistance from their extended family and friends during their baby's admission.<sup>6,10</sup>

Few studies that address the impact of social isolation and visiting restrictions on parental confidence and preparedness for discharge due to COVID-19 have been published.<sup>11</sup> Griffin *et al.* completed a prospective observational cohort study. The team reviewed all mothers admitted to their service with 78 (3.6%) positive for SARS-CoV-2.<sup>12</sup> Physical Isolation of the mothers from their babies was recommended in 62 cases, which the team concluded placed a significant burden to mothers, infants and staff. An online survey to ascertain parental perceptions of the impact of restricted visiting policies was completed across six neonatal intensive units in the United Kingdom, where visitation was restricted to a single visitor. The participants viewed the policies as too restrictive 62% (138/219) and 41% (78/191) reported being unable to bond enough and 27% (51/191) reporting not being able to participate in their baby's daily care. 36% (75/209) of respondents reported the restrictions had a mild to severe impact on breast feeding.<sup>1</sup>

While COVID-19 has impacted on all aspects of health care, during the study period there had been no cases of women with COVID-19 infection birthing or babies with COVID-19 infection admitted to the NICU and special care nursery (SCN) at the Canberra Hospital. Standardised restrictions were introduced across Canberra Health Services, including the NICU/SCN. During the study period, only parents were able to come into the NICU/SCN to spend time with their baby, and for a period it was only one parent at a time once a day. This was updated gradually with restriction changes to one parent all day with the second parent allowed to visit their baby for a maximum of 1 h a day. At the onset of COVID-19 pandemic, shared facilities such as the family tea rooms were closed. Face-to-face group-based parent education and support was placed on hold due to COVID-19 restrictions. Our team acknowledges COVID-19 has affected the parent support received from both the multidisciplinary neonatal team and also from family, friends and other parents and that this may impact on parents' preparedness for discharge and emotional wellbeing. To address these challenges for future pandemics, it is essential to evaluate what affect the restrictions have had on parental stress and confidence at discharge. Through parent perceptions, we aim to review our current service to address parent needs.

## Methods

### Project aims

- To evaluate the impact of visiting restrictions implemented due to COVID-19.
- To evaluate the impact of reducing parental presence with their baby on parental stress and confidence at discharge.

### Project design

We performed a single-centre, survey-based, prospective descriptive study involving parents of infants who were admitted to NICU/SCN. The survey has been developed and used previously by the NICU research group to assess parental stress and discharge confidence (ETH.10.16.217). We updated the survey to include a section regarding COVID-19 social/visiting guidelines. The current version is composed of seven sections that include questions regarding: parent demographics, restrictions during COVID-19, parental knowledge and understanding, parental role, communication and parental stress (admission/ discharge) with open comments sections.

### Study setting

The study was completed in a tertiary NICU/SCN that provides intensive and special care for approximately 800 neonates 24–44 weeks gestation annually. The NICU/SCN admits neonates from a large geographic area that encompasses the Australian Capital Territory, Murrumbidgee and Southern NSW Local Health Districts. Approximately 30% of neonates home addresses are more than 100 km (regional) from the hospital. Parents of regional families can be accommodated in an onsite Ronald McDonald House (home care facility).

### Study recruitment

The research team developed a database of baby's discharged from NICU/SCN during the first 6 months of social/visiting restrictions due to the COVID-19 pandemic, between April and October 2020. Parents whose baby(ies) was admitted to the NICU/SCN for ≥10 days were invited to participate. Parents of a deceased baby (singleton) were excluded from the study. If a baby has been placed with a carer other than the biological parents, they were excluded from the study. Parents who met inclusion criteria were mailed a copy of the survey 4–6 weeks post-discharge.

### Data collection and analysis

Returned surveys were manually entered into an Excel spreadsheet that was exported to SPSS for analysis (version 20). Demographics included: gestation, length of admission, maternal and paternal age groups, education level and home address. The survey used a five-level Likert scale, results represented are a combination of responses to questions. For quantitative analysis results agree and strongly agree (Table 3) and very and extremely stressful (Table 4) were combined. Comparisons were made between several groups: Home address (Canberra/Regional), Gestation (<32 weeks/>32 weeks), and Time period of Admission (April–July/August–October). Analysis showed no significant differences between these groups; therefore, total group results have been reported. Thematic analysis of qualitative data was undertaken following a descriptive approach.

### Ethics approval

Study protocol and survey was approved by the ACT Health Human Research Ethics Committee's Low Risk Sub-Committee 2020.LRE.00124.

**Table 1** Characteristics of parents who completed survey

Characteristics ( <i>n</i> = 33)	<i>n</i> (%)
Parent who completed survey	
Mother	31 (93.4)
Father	2 (6.6)
Maternal age groups	
18–24	3 (9.1)
25–34	18 (54.5)
35–44	12 (36.4)
Partner's age groups	
18–24	3 (9.1)
25–34	18 (54.5)
35–44	12 (36.4)
45–54	1 (3.0)
Mothers' education level bachelor's degree or higher	19 (57.6)
Partner's education level bachelor's degree or higher	6 (18.1)
English is language spoken in home	27 (81.8)
First child	16 (48.4)
Previous child admitted to a NICU/SCN	1 (3.0)
	<b>Mean (range)</b>
Infant gestational age (weeks)	33.6 (24–41)
Infant's length of admission (days)	28 (10–120)

**Table 2** Parental feedback on COVID19 restrictions

	<i>n</i> (%)
Visiting restrictions during baby's Admission	
One parent all day and together 1 h a day	16 (48.5)
Both parents visiting separately	5 (15.1)
Both parents visiting together	6 (18.2)
All answers ticked	4 (12.1)
Single parent	2 (6.0)
Parent feedback on COVID19 Guidelines	
I received information on visiting guidelines	17 (51.5)
I felt comfortable with the social/visiting restrictions	13 (39.4)
I felt comfortable with info about handwashing	27 (81.8)
Impact of restrictions on contact with their baby and extended family	
Guidelines had an impact on the time I was able to spend with my baby	22 (66.6)
Guidelines had an impact on time I could spend with partner	26 (83.8)
Guidelines had an impact on my other children	14 (87.5)
Guidelines had an impact on contact with support people	28 (84.8)

## Results

### Characteristics of parents who completed survey

Parent surveys were completed by 33/105 parents, with mothers predominantly completing these (93%). Over 50% of

**Table 3** Parental perception of knowledge, parental role, and communication

	Agree/strongly agree, <i>n</i> (%)
Knowledge and understanding	
I was able to access parent education	18 (54.5)
I understood the medical condition and treatment	27 (81.8)
I felt that my baby was ready to be discharged from NICU/SCN	31 (93.8)
I understood the care plan and follow-up appointments	27 (81.1)
I understood my baby's expected growth and developmental milestones	25 (75.8)
I felt confident that I was able to provide a safe sleeping environment	30 (90.9)
Parental role	
I have had sufficient hands-on experience	29 (87.8)
I understand how to feed my baby	32 (96.9)
I have had adequate training and practice tube feeding if applicable	19 (90.5)
I understand how to give supplements and medication if required.	20 (87.1)
I can recognise abnormal breathing in my baby.	25 (75.7)
I know how to recognise/respond to an emergency situation	28 (84.8)
Communicating with staff	
Staff regularly communicated with me re baby's condition	28 (84.8)
Information given to me was consistent	20 (60.6)
Staff ensured I understood what they were telling me	27 (81.8)
Staff communication re plan for D/C has been clear/informative	23 (69.6)
I was given several days' notice to prepare for D/C	20 (60.6)
The D/C process felt rushed and uncoordinated	11 (33.3)

respondents and their partners were aged between 25 and 34 and for 48% of respondents this was their first child. There was a wide range of gestational ages: mean (33.6 weeks) and length of stay: mean (28 days) in hospital. Demographics are shown in Table 1.

### Parental feedback on COVID19 restrictions

Survey respondents (48%) indicated they were present in the unit when visiting was limited to one parent all day with the second parent allowed to visit their baby for a maximum of 1 h a day. Only 51% indicated they received information on the visiting guidelines and only 39% reported feeling 'comfortable' with the visiting restrictions. Notably, 82% were comfortable with handwashing information. Most respondents indicated the visiting restrictions impacted their ability to spend time with their

**Table 4** Parent's perception of stress during admission to NICU/SCN and post-discharge

	Very/extremely stressful, n (%)
Parental stressor scale during admission	
Being separated from your baby	25 (78.0)
Not feeding your baby yourself	16 (50.0)
Feeling unable to care for/comfort/help your baby	21 (75.0)
Seeing your baby having tests and procedures	17 (54.8)
Seeing your baby in pain/distress/difficulty breathing	16 (57.1)
Not understanding your baby's condition and/or progress	14 (69.5)
Overall, how stressful has it been for you?	17 (51.6)
Parental stressor scale post discharge	
My baby no longer being monitored	5 (18.5)
Going home on tube feeds	5 (38.4)
My baby having on-going breathing difficulties	6 (54.5)
The possibility of my baby having an apnoea at home	4 (22.2)
My baby still being very small	4 (20.0)
The prospect of being alone with my baby	2 (8.0)
Breastfeeding successfully at home	8 (32.0)
Overall, how stressful was the D/C process for you	7 (21.2)

baby, their partner, their other children and their other support people (Table 2). Respondents described the effects of separating parents for visiting, with many providing feedback on their perception on how detrimental it was to their mental health and increased sense of isolation, especially for first time parents. This was accentuated for first time mothers and families from outside Canberra, due to limited contact with their family. During the period when only one parent could visit, fathers described their angst as they felt they had to choose not to visit to enable their partners to be present to, spend time with their baby express and initiate breastfeeding in preparation for discharge.

### Parental perception of knowledge, parental role, and communication

Only 54% of survey respondents agreed they were able to access parental education. However despite this, survey questions relating to knowledge and understanding of their baby(ies) and their medical conditions were answered positively by most respondents (Table 3). Parents also answered positively about their confidence with their role and parenting skills. Survey respondents were positive about some aspects of staff communication; however, consistency was only reported positively by 61% with discharge planning and processes reported as unclear or rushed by approximately one third of respondents (Table 3).

Many of the participants provided responses regarding restrictions in the free text sections of the survey. Survey results

showed that only 39% of parents reported feeling 'comfortable' with the restrictions. Many respondents commented that in the context of the NICU/SCN environment it did not make sense to separate families, when parents were in the same household: in addition to highlighting the inconsistency both of the rules and adherence to them. Families felt that treating parents as a single 'entity' for infection control purposes made more sense given they were close contacts living together outside of the hospital and if one was infected both were likely to be. Comments also highlighted psychological and emotional effects of restrictions and disruptions to family structure and family life outside of the NICU/SCN. Mothers most commonly reported time with their partners or other children was limited and fathers reported that due to restrictions they had limited time with their new baby and partner. The need for more psychological support was also highlighted as being lacking but essential during their baby's admission period.

### Parent's perception of stress during admission to NICU/SCN and post-discharge

Our survey respondents found separation from their baby, feeling unable to care for/comfort or help their baby and not understanding the medical condition of the baby as the most stressful aspects of their time in NICU/SCN. Overall, 52% of participants found their baby(ies) time in NICU to be very or extremely stressful. Overall, taking their baby home was less stressful with only 21% rating it very or extremely stressful (Table 4). Ongoing breathing difficulties after discharge were stressful for those families where this was reported as an issue. Feeding-related concerns – tube feeds at home and/or breastfeeds – were a source of significant stress for a third of respondents to these questions.

When considering feedback to support families during this stressful inpatient period, respondents discuss openly the emotional impact of restrictions, with many describing positive aspects of support from lactation consultant and social work as well as the NICUCAM (password protected webcam on each bed in the SCN) access allowing families to 'see' the baby remotely. Post-discharge support with NAPSS (nursing home visiting support programme predominately aimed at preterm babies) was mentioned positively. Many also acknowledge the complexity of the ever-changing situation we all were placed in due to COVID-19, going further to thank the NICU/SCN staff for caring for their baby(ies).

### Discussion

This study has explored the impact of social/visiting restrictions on families in a tertiary NICU/SCN during the outbreak of COVID-19 in Australia. Participant responses have outlined several issues that need to be considered in future clinical practice. Participant responses reported hospital restrictions should consider the family as a unit, especially the parental dyad being considered as one when their baby is admitted to a neonatal unit.<sup>3</sup> Family-integrated models of care have supported some NICUs to consider the important of both parents as active care givers rather than as visitors.<sup>7,8</sup> Our families perceived the restrictions were too strict, highlighting the importance of following a family centred approach where specific guidelines are available to

neonatal units based on risk to neonates, staff and families while considering the family unit as one, and the effect on the whole family.<sup>1,11</sup> These results reflect the views of other researchers that initially there was little guidance available to assist hospitals with the development of NICU visitation policies.<sup>11,13</sup>

While limited evidence is currently published in relation to the impact of COVID-19, restrictions that limit the time parents are together with their baby(ies) have shown to have a significant psychological and emotional impact on the family unit.<sup>2,12</sup> Parents in our study have described their feelings of isolation and lack of social support during their baby's admission, showing how COVID-19 has exacerbated what is already a stressful experience.<sup>4</sup> Many families described the complexity of choosing which parent would visit their baby each day, with the importance of fathers often overlooked due to mother's need to provide breastmilk for their infant.<sup>14,15</sup> This study provides evidence that parental support should include psychological input. Families placed in such a vulnerable position may find it be difficult to engage with their baby and staff compounding the impact of isolation to long-term bonding, emotional closeness, and family relationship issues.<sup>2,3,11,16,17</sup> Further efforts to maintain the principles of family-integrated care principles based on the core tenet that parents are central to care their baby supported by evidence regarding the benefits of mothers' own milk, kangaroo care, early parental bonding as well as education and preparation for discharge as factors that affect both short- and long-term neonatal neurodevelopmental outcomes.<sup>7,8,13,15,17</sup>

One of the main issues described by respondents was the inconsistency of information they were given by staff during their baby(ies) admission. Consistency of information is commonly reported as being particularly difficult to facilitate due to the nature of staffing in a NICU (rotating shifts), communication between different multidisciplinary team members as well as differing communication styles and understanding levels of staffing and parents.<sup>18</sup> Single parent visiting limited the communication received by the second parent, with parents at times hearing important information from different staff members at different times. Respondents identified this was exacerbated by the continually changing advice regarding COVID-19 restrictions, with half reporting not receiving written information on visiting guideline. While staff will have communicated with families about restrictions, this response highlights that many families felt inadequately informed and a more systematic approach to information provision may have been required. Families were not quite sure if they would be able to visit their baby on any given day and how that would impact on spending time with their baby, highlighting the challenges of supporting family-integrated care during the turbulence in the early stages of the pandemic.<sup>11</sup> The study NICU/SCN has webcams in SCN that allow families to see their baby from electronic devices and survey respondents described the benefits of seeing their baby from home and sharing with their family but as suggested there is a need to develop alternative means of communication with families, through video conferencing, text and phone calls.<sup>2,11</sup> Respondents also described the process of discharge as being rushed and uncoordinated. Transitioning to discharge for a baby in NICU/SCN has been identified as a period of higher anxiety for families and providing information and training parents is required for them to gain confidence and be prepared to take their baby

home.<sup>19–21</sup> Evidence has shown initiatives such as the implementation of a communication framework that is based on (i) building/maintaining relationships; (ii) exchanging information; (iii) (sharing) decision-making and (iv) enabling parent self-management may facilitate family-integrated care.<sup>22</sup> Both parents need to be provided information to improve their health literacy and family support during and post discharge to facilitate discharge and potentially reduce readmission and provide cost-savings. Supports may be both practical and psychological through interventions that include technology and home services.<sup>19–21</sup>

## Limitations

This study is limited by the relatively small number of respondents from a retrospective single centre which may create bias and limit generalisability. This study was prior to vaccination, widespread community mask use and the delta/omicron outbreak all which affect risk of transmission, consequences of infection and parental perception. We also acknowledge stress levels and resilience of parents may have been affected by several life-style factors and these families may have been directly affected due to pregnancy during a terrible Australian bushfire season in addition to the wider effects of COVID-19 on family members locally, interstate and internationally. There is no published comparative pre-COVID-19 control group to quantify the changes related to social visiting restrictions. However, the study group surveyed a small number of families of extreme preterm infants at discharge in 2016 ( $n = 10$ ). Interestingly despite being a more preterm cohort (95% less than 32 weeks gestational age) with a longer length of stay (10–15 weeks), the overall percentage of parents reporting high stress was similar at discharge (21% vs. 20%) but less during admission (40% vs. 50%). If it was not for COVID-19, this preterm cohort would be expected to experience a more stressful NICU stay than our current study group.

## Future research

This project provides an important milestone in the effect of COVID-19 restrictions on NICU families early in the history of the pandemic. Expanding the survey to other hospitals and at different times during the COVID-19 pandemic with changes in COVID-19 numbers, changes in community behaviour, emerging strains and vaccination status is important to quantify the effects of the pandemic on families. Repeating this study with future refinements of visiting policies, innovative COVID-19 safe parental supports, and other mitigation strategies that support less restrictive visiting (masks, vaccinations, rapid testing) will help to identify the strength and weaknesses of such programmes.

## Conclusion

COVID-19 restrictions have had a significant impact upon the families of NICU/SCN babies increasing the stresses on families during an already stressful time. This survey has identified some of the short-term impacts; however, long-term impacts on family functioning, bonding and child development are yet to be assessed. These results are important in the design of supportive family-integrated and COVID-19 safe environments for neonates



that minimise harms to families. This highlights the complexity of balancing COVID-19 risk versus emotional burden to families.

## Acknowledgement

Staff time and study costs (printing, etc) were provided within the budget of the Department of Neonatology, The Canberra Hospital, as part of routine quality improvement and clinical activities. Open access publishing facilitated by Australian National University, as part of the Wiley - Australian National University agreement via the Council of Australian University Librarians.

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