

ORIGINAL ARTICLE

Exploring the needs and coping strategies of New Zealand parents in the neonatal environment

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Aim: Having an infant admitted to a neonatal care facility can be highly distressing for parents given the fragile state of their child and the often-unfamiliar environment. This study aimed to explore the needs and coping strategies of parents in this setting.

Methods: An online qualitative survey was used to explore the needs of parents who had a child discharged from a New Zealand neonatal unit in the past 12 months. A total of 394 parents participated in the study (387 mothers, 5 fathers), providing 970 responses across three open-ended questions examining their needs, unmet needs and coping strategies. The study included participants across both neonatal intensive care units and special care baby units, with prematurity (47%) the most common reason for admission. An inductive form of thematic analysis was used to analyse the data.

Results: Four themes were developed that capture the needs and coping strategies expressed by parents in this study: communication and information; physical contact and access to the baby; emotional and non-medical support; and involvement, autonomy and respect.

Conclusions: The themes developed largely centre around the struggle parents face when confronting the uncertainty of the neonatal environment and the difficulty in establishing their parental role. Parental distress may be reduced through communicating accurate information regularly and providing empathetic understanding, while opportunities for physical contact and involvement may assist in raising parental confidence and scaffolding the journey to independent care of their infant.

Key words: infant; needs of parents; neonatal care; neonatal intensive care; neonatology.

What is already known on this topic

- 1 The neonatal experience can be a psychologically distressing time for parents
- 2 Parents of neonatal infants have a range of needs and rely on a variety of coping strategies in response to unmet needs

What this paper adds

- 1 A number of parental needs continue to go unmet for New Zealand parents of neonatal infants
- 2 Accurate and regular communication, empathetic understanding, opportunities for physical contact, and parental involvement may assist in reducing parental distress within the neonatal environment
- 3 Parental needs in the neonatal environment can evolve over time, such as the growing importance of online support groups

Neonatal care facilities are specialised medical units focusing on the care and treatment of vulnerable infants, including those born prematurely, at low birthweight or with congenital abnormalities. These facilities are typically categorised into levels relating to the needs of the infants for whom they provide care. Level III or neonatal intensive care units (NICUs) provide the highest

level of care with facilities equipped to treat extremely premature babies (i.e. from 24 weeks gestation). Level II units or special care baby units typically provide care for babies born from 32 weeks and above, with some units (i.e. Level II+) equipped to provide care for infants over 28 weeks.¹ While advances in technology have led to increases in rates of admission and subsequent survival,² the admission of a child to a neonatal unit can be a distressing experience for parents. A clearer grasp of how to manage the distress that typically accompanies parents throughout this experience is required.

In many ways, the neonatal experience presents a perfect storm of disturbance to the expected parental journey. The overwhelming and unfamiliar environment, the physical separation from their infant, the visual fragility of the newborn and the

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abrupt disruption to the anticipated parental role all contribute to parental distress.³ As a result, the initial introduction to the neonatal unit typically elicits feelings of guilt, anxiety and depression among parents.^{4,5} The harmful effects of this turbulent period of separation are not isolated to the experience itself; rather, the impact of neonatal admission can be felt long into the future, with associated negative outcomes for both parent and child.^{6,7}

With this in mind, it is important to understand the type of support that can provide parents with the best possible outcomes. An integral step towards this is gaining a comprehensive understanding of the needs parents typically have during this period. A systematic review conducted by Cleveland⁸ provides an overview, identifying the presence of six recurring needs: the need for information and feeling included in the care of the infant; the ability to protect the infant by vigilantly watching over them; physical contact with the infant; the feeling of being perceived positively by staff; individualised care; and the development of a therapeutic relationship between the parents and the nursing staff. A recent integrative review by Adama *et al.*⁹ found six similar themes: information needs, emotionally intelligent staff, hands-on support, targeted support, emotional needs and practical needs. Research has demonstrated that parents of neonatal infants rely on a variety of coping mechanisms in response to these needs, including participating in the infant's care, absence from the unit, information gathering, reliance on family and friends, and engaging with other families in the unit.¹⁰ Extant literature has largely focused on mothers and emphasises the importance of understanding which of their needs are going unmet. When needs are not met, this can cause stress and possibly precipitate a crisis; in contrast, when individual needs are met, mothers display greater responsibility and a sense of confidence in their parental role.¹¹

While the studies reviewed in the aforementioned papers provide a useful foundation for understanding parental needs and coping strategies within the neonatal environment, the majority of this research has been conducted in North America and Europe. Contextual research is important in this area given the differences across the health-care systems and demographics between countries, which is particularly salient considering New Zealand's unique characteristics. The country has a culturally diverse population,¹² low population density,¹³ and a centralised approach to many specialised health-care services that has been criticised in the past for its inaccessibility for rural populations.¹⁴ While local studies in the area have been published recently,^{15,16} there is still a lack of research examining the needs of New Zealand parents of neonatal babies. This study aims to address that gap by exploring the parental needs, coping strategies used and the extent to which these needs are being fulfilled for New Zealand parents of neonatal infants.

Methods

Research and survey design

The data for this study were collected via open-ended questions within a larger survey hosted on Qualtrics that also contained quantitative items used to test hypotheses not addressed in this manuscript.¹⁷ Ethics approval for the overarching study was granted by Massey University's Ethics Committee Southern A

(Application 18/64) on 5 November 2018. Informed consent was obtained from participants. Although the present study reports only exploratory (non-preregistered analyses), the overarching study was preregistered at <https://osf.io/28sn6>. Qualitative data relevant to the present study were collected from the three open-ended questions. These questions asked parents: (i) to list any needs they experienced during their neonatal stay as the parent of the baby; (ii) to list any methods they found helpful in meeting these needs; and (iii) whether any of their needs went unmet and to list them if that was the case. Participants answered these questions using open-ended text boxes, providing parents with the opportunity to describe their experiences in their own words. A decision was made after the data had been collected to analyse the responses from these three questions in a separate study due to the sheer volume of data that was collected. As such, a specific sample size was not pre-determined prior to the present study. However, data saturation was reached due to the lack of new codes and themes by the end of the analysis.

Table 1 Demographic characteristics of the sample

Parent details	Mean	n (%)
Age	30.9	
Gender		
Female		385 (97)
Male		8 (2)
Gender diverse		1 (0)
Ethnicity		
Pākehā/New Zealand European		343 (87)
Māori		44 (11)
Asian		10 (3)
Southeast Asian		8 (2)
Pacific peoples		10 (3)
Other		31 (8)
Education level		
Primary school		1 (0)
Intermediate school		5 (1)
Secondary school		91 (23)
Technical or trade certificate		44 (11)
University or polytechnic diploma		65 (16)
University degree		187 (47)
Employment status		
Employed full-time		55 (14)
Employed part-time		40 (10)
Unemployed		76 (19)
Retired		0 (0)
Student		8 (2)
Maternity/Paternity leave		203 (52)
A sickness benefit		12 (3)
Relationship to the baby		
Mother		387 (98)
Father		5 (1)
Children in household		
0		192 (49)
1		117 (30)
2		53 (13)
3		19 (5)
4+		13 (3)

Table 2 Neonatal admission characteristics of the sample

Neonatal admission details	Mean	<i>n</i> (%)
Level of unit admitted to		
Level II		117 (30)
Level II+		53 (13)
Level III		224 (57)
Reason for admission		
Prematurity		187 (47)
Small for gestational age		30 (8)
Illness		81 (21)
Other (e.g. heart condition)		95 (24)
Infant birthweight, g	2627	
Length of time admitted, day	31.9	
Multiple infants (e.g. twin)		
Yes		43 (11)
No		350 (89)

Setting and participants

New Zealand has a total of 23 units spread across the country that are equipped to provide neonatal care and includes units at level II, level II+ and level III. Level I units also exist, but are less common in New Zealand and typically provide care to infants with minimal complications. The present study included parents with an infant admitted to a level II, level II+ or level III unit (Tables 1, 2). While parents admitted to a level I unit were also eligible, given the limited population admitted to these units, none completed the survey.

All participants had an infant admitted to a neonatal unit in New Zealand between March 2018 and June 2019. No restrictions were placed on age, length of stay or severity of condition. Those who were admitted beyond the last 12 months or answered 'no' to the consent question were excluded. On average, the infants of the parents in this study were admitted for 31.9 days (range = 1–467 days, SD = 64.1) with prematurity (47%) the most commonly cited reason for neonatal admission. Recruitment was achieved primarily through Facebook advertising and posters across the Palmerston North neonatal unit. As an incentive, participants went into the draw to win 1 of 10 \$75 GiftPay vouchers.

Data collection and analysis

To qualify for the present study, participants had to be the parent of a child discharged from a neonatal unit in New Zealand in the past 12 months and provide a response to at least one of the three open-ended questions. The median completion time was 14.6 min. An inductive form of thematic analysis was adopted to analyse the data, largely following the guidelines outlined by Braun and Clarke.¹⁸ This approach was selected for its flexibility, its suitability for working with substantial data sets, and its facilitation of data-driven analysis. NVivo 12 was employed to support the analysis of the data. A 'bottom up' inductive approach was used, with themes developed through an exploration of the specific words used by the parents in this study as opposed to applying a preconceived theoretical framework to the data. Analysis

and coding of the data were conducted by the lead author (AD) with input from the remaining authors. The lead author is a postgraduate psychology student with 7 years of experience conducting commercial qualitative market research.

Reflexivity statement

The lead author is a male Pākehā with no children or lived experience of a NICU admission. The second author is a young female Pākehā with no children or lived experience of a NICU admission. The third author is a male Pākehā with one young child, but he has not had lived experience of a NICU admission. The fourth author is a female Pākehā with two children (one young adult, one teenager) with lived experience with both children of NICU admission. In interpreting the data, the lead author was cognisant of how his gender, lack of parental experience and lack of neonatal experience were all relevant and limiting in terms of his understanding of the data. However, the lead author was able to draw upon the relevant experiences and input of the other authors throughout the analysis.

Results

In total, 394 parents (387 mothers, 5 fathers, mean age = 30.9 years old, range = 17–45) participated. 970 responses were provided across the three questions; 385 responses were received for the identified needs question, 313 responses for the unmet needs question and 272 for the coping strategies question. Overall, the analysis revealed a multiplicity of needs and coping strategies with a high degree of variability regarding whether parents felt their needs had been fulfilled. Four overarching themes were developed through the thematic analysis: communication and information; physical contact and access to the baby; emotional and non-medical support; and involvement, autonomy and respect. Considering how participants' needs, unmet needs and coping strategies were inextricably linked across their responses, the themes take into account the responses received across all of the questions.

Communication and information

The most prevalent need expressed by parents was the need for communication and information. An induction to the unit that included information around expectations, the support available, a structured plan and milestones on the path towards discharge was welcomed by those parents who received it, but not always provided. A perceived lack of accurate and regular updates on their infant's condition was also a source of distress for many parents. Inconsistent information was particularly disruptive, with some participants left feeling anxious following miscommunications that occurred at times during handovers between nursing staff and doctors.

One parent recalled:

There was poor communication between staff in the unit, leading to conflict with staff, inconsistencies in the care of my baby, and a lot of stress! (Mother, 39 years old)

To cope with the perceived lack of communication, parents recalled seeking out their own information through online searches, online support groups, talking to other families in the ward, and directly asking questions to staff.

Physical contact and access to the baby

While the fragile state of infants admitted to neonatal care units and the equipment used in response to their medical instability often resulted in restricted opportunities for parent-infant contact, this did not dampen parents' desire for physical contact with their baby. As such, opportunities for skin-to-skin touching and breastfeeding were cherished by many and seen as valuable opportunities for bonding.

One parent recalled:

I needed to have physical contact with my twins so that I could bond with them. I felt this was important as there was very little I could do to care for them in the early weeks so just being able to hold them and be near them was very special. (Mother, age not provided)

In lieu of unrestricted physical contact, parents often expressed a need to be present and visit their baby as often as possible. When staying in a separate room, parents typically appreciated it when nurses contacted them when the baby had awoken and was ready to be fed.

Emotional and non-medical support

The neonatal experience was often recounted as emotionally exhausting for parents, with some expressing that staff should have demonstrated greater empathy and understanding of the emotional difficulties that being abruptly thrust into the neonatal environment entails. Additionally, many parents felt their needs were overlooked and that offering more mental health resources would be welcomed. When such support was found lacking, parents recalled relying upon their spouse, immediate family members, other families in the unit, online support groups, and friends with experience in a neonatal unit.

One parent recalled:

I felt only useful to feed my baby. Their sole concern was for my baby and there was no support offered for me. I feel like that's why I can spontaneously cry when I think about that time, even though my boy is thriving now (Mother, 33 years old)

Involvement, autonomy and respect

Parents often expressed a desire to be involved in their infant's care and to be included in the decision-making process. While the expertise of the neonatal staff was respected and the needs of the infant were rightfully prioritised, parents often recalled feeling impotent regarding previously held expectations of their parental role. This was somewhat alleviated for those who felt they were kept in the loop, involved in two-way conversations and encouraged to be active participants in their infant's care. When this was not the case, parents were often left feeling that

their voice was neither respected nor heard by staff and that the baby was not theirs but rather under the guardianship of the unit.

One parent recalled:

We had to push for discussion with staff as opposed to just being told what was going to happen – we wanted to have a discussion and make decisions ourselves. (Mother, 38 years old)

A lack of privacy and a perceived absence of understanding regarding issues such as low milk supply left some parents feeling that their well-being was compromised. In such situations, parents recalled pushing for greater involvement, having their partner or midwife advocate for them, or seeking emotional support from personal sources. Some parents commented on how involvement in their infant's care boosted their confidence and left them better prepared for discharge; for others who felt these opportunities were lacking, discharge represented a genuine fear as they were concerned about their ability to independently care for their child.

Discussion

The four themes developed in this study capture how parents experience the often-challenging neonatal environment. To cope with uncertainty, parents appreciate consistent communication and empathetic understanding, while they seek the opportunity for involvement and physical contact with their infant to reclaim a sense of their parental role. These themes are largely in line with the suggestions made by existing international research to support neonatal parents. For instance, Brett *et al.*¹⁹ draw attention to the importance of encouraging and involving parents in care, including parents in information exchanges, and the role of support groups. While similarities can be drawn between the findings of earlier reviews by Cleveland⁸ and Adama *et al.*,⁹ differences were also found. For instance, while Cleveland⁸ recognises the role of peer support, this study suggests that online support groups – particularly through social media platforms – now play a more prominent role in meeting the emotional and informational needs of present-day neonatal parents. Reliance on such forms of support will likely increase with time, representing an avenue for future research.

Several important implications emerge from these findings. A consistent message is the importance of encouraging parental participation in an infant's care and keeping parents regularly informed of their baby's condition. If desired, encouraging parental involvement – particularly skin-to-skin contact – may gradually bolster their confidence and self-efficacy.^{20,21} This can be further enhanced by communicating with parents regarding their child's progress, providing individualised information on their infant's condition, and ensuring that parents feel their voices are heard regarding decision-making. This is in line with recent local research in the area, with a study by Hames *et al.*²² finding that the provision of appropriate information at different stages of the neonatal journey can allay concerns and alter parental perceptions of treatment efficacy and understanding of their infant's condition. Another consistent message from the present study is how encouraging parental participation in care and providing regular information not only addresses a

desire for control amidst uncertainty, but may further assist in supporting independent parenting. Additionally, the present study supports recent research recommending more structured and individualised discharge plans that can alleviate uncertainty for parents and assist in scaffolding the road to parenting outside the neonatal environment.^{23,24}

This study emphasises that medical care and support should be delivered with empathy and understanding by staff, within optimally collaborative relationships. When adequate emotional support is absent, participants' responses indicated that vulnerable emotional states can be exacerbated and unnecessary emotional distress caused. Participants typically demonstrated a reliance on authentic sources of support, including other families in the ward, contacts with neonatal experience and online support groups. These groups were seen as offering a form of emotional support and trusted information that transcends what the unit itself can provide. While this should not be viewed as a substitute for professional care, it can play an important complementary role.

Limitations

There are several limitations of this study. Firstly, the depth of the answers was limited by the open-ended text response format of the questions. Given the sensitive nature of the topic, aspects of face-to-face interviews such as tone and non-verbal communication would likely have enhanced the richness of the responses. Secondly, this study had a notable lack of responses from fathers and those that did respond were typically reticent to speak directly to their individual needs. Some mothers also recounted how opportunities for participation in their child's care were directed at them rather than the father, and that fathers were not readily offered accommodation and meals. While this may be suggestive of the secondary role fathers are tacitly assigned within this environment, the ability of this study to draw conclusions based on so few responses from fathers themselves is limited. Lastly, no criteria regarding the length of admission were applied. It is reasonable to assume that parental needs and coping strategies differ across the period of time spent within the neonatal environment.

Conclusions

The present study identified four themes that are largely centred around how parents respond to the uncertainty of the neonatal environment alongside a strong desire to fulfil their parental role. Providing parents with consistent and accurate information and treating them with empathy and understanding may contribute to alleviating the distress many parents experience during this time. Additionally, providing opportunities for physical contact and parental involvement may foster confidence and a greater sense of autonomy that can scaffold the journey to independent care for their infant. Parents also expressed a need for emotional support. While informal sources of support such as online support groups should not be considered a replacement for appropriate mental health care in the neonatal unit, the support and lived experience offered by members of such sites may complement more formal sources of mental health support.

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Nature's embrace by Andrea Pinto (age 15) from "A Pop of Colour" competition, Children's Hospital at Westmead Art Youth Program