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ORIGINAL ARTICLE

Parental experiences of family-centred care from admission to discharge in the neonatal intensive care unit

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Aim: It has been increasingly recognised that family-centred care (FCC) is associated with enhanced well-being for both parents and infants in paediatric settings, including the neonatal intensive care unit (NICU). Over the past 4 years, our NICU has increasingly adopted a collaborative philosophy of care. The purpose of the study was to examine parental experiences of FCC during both the admission and discharge time points in order to examine differences in parents' experiences and identify areas for improvement.

Methods: We conducted interviews at two time points (admission and discharge) with 83 parents (mothers and fathers) of premature and medically fragile infants and analysed the data using thematic analysis.

Results: Three key themes (and sub-themes) were identified: disempowerment, hierarchy between parents and staff and the father's peripheral role. The themes were equally prevalent across admission and discharge.

Conclusions: The challenges relating to FCC reported by parents at both admission and discharge represent some of the key barriers that parents still face in terms of being truly involved in the care of their infant in the NICU. Similar themes at both time points suggest that parents need equal amounts of support during their stay in NICU, irrespective of the level of care the infant is receiving and whether they are approaching discharge. Implications for improving FCC more generally are discussed.

Key words: neonatal intensive care unit; New Zealand; parent; premature birth.

What is already known on this topic

1 Increasingly neonatal intensive care units have adopted family-centred care (FCC) to meet the developmental needs of infants and include parents in their care.
2 Despite increasing discourse surrounding FCC, questions remain about successful implementation and whether parents have unique needs at admission and discharge.

What this paper adds

1 Significant obstacles to FCC were reported.
2 The challenges reported by parents did not noticeably differ between admission and discharge nor between the level of care.
3 This suggests that parental needs for FCC stay relatively consistent during the entire neonatal intensive care unit stay.

Parents of infants admitted to neonatal intensive care units (NICUs) have been shown to experience high rates of psychological distress in comparison to parents of full-term, healthy infants.[1–3] The American Academy of Pediatrics has advocated that paediatric settings adopt family-centred care (FCC),[4,5] an approach in which the child's family collaborates with healthcare providers and which ensures that the child's developmental and psychosocial needs are met. Interventions using FCC in NICUs have shown positive effects on both short and long-term infant health and developmental outcomes,[6,7] positive long-term effects on mother–child interactions[7] and reduced length of hospital stay,[8–10] as well as increases in both parental and staff satisfaction.[11,12] Moreover, studies have also identified that nurses are generally interested in FCC and want to receive training and, above all, leadership to incorporate FCC into NICUs.[13]

Despite promising evidence for implementing FCC in NICUs, both quantitative and qualitative studies have identified many obstacles to doing so, including staff behaviours reinforcing the traditional notion of NICU staff as 'gatekeepers' of the infant,[5,14,15] staff workloads, lack of FCC facilities and inadequate training.[14,16–19] Furthermore, the literature on FCC lacks sufficient large-scale studies and randomised trials demonstrating which aspects of FCC are the critical components related to both morbidity and cost-effectiveness outcomes.[18] This is partly why FCC varies considerably amongst NICUs[18,20] and why some have suggested that implementing FCC in NICUs has stalled.[21]

In light of the increasing discourse surrounding FCC, a qualitative study was carried out in our NICU in 2012 (DJ Garton, *The Role of Providing Developmental Care for Babies Born Less than 30 Weeks Gestation in the Newborn Intensive Care Unit: A Maternal and*

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Nursing Perspective, unpublished Master's thesis, 2013), which examined both mothers' and nurses' experiences of developmental care, a philosophy that encompasses FCC principles. The findings demonstrated that, although there were some aspects of developmental care that were being delivered, there was a lack of consistency in how it was applied. Nurses also reported the need for further education and training in FCC and highlighted time constraints, workload and lack of leadership as barriers to FCC.

Since the 2012 study was undertaken, our NICU has increasingly adopted a collaborative philosophy of care, which focuses on working in partnership with families. We were therefore interested in examining the experiences of parents with infants admitted to the NICU within this new framework of collaborative care. We were especially interested in examining parents' perceptions and satisfaction with care at both the admission and discharge time points, which may have unique stressors and challenges. To our knowledge, no previous studies have compared parents' experiences at both admission and discharge from NICU. Previous research has utilised cross-sectional or retrospective designs, which have methodological limitations. We also wanted to examine the experiences of both mothers and fathers as, until recently, fathers' experiences and stressors, especially within an FCC framework, have been largely overlooked.[22,23] Our study thus had three objectives: (i) examine parental feedback on how well we are currently delivering FCC; (ii) examine whether differences exist between admission and discharge; and (iii) examine the unique experiences of both mothers and fathers.

Methods

Setting

This study took place at the National Women's Health NICU, a tertiary hospital and New Zealand's largest NICU, which admits around 1000 infants annually. There are 16 intensive care and 30 high-dependency care and low-dependency care cots. There are also four parent rooms within the NICU, used mostly to accommodate parents to be with their baby for 1–2 nights prior to discharge. The NICU team consists of neonatologists, registrars, clinical charge nurses, nurse educators and nurse specialists.

Study design and participants

Eighty-three parents of medically fragile and premature infants admitted to the NICU in Auckland were recruited in 2016 to participate in a mixed-methods study. Our aim for the qualitative component was to examine parents' overall experiences of care across the NICU admission, their perceptions of NICU staff, how information was received and their suggestions for improving care in the NICU. Parents were interviewed at admission and discharge. Parents whose infants were receiving palliative care, parents experiencing severe psychological distress, parents with complex psychosocial circumstances and parents whose infants were admitted for an overnight stay were excluded.

A consecutive sampling method was used to recruit eligible participants. We interviewed all participants who were recruited for the mixed-methods study as we wanted to examine the frequency of themes and whether themes differed between admission and discharge (83 admission interviews and 78 discharge interviews were coded in total). We followed the Consolidated Criteria for Reporting Qualitative Studies checklist.[24]

The study received ethics approval from the University of Auckland Human Participants Ethics Committee (reference number 017182).

Data collection and theoretical approach

The parents' and infants' characteristics were assessed in the baseline questionnaire or extracted from clinical records (Table 1).

The recruiting and interviews were conducted by a postgraduate student (J Hames) with one parent or both parents in a private interviewing room in the NICU. The parents were given the option to be interviewed together or separately. A semi-structured interview schedule was used to guide the interviews and was used at both time points (Table 2). The questions did not ask about FCC but rather about care in general.

The interviews were recorded by hand by J Hames (verbatim note taking) and written up directly after each interview. The decision not to audio record was to allow the participants to freely give feedback on their experience in the NICU. The use of field notes is often used in mixed-methods studies, which allows a cost-effective method for gathering a large sample of qualitative data.[25]

After transcription, two members of the study team (A Serlachius and J Hames) and an external researcher coded the interviews and grouped the data into themes. Where differences arose, the three researchers met to resolve any coding differences, in line with the qualitative process of investigator triangulation. A list of key themes and a selection of transcripts were also reviewed by the rest of the research team.

We analysed the qualitative data using theoretical thematic analysis (a deductive approach), as we had specific research questions in mind.[26] We analysed the data at an interpretative level, whereby we aimed to understand the underlying assumptions rather than just the semantic content of the data.[26,27] Due to our large dataset and our interest in examining whether themes differed from admission to discharge, we also examined the prevalence of themes by reporting how many interviews contained a particular theme.

Results

Participants

We interviewed 63 mothers and 20 fathers of whom 40.7% were European New Zealanders, 19.7% were Māori or Pacifica, 20.5% were Indian, and 18.4% were other ethnic groups (Table 3). The mean age of the parents was 32.5 years (standard deviation 6.2). A majority of infants were admitted to NICU due to prematurity (Table 1). A majority of infants (61.9%) were admitted to Level II (high-dependency care for stable infants), and 38.1% had been admitted to Level III (high-dependency care for very low-birthweight infants).

Themes

Three key themes (with sub-themes) were identified: (i) disempowerment; (ii) hierarchy; and (iii) fathers' peripheral role

(Table 4). The identified themes centred on parents' perceived challenges of FCC from admission to discharge. Due to space constraints, we have not included themes relating to perceived enablers of FCC, which included 'staff support' and 'family-friendly spaces'.

Disempowerment

The first theme focused on factors in the NICU that contributed to parents feeling disempowered in their role as a care giver. The two sub-themes included: (i) lacking control; and (ii) ownership and proximity to baby.

Lacking control

Parents frequently discussed their need for more information and to feel involved in the care of their infant as this helped them feel more in control and less anxious in an otherwise highly stressful and uncertain environment. One mother said: 'Not being allowed to read his files was stressful. It's all about my baby. I wanted to know everything going on. It's my baby and me. It puts you at ease knowing what's happening' (Mother, Discharge, #18). A father described how he wished clinical staff would consult parents on all decisions: 'Every decision I want doctors to talk to parents. Give us some preparation' (Father, Discharge, #24).

Many of the parents also spoke about how they often felt like bystanders simply watching their child and how helpless this made them feel: 'This information wasn't volunteered and I didn't know what to ask. You can't be with them all the time and what can I do. You twitch [twiddle] your thumbs by the incubator while they're sleeping' (Mother, Admission, #40).

Ownership and proximity to baby

A theme often co-occurring with lacking control was sense of ownership and needing to feel close to their baby. For example, many parents reported feeling frustrated at not being allowed to read their own child's medical files (the 'red file'), despite being his or her rightful guardian: 'I would like to be more informed-I would've liked to know as much as possible. And I want to read the red file but we're not allowed unless we do it with a doctor. He's my son. I want to know everything' (Mother, Admission, #1). Another father emphasised the importance of proximity: 'We have to go home every day and come in twice a day … . Our presence with our baby. We want to be close. For nearly everything' (Father, Admission, #47).

Table 1 Infant characteristics

Infant characteristics	All admissions, *n* = 67
Gender, *n* (%)	
Female	33 (49.3)
Male	34 (50.7)
Gestation, weeks, mean (SD)	33.7 (3.9)
Preterm, *n* (%)	55 (82.1)
Full term, *n* (%)	12 (17.9)
Birthweight, g, mean (SD)	2019.3 (828.6)
Length of stay, days, mean (SD)	28.7 (27.2)
Parity, *n* (%)	
Singleton	56 (83.6)
Multiple	11 (16.4)
Diagnosis, *n* (%)	
Prematurity	30 (44.8)
Respiratory distress syndrome	9 (13.4)
Intra-uterine growth restriction	8 (11.9)
Hypoglycaemia	4 (6.0)
Jaundice	3 (4.5)
Surgical	2 (3.0)
Other	11 (16.5)

SD, standard deviation.

Table 2 Interview schedule

1 To begin, I'd like to start off by getting to know a bit more about you and your family. Can you tell me about the events leading to your admission?
2 What aspects of your baby's admission to the unit have you found the most stressful?
3 What did you find most helpful from the staff during your baby's admission to the unit?
4 After your baby was admitted to the unit, how have you received information about your baby's condition, the progress they've made and the procedures they have gone through?
5 Do you have any other comments about your experience with having a baby in the unit? Maybe you would like to comment on what made things better or worse for you?
6 Are there any changes that you would suggest be made to the unit to improve parents' experiences during admission?

For the discharge interview, the word admission was changed to discharge.

Hierarchy

The second key theme depicted the hierarchy or divide between parents and NICU staff. This divide was often exacerbated by the busy NICU environment and restricted access to NICU. Three sub-themes were identified: (i) feeling like a burden; (ii) staff as gatekeepers; and (iii) role of parent.

Feeling like a burden

Parents often described feeling like 'kindergarten children' or a 'hassle' to staff and how reluctant they were to disturb or bother the staff. They discussed how, despite everything being new to them, they did not always feel comfortable asking staff for help. One of the parents even acknowledged that asking staff for help would have made them feel more confident but were nevertheless reluctant to be a burden: 'We felt not to bother them like kindergarten children. But it would've made us more confident and comfortable' (Mother, Admission, #39). Another father described an encounter his wife had with a nurse: 'She called me up the other day because the nurse told her off. Parents have to be authoritative. But some of the staff are doing this every day so it's second nature to them. But for us it's our first time as parents. We have no clue' (Father, Admission, #6).

Staff as gatekeepers

The notion of NICU staff as 'gatekeepers' was apparent in that parents felt they needed to ask for permission to check their

Table 3 Parent characteristics

Parent characteristics	All parents, *n* = 83	Mothers, *n* = 63	Fathers, *n* = 20
Unit, *n* (%)			
Level III NICU	32 (38.1)	25 (39.1)	7 (35.0)
Level II NICU	52 (61.9)	39 (60.9)	13 (65.0)
Age, years, mean (SD)	32.5 (6.16)	31.9 (5.90)	34.3 (6.58)
Ethnicity, *n* (%)			
NZ European	33 (40.7)	25 (41.0)	8 (40.0)
Māori	9 (11.1)	8 (13.1)	1 (5.0)
Pacific Islander	7 (8.6)	5 (8.2)	2 (10.0)
Indian	17 (20.5)	11 (18.0)	6 (30.0)
Asian	6 (7.4)	4 (6.6)	2 (10.0)
Other	9 (11)	8 (12.9)	1 (5.0)
Marital status, *n* (%)			
Single	7 (8.4)	7 (11.1)	0
Married/*De facto*	75 (90.4)	55 (87.3)	20 (100)
Divorced	1 (1.2)	1 (1.6)	0
Employment status, *n* (%)			
Employed full-time	50 (61.7)	33 (53.2)	17 (89.5)
Employed part-time	8 (9.9)	8 (12.9)	2 (10.5)
Unemployed	16 (19.3)	14 (22.6)	0
Work at home	2 (2.5)	2 (3.2)	0
Student	5 (6.2)	5 (8.1)	0
Level of formal education, *n* (%)			
Primary school	1 (1.3)	1 (1.6)	0
Secondary school (fifth form)	7 (8.8)	6 (9.8)	1 (5.3)
Secondary school (sixth or seventh form)	11 (13.8)	11 (18.0)	0
Technical trade or certificate	8 (10.0)	5 (8.2)	3 (15.8)
Polytechnic diploma	5 (6.3)	1 (1.6)	4 (21.1)
University degree	48 (60.0)	37 (60.7)	11 (57.9)

NICU, neonatal intensive care unit; NZ, New Zealand; SD, standard deviation.

child's chart and, in a few cases, felt they were reprimanded for touching their infant without permission: 'He was upset so I was rubbing his foot and hand. The nurse came in and growled at me to try not to disturb him' (Mother, Admission, #61). Another mother reported: 'Even though I know you're allowed to be in whenever you like, it's a hospital environment. It's very sterile and I'm not always sure when I can or can't touch him' (Mother, Discharge, #30).

Role of parent

Parents also described incidents such as wishing to care for their infant but finding that it had already been done and how this made them feel like the few duties they could do for their child were taken away from them. They described feeling redundant and how they needed a purpose and to feel as if they were caring for their infant: 'You're going through so much, and you don't feel like it's your baby unless you do the cares. It gives you a sense of normality and time with your baby' (Mother, Discharge, #83). Another father reported: 'And one morning my wife came into PIN [Parent Infant Nursery] and had already prepared the breast milk … . She was told the baby had already been fed. So it was wasted. It's extremely stressful. And she's extremely stressed about not expressing enough milk already. She goes home in tears and doesn't argue with the nursing staff. She is in an extremely vulnerable emotional state. And she asks am I not a good mum?' (Father, Admission, #6).

Fathers' peripheral role

Both fathers and mothers brought up the idea of the 'peripheral' role of fathers in the NICU. Subthemes included: (i) fathers as secondary; and (ii) fathers as primary support person.

Fathers as secondary

The view of fathers as secondary to mothers seemed to be reinforced by the NICU environment in what parents described as the lack of essential facilities and spaces for fathers. As one father described: 'I think they should encourage us more to come in the wards. I don't see any men in the wards. Just having somewhere for us to sit' (Father, Admission, #48).

Interestingly, many mothers also commented on how fathers seemed out of place and uncomfortable in the NICU, despite often being the mother's main source of support: 'It would also be nice to have a father's room. Just for them … . Sometimes I think he has an imposter feeling, like he doesn't belong. I think sometimes he can feel secondary and left out' (Mother, Admission, #13).

Fathers as primary support person

Several of the fathers discussed how important it was for them to support their partner, but how the lack of facilities made this much more difficult: 'As a dad, there's food supplied for Emily but not for me. In terms of encouraging dads to be here it makes it harder … . As dad, we don't have much to do but support mum. The thought is put into supporting mum but not supporting the people who support mum' (Father, Discharge, #29).

Discussion

The themes identified in this qualitative study centred around parents' experiences and perceptions of care during admission and discharge in New Zealand's largest NICU. The study was conducted in order to gain feedback from parents on how well we are currently delivering FCC and to examine differences in parents' experiences between admission and discharge.

The quotes grouped under the themes of disempowerment and hierarchy illustrate the power imbalance, which still exists between parents and staff in most NICUs around the world, where parents are often viewed as guests allowed to visit their child.[5,28] These themes demonstrate that there are still aspects in the NICU environment and staff behaviours that perpetuate the divide between parents as the 'spectators' and staff as the 'experts'. Parents' experiences, such as not wanting to burden staff with questions or asking for help, highlights the difficulty families face in challenging these norms. Furthermore, this division between parents and staff may discourage parents from taking a more active role in caring for their infants. This is especially important, as it has been shown that mothers actively seek

Table 4 Themes from admission and discharge interviews

Themes and subthemes	Number of interviews theme was in (admission)	Number of interviews theme was in (discharge)	Example quotes
Disempowerment Lacking control Ownership	38 out of 83	45 out of 78	'You really have to ask. I was given no updates in the morning … . I would have to give a call to ask if he's ok. And if he's ok, there's nothing really to tell. Nobody volunteers information, you have to ask. You see the staff making notes in the red file' (Mother, Admission, #7) 'Once I was familiar with the room I knew I could check his chart. But before that I didn't want to step on anyone's toes' (Mother, Admission, #13)
Hierarchy Feeling like a burden Staff as gatekeepers Role of parent	25 out of 83	30 out of 78	'It's difficult not knowing when my husband can take time off work because we don't know about discharge, but I don't want to pressure the staff too by asking' (Mother, Discharge, # 45) 'Some nurses want to undo the tubes because it's a nurse's job, but I feel I can do it. But I suppose they are trying to keep the babies safe' (Mother, Discharge, #23)
The fathers' peripheral role Fathers as secondary Fathers as primary support	10 out of 83	10 out of 78	'The only thing I guess is it was hard to stay on a stool overnight. Sarah got a bed and I was hoping to fall asleep by my baby's incubator. It was kind of difficult to hang around so I ended up going home' (Father, Admission, #59) 'Leaving the hospital, especially the night with baby's first night on her own and off monitors, that was a little hard and knowing Rebecca was all by herself. That was distressing for me' (Father, Discharge, #48)

opportunities to parent their infants in NICU, and if these opportunities are not provided they report increased anxiety and problems with bonding.[29]

There were no obvious differences in themes that were brought up by fathers in comparison to mothers. The similarity across themes may be due to the fact that only half of the fathers were interviewed individually (10 fathers), while the other 10 fathers were interviewed at the same time as the mother. One of the prevalent themes concerned the role of fathers in NICU, which has only recently become a focus of research in its own right.[22] A recent study[30] found similar rates of anxiety and depression in mothers and fathers of premature infants admitted to NICU, demonstrating that fathers need as much support as mothers. Both fathers as well as mothers emphasised how they were negatively affected by the perception that fathers' roles are considered secondary in the NICU. The lack of facilities and services in the NICU for fathers likely reinforce this perception, thus highlighting the need for father-friendly initiatives in our NICU. We have previously run social support groups for fathers (facilitated by a male neonatologist), which were well received. The current study confirms the need to offer similar services on an ongoing basis and provide more resources and facilities (e.g. chairs) to support fathers in our unit.

We were surprised that perceptions of FCC did not noticeably vary between the admission and discharge interviews. It might be expected that as parents approached discharge, they would naturally describe their experiences as more hands-on and collaborative as they took on more responsibilities in preparation for discharge. Although many parents praised the increased responsibility they received when they were moved to the parent infant nursery (low-dependency care) and to parent rooms, their perceptions of barriers to FCC (e.g. feelings of disempowerment) were also relatively consistent between the two time points. One possibility for these results could be that nurses who are new to NICU generally tend to start in the low-dependency areas and may not have the confidence or knowledge to be able to 'hand-over' to parents.

It was also unexpected that parents had relatively similar experiences and views, irrespective of the level of care their infant was receiving. These findings are in line with a previous study

we conducted,[31] where we found that parents rated their infants as sicker and more seriously ill than did neonatologists, suggesting that the NICU experience is stressful for the vast majority of parents, irrespective of how sick the infant is. However, in most NICUs, psychosocial support is often prioritised for parents with sicker infants. In light of these findings, we are currently considering how to ensure FCC is maintained and reinforced over the duration of the NICU stay.

Perhaps the most important information that we gained from the parent interviews was a snapshot into how aspects of FCC in the NICU have evolved. The current study deliberately focused on the reported barriers to FCC, and despite some steps in the right direction (e.g. enhanced staff training during orientation), the qualitative data make clear the fact that FCC should ideally be a part of ongoing education for staff working in NICU. It is recognised in the literature that NICU staff working in a highly stressful environment need ongoing support, education and tools in order to be able to provide FCC and adequate support to families.[32] We therefore intend to continue integrating FCC into the unit and engaging and training staff in the benefits of FCC. We believe this requires more formal training for NICU staff than is currently being offered, particularly for senior clinical staff, who play an influential role in ensuring that FCC is adopted by the NICU, due to their prominent relationship with parents and other clinical staff.[14] In addition to the importance of ongoing training for staff, several approaches have been developed for parents, such as creating opportunities for family empowerment,[10] which helps empower parents to care for their infant and challenges often-ingrained assumptions about parent/staff roles. We are currently considering whether a similar programme could be evaluated in our NICU.

The strengths of our study include a large, qualitative dataset, which was ethnically diverse and included mothers and fathers who were interviewed at two time points. We also had remarkably little attrition from admission to discharge and interviewed the majority of parents before they were discharged rather than retrospectively, which adds to the validity of our study. Limitations include that we only interviewed parents and not NICU staff. We also did not interview fathers and mothers separately, which may have allowed more unique experiences to emerge. We also examined parents from one NICU; therefore, results may not be generalisable to other units around the world.

Conclusions

Despite the long-standing discourse and recommendations to improve FCC,[5,33] parents in the NICU still face significant barriers to FCC. Interestingly, key themes were raised at both the admission and discharge time points, indicating that parents face similar challenges to FCC throughout their entire NICU stay. Continuing to integrate FCC for the whole NICU team seems a timely and logical next step.

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