

Facilities for presence and provision of support to parents and significant others in neonatal units

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Abstract

Aim: To describe parental facilities for staying in neonatal units, visiting policies and access to emotional support during hospitalisation.

Methods: A cross-sectional design was used in which a survey was presented to all neonatal units in Sweden; 34 out of 38 units participated (89%).

Results: The findings showed that in 50% of the units, parents could stay 24/7 for the infant's entire hospital stay. In 32% of the units, siblings could stay the night with their parents. Units had policies on restrictions for visits by siblings (80%), grandparents (59%), friends and relatives (71%). All units offered counselling to parents, and some units offered peer-to-peer groups (24%), diaries (35%), relaxation techniques (6%) or Internet parental forums (6%). All units enabled parents to be at home with their infant and to visit the unit for check-ups (35%) or to have staff visits at home (65%).

Conclusion: Facilities for parents to stay with their infant during hospitalisation and to have significant others visit are good, but there is room for improvement. During the transitional phase to being at home, parents are facilitated in being at home before the infant is discharged and are supported by the unit, which must be considered beneficial for parents.

KEYWORDS

emotion, neonatal care, parents, professional support, social support

1 | INTRODUCTION

In neonatal care, we can increasingly save infants born at 22 weeks of gestational age and onwards and achieve a lower neonatal morbidity.¹ This presents us with the challenge of not only ensuring the infant's viability but also providing care that promotes positive parental physical and mental health and that facilitates the development of a secure parent-infant relationship. Many parents are affected by the experience of neonatal care, irrespective of whether their infant is born preterm

(<37 gestational weeks, gw) or ill at term. Parents often face surreal, chaotic and deeply distressing situations in the neonatal intensive care units (NICUs). They are not mentally prepared for the experience and may put their "life on hold". This represents a strategy of blocking their emotions and enduring the situation, which can result in alienation from their own needs, from their infants or from being the parents.² Many parents of infants receiving neonatal care exhibit symptoms of depression and/or psychological trauma during the infant's time in the NICU,³ with subsequent negative parental mental health and child outcomes.⁴ Several studies have highlighted that parent-infant separation is one of the most influential factors in depression and anxiety.

Abbreviations: CPR, Cardiopulmonary Resuscitation; GW, Gestational weeks; NICU, Neonatal intensive care unit.

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Thus, emerging evidence suggests that the architectural design of NICUs is of utmost importance for parental involvement, parent-infant relationships and well-being.⁵ There is a trend towards building new NICUs with a single-family room design. This design provides the family with an opportunity to be with their infant in the NICU day and night, which is beneficial, for example for a shortened length of hospital stay and competence in the parental role.⁵⁻⁷ The proportion of NICUs that enable parents to stay day and night for the whole of the hospital stay is probably low globally and varies greatly within and between countries. Greisen et al⁸ showed that the percentage of parents who could spend the night in participating units during 2004-2006 ranged from 14% in Spain to 78% in Sweden.

A study by Coppola et al⁹ reported that more than 80% of the parents felt the need to share their experiences during their time at the neonatal unit. Staff, especially nurses, have been highlighted as partners in this sharing and as being vital for parents' involvement in their infant's care and for the parents feeling like competent caregivers.¹⁰ However, it is suggested that support from family and friends, who are the ones who normally provide support, is vital for parental satisfaction with neonatal care.¹¹ It is argued that parents of preterm infants may have smaller support networks due to family and friends not knowing how to respond.¹² Furthermore, some parents may want or need to share experiences with others but may avoid doing so because of feelings of social isolation, guilt, and shame and thinking that others do not understand.² Depending on the architectural design of the NICU, parents are more or less able to share their experiences with other parents as well as with significant others during their NICU stay.¹³ Findings from qualitative, cross-sectional and case-series studies report that peer-support and/or professional-led support groups for parents in NICUs may relieve anxiety, give parents an opportunity to communicate with staff and help parents gain confidence in their parenting skills.¹⁴⁻¹⁶ "Peer-to-peer groups" (ie parents meet with or without a "facilitator" who is usually a nurse) have been implemented internationally and are used in Swedish NICUs, although the extent of usage is not known. Few studies have been conducted on the involvement and influence of significant others in the NICU setting. Greisen et al⁸ showed that most of the participating units in Denmark, the UK, the Netherlands and Belgium allowed siblings, grandparents and friends to visit. The participating NICUs in Sweden were much more restrictive towards visits by extended family. Hence, there is a need to understand the extent to which relatives and friends can visit and what types of support they are given, so that they, in turn, can understand and support the parents. The aim of this study was to describe parental facilities for staying in neonatal units and their access to emotional support. Furthermore, the aim was to describe the units' visiting policies and the support provided to siblings, grandparents and significant others.

2 | METHODS

A cross-sectional design was used, in which a survey was presented to all neonatal units in Sweden in May 2017. All neonatal units,

Key notes

- Swedish neonatal care has good facilities for 24/7 parental presence, but there is room for improvement.
- Restrictions on the presence of siblings and significant others in neonatal units are common; 80% of the units have such restrictions.
- Feasible interventions that aim to support parents emotionally are essential, and more research is needed to evaluate the effects of interventions on parents.

including those providing basic care to the most intensive, were eligible to participate. The information letter asked that the person answering the survey should be the manager (eg head nurse) or another member of staff from the unit who was well experienced with the care provided. The survey was developed by the authors and comprised questions on the units' facilities regarding parental stay and sleeping accommodations, the provision of breakfast and lunch/dinner, the activities and/or professionals in place the provision of psychosocial support, and questions on visits and support for siblings, grandparents and friends. Most questions were open-ended but there was space for comments or descriptions related to the questions asked. For example, we asked the units to exemplify other forms of support they gave to parents other than the specified or to describe what types of restrictions they had for siblings, grandparents and friends. As there were no data on infants, parents or staff, ethical approval was not needed.

2.1 | Statistical analysis

The data are presented as frequencies (percentages). Chi-square tests and Fisher's exact tests were performed to examine the differences between groups, and a two-sided 5% level of significance was used. Data were analysed in the SPSS version 23 (IBM Corp., 2016).

3 | FINDINGS

3.1 | Participating units

Out of the 38 units that cared for preterm and/or ill infants at birth, 34 units participated (89%). Of the 34 participating units, one unit delivered level 1 care, which was basic care of infants born at 35 to less than 37 weeks gestation who were physiologically stable, and where infants could be stabilised until transfer. Six units provided level 2 care in which infants born at least 32 weeks gestation or weighing at least 1500 g had a possibility of brief duration of respiratory support. Twenty-seven units delivered level 3 care, ranging from care of infants born at least 28 weeks gestation or weighing at least 1000 g, with possibility of mechanical ventilation (level 3a) to extracorporeal membrane oxygenation or surgical repair of complex congenital cardiac malformations (level 3c).¹⁷ Most units (n = 26)

TABLE 1 Parental facilities for staying, eating and emotional support in 34 neonatal units

	n	%
Mother has a bed/own room in the neonatal unit		
Entire neonatal stay	21	62
If available	9	26
Specific mothers	4	12
Father has a bed/own room in the neonatal unit		
Entire neonatal stay	17	50
If available	13	38
Specific fathers	4	12
Are parents offered breakfast?		
Yes, offered for free to both parents	16	47
There is breakfast to be bought	6	18
They have to make breakfast themselves	12	35
Are parents offered lunch/dinner?		
Yes, offered for free to both parents	1	3
Yes, but offered for free to only one parent	2	6
There is lunch/dinner to be bought	7	21
They have to make lunch/dinner themselves	24	70
Are parents offered to see a psychologist?		
Yes, all	4	12
Yes, some	11	32
No	19	56
Are parents offered to see a hospital social worker?		
Yes, all	28	82
Yes, some	6	18
Do parents have a named contact person?		
Yes, most parents	21	62
Yes, some parents	13	38
Are parents offered peer-to-peer groups?		
Yes, all	6	18
Yes, some	2	6
No	26	76
Is there a specific WEB parental forum linked to the unit?		
Yes	2	6
No	32	94
Are there information meetings for parents?		
Yes, for all	4	12
Yes, for some	1	3
No	29	85
Are parents given a diary?		
Yes	12	35

(Continues)

TABLE 1 (Continued)

	n	%
No	22	65
Are parents offered any relaxation techniques?		
Yes	2	6
No	32	94
Transitional support close to discharge		
Parents can take their baby home and have visits from the unit	22	65
Parents can take their baby home and visit the unit	12	35

were solely neonatal (one level 2 and 25 level 3), seven units were combined neonatal-paediatric units (one level 1, four level 2 and two level 3 units), and one was a combined neonatal-maternity unit (level 2). The number of cots for level 1 and 2 units (ie special care nurseries) ranged from 4 to 8 and for level 3 (ie NICUs) ranged from 6 to 23.

3.2 | Parental facilities for staying in neonatal units

Findings showed that more than half of the neonatal units (62%) offered all mothers to stay in the unit, that is have a bed in one's own or a shared room for the entire the time that the infant was admitted to the neonatal unit (Table 1). There were no differences between the special care nurseries and the NICUs in regard to the facilities for mothers' stay; 57% of the special care nurseries had rooms for all mothers to stay 24/7 and 63% of the NICUs. In half of the units (50%), fathers could stay and have a room in the unit. There was a significant difference in the level of care in that 59% of the NICUs had facilities for fathers to have room 24/7 compared with 14% of the special care nurseries ($P < .05$). In units with less capacity for parents to stay 24/7, families were prioritised when the mother was breastfeeding, the infant was critically ill or soon to be discharged, or the family lived far away from the unit.

Almost half of the units offered both parents breakfast for free, while lunch/dinner had to be bought or made by the parents themselves in most units (Table 1).

3.3 | Emotional support for parents

Some units had a psychologist, and most units employed or had an affiliated hospital social worker; some units offered counselling to all parents, whereas some offered counselling only to families with critically ill infants or infants born very preterm (<32 gestational weeks) (Table 1). All units employed a "contact person" system, that is a named person from the staff, usually a nurse, who had a more overarching and in-depth responsibility for the family. Most units used a contact person for all families, whereas some units only used the person for families with an expected hospital stay longer than 1 week.

A quarter of the units (24%) had peer-to-peer groups functioning in the neonatal units. They were often run once a week with

a member of the staff as the leader/facilitator and were voluntary for parents. Some units described that they had themes that were discussed in the groups in combination with discussions on topics of choice, that is topics based on parents' needs and wishes. Some units were visited by the parental organisation but these visits were not systematically scheduled, and two of the units had Facebook groups for parents who had been or were admitted to the neonatal unit. Some units had information meetings for parents, which mainly encompassed teaching parents Cardiopulmonary Resuscitation (CPR).

Diaries for parents were provided in 35% of the units, and two units offered some kind of relaxation techniques; one unit offered massage once a week, and one had light therapy as an option for parents. A question was also asked about whether the unit offered any physical activity, to which all units answered "no".

All units enabled parents to be at home with their infant and provided support before the infant was discharged, either by parents visiting the unit for check-ups or by the staff visiting the home. The latter approach was used by 65% of the units. There was a significant difference between the special care nurseries and the NICUs; 78% of the NICUs visited the family at home compared with 14% of the special care nurseries.

3.4 | Support for siblings and significant others

In 32% of the units, siblings could stay with their parents and sleepover as much as the family wanted (Table 2). In 44% of the units, the siblings could stay on occasional nights and in 24% not at all. Visits by siblings were unrestricted in 20% of the units, while the majority (80%) had restrictions, for example not being ill, having been home from preschool/nursery more than 5 days before the visit. There were no differences in restrictions (yes vs no) related to whether the mother could stay in the unit or not. A majority of units had access to play therapy at a nearby children's ward, and 32% had a room or an area where siblings could play at the neonatal unit. Four units provided films/books or leaflets with information to the siblings.

Grandparents were able to visit in all but one unit; 59% had restrictions on grandparents' visits. Three units did not allow other relatives and friends into the unit, and 71% had restrictions. In total, 80% of the units had restrictions on significant others (ie grandparents, relatives and friends). These restrictions encompassed regulations/policies such as a maximum of two visitors/day, no visits >2 hours, not being sick, no visits to areas of other parents and infants, or not being a replacement for the parents. There were no differences in restrictions (yes vs no) related to whether the mother could stay in the unit or not. There was no oral or written information or support provided to significant others apart from one unit in which the grandparents were provided with written information and offered counselling if needed.

4 | DISCUSSION

The main findings of this study show that parental facilities that enable mothers and fathers/partners to be close to their infants during

TABLE 2 Visiting by and support to siblings and significant others in neonatal units

Visiting		
Siblings can stay and sleepover in the room with parents		
Entire neonatal stay	11	32%
Sometimes	15	44%
No	8	24%
Siblings can visit		
Yes	7	20%
Yes, but with restrictions	27	80%
Grandparents can visit		
Yes	13	38%
Yes, but with restrictions	20	59%
No	1	3%
Friends and relatives can visit		
Yes	7	9%
Yes, but with restrictions	24	71%
No	3	20%
Support		
Support for siblings		
Play therapy at children's ward	26	76%
Play area in the neonatal unit	11	32%
Written material/film	4	12%
Other types of support	2	6%
Support for grandparents, friends and relatives		
Written material/film	1	3%

neonatal care are present in half of all the Swedish neonatal units. Furthermore, emotional support for parents by implementing interventions and enabling the presence of significant others is undeveloped and restricted.

Our findings show that a majority of Swedish neonatal units provide opportunities for infant-parent closeness, that is letting the parents stay with their infant day and night. Having the opportunity to stay overnight and/or having a single-family room is not only positive for parental presence but also for the initiation and duration of skin-to-skin contact.^{18,19} A single-family room is also a space where parents are more likely to feel emotionally close, attuned to their infant's needs and emotionally supported by staff.^{13,20,21} Although fewer units in our study allowed unlimited father- than unlimited mother-staying facilities, there has been a paradigm shift in that fathers' needs and role are acknowledged and supported. Traditionally, the role of the father has been to provide emotional and practical support to the mother.²² Recent research shows that fathers want to be more involved in the care of their hospitalised infants and be acknowledged as equal caregivers.^{23,24}

Many of the more systematically implemented interventions aimed at providing emotional support to parents that have been used in Swedish neonatal units have not yet been assessed in terms of their effectiveness on parental stress or well-being. One could

argue that it is difficult to implement one or more interventions that would suit all parents. Some parents probably prefer to talk and share their experiences with other parents, while others may be more inclined to write in a diary. While opportunities for parents to share and reflect on their experiences appear to be beneficial,²¹ there is currently a knowledge gap in terms of how this support should be provided and the effectiveness of different support models. Furthermore, if interventions prove to be successful, they need to be achievable and sustainable. The expressed goal for neonatal care worldwide²⁵ is that it should be provided on an equal basis, no matter where you are born or cared for. Significant differences in the care for new-born infants and/or support for their parents are therefore not acceptable. Interventions and changes in care and policies must be evidence-based and based on parental needs and preferences and not based on tradition, beliefs or unequal resource distribution. Thus, evaluations of attractive, acceptable and feasible interventions in neonatal units that support parents emotionally are needed. One important intervention that was used in all participating units was the transitional support around the time of discharge. Being able to be at home with the infant and yet have explicit support from the unit has previously been shown not to be harmful but potentially beneficial.²⁶ By providing support for days and weeks until the parents feel ready for the infant to be discharged, the gap between hospital and home care is reduced and the family's adaptation to life at home is facilitated.²⁷

Very few studies have been conducted on the influence of having parents' significant others present and involved in neonatal care. Most studies have been qualitative, describing the ambivalent feelings after having a grandchild born preterm, the confused state, the need for knowledge in order to cope and to support, and a desire to be included.²⁸⁻³¹ Thus, grandparents, and probably friends as well, experience a stressful situation that may limit the possibilities of providing support to parents. McHaffie's²⁸ findings on what parents want from grandparents showed that the three top appropriate roles for grandparents were perceived to be: (a) supporting the parents emotionally, (b) visiting the baby and (c) establishing a relationship with the baby themselves. As shown by our study, as well as the study by Greisen et al,⁸ few neonatal units allow grandparents or friends into the units without restrictions (eg accompanied by parents or with staff agreement). This is a cause for concern. For decades, neonatal units have been separating infants and parents, and now, when we have the opportunity to enable parents to stay in close proximity with their infant, we block parents from their natural support: their friends and family. Several studies have highlighted the need for improved emotional support for parents during neonatal care.²⁰ By units enabling the presence and involvement of parents' significant others, based on parents' preferences, parental well-being might be positively influenced and the transition to home eased.

The high response rate to the survey gives a good picture of how Swedish NICUs handle physical, social and psychological support for parents. A limitation is that we only have the reports from a single member of staff (ie manager or someone well experienced with the

care provided) on the policies and facilities, which might differ from actual fulfilment.

5 | CONCLUSION

Facilities for parents to stay with their infants 24/7 during neonatal hospitalisation are present in half of the Swedish neonatal units. During the transitional phase to being at home, parents are facilitated by all units to be at home with their infant for days and weeks before the infant is discharged with support from the unit, which must be considered beneficial for the parents. The current practices restricting the presence of siblings and significant others are causes of concern, as siblings, friends and family constitute an important part of the family network and vital support for many parents. Evaluations of attractive, acceptable and feasible interventions that support parents emotionally in neonatal units are needed.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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