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Parental presence when their child is in neonatal intensive care

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Background and aim: When a newborn baby needs care in a neonatal intensive care unit (NICU), the parents are welcome to stay with their child whenever they wish. The aim of the present study was to investigate the time per day parents are present together with their child at the NICU and to identify factors that facilitated and obstructed their presence.

Methods: In a descriptive study 67 parents of 42 children from two NICUs registered all time they spent at the NICU and then took part in a structured interview.

Findings: Parental presence at NICUs varied depending on types of accommodation offered. Those who stayed in parent rooms at the units showed a significantly higher presence with their children than parents who stayed at family hotel, at home or on a maternity ward. Factors that motivated parental presence were primarily the willingness to take parental responsibility, the child's condition requiring it, and the want to have control. Good treatment by the staff, a family-friendly environment and high quality care were main facilitating factors for parents to be present at the NICU. Obstructing factors were primarily ill health by parents, a non-family-friendly environment, care of the home and of children at home.

Conclusions: The result shows that there is a need to develop a family-friendly environment that provides optimal conditions for parents to be with their child in a NICU and to consider the parent's own reason for being or not being present.

Keywords: parental presence, newborn caring, neonatal intensive care unit.

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Introduction

Becoming a parent is part of life and often seen just as natural as the child being born healthy. When a child is born prematurely or is ill and needs care at a neonatal intensive care unit (NICU), this experience is completely different. All children, regardless of age, have a right to have their parents with them throughout their stay in hospital (1, 2). However, this is not always possible during care at a NICU. Simultaneously, the importance of an early, close mother-child relationship to the child's development is well known (3–6). Mothers who are cared for together with their sick children experience increased participation and reinforced parent identity (7–9), and fathers express the same thing. The NICU should therefore be family-centred in promoting family health, and physical presence and participation of parents (7–11). Research has also shown that active participation by the parent in the care of the child promotes bonding between the parent and child, reduces psychological stress and worry about the child (12–14). Further, these develops parenting and the ability to care for and interpret the child's signals (13, 15, 16), and gradually prepares for the child going home (17, 18).

Many hospitals integrate care of the mother and child (19). However, in generally this type of care is accepted in theory but not fully practised; parents still do not participate fully in the care of their child at NICUs. The child's medical condition and the high-technological NICU environment demand expert knowledge and, the control of the boundaries for participation and care often comes second to professional care of the child. Often the environment is an obstacle for parental presence and participation (20–25).

In many countries, as in Sweden, legislation and regulations stress that parents are responsible for his/her child's needs for good care being met, and has a right and duty to decide on issues concerning the child when it is cared for in hospital (26). When a child in Sweden is in patient the

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parents can receive economic compensations for loss earnings, allowing them to stay in the hospital with their child (27). In order to take this responsibility, parents must be given the opportunity to be present and take part in their child's care; health care staff should see the parent as a 'partner' in the care of the child and invite him/her to participate (28, 29). What about parents' presence at NICU?

Studies from Finland have showed that mothers were present with their child in the NICU on average 6.7 days/week and the fathers 4.8 days/week (30). The children of mothers who were daily present got fewer behavioural and emotional problems at school age than those mothers were less presence (31). A study from England has showed that parents with more than one child or with a child older than one month at a NICU were present less frequently, and that 75% of mothers who visited their children took part in their child's care while only 20% of visiting fathers did so (13). Other studies show that health care staff takes the presence of parents at NICUs for granted, while at the same time deciding what the parents are allowed to do (23, 25, 32, 33). The aim of this study was to investigate the time per day parents are present together with their child at NICUs and to identify factors that facilitated and obstructed their presence.

Method

The context

The study was conducted at two NICUs: one at a university hospital and one at a county hospital in a smaller city. Both hospitals were located in the same Swedish region, implying similar political and financial management systems. The NICU at the university hospital had 22 beds and a staff of 120, and the local NICU had 15 beds and 60 staff. Both of the NICUs had two intensive-care rooms, one had also two ordinary care rooms and the other had one. Other important rooms were the parent rooms where parents could stay alone or together with their child if the child's condition allowed it. One of the NICUs had two parent rooms and also offered accommodation at a family hotel in the hospital grounds. Mothers were offered care on maternity wards in the same building as the NICU. The other NICU had five parent rooms, each one with two beds, four of which were occupied mostly by mothers and one that was intended for parent couples. This NICU also offered rooms for parents to stay overnight in an adjoining unit, but no family hotel. In this hospital NICU and the maternity wards were not placed in the same building.

Design and ethics

To gain more information about attendance of parents with their children at NICUs and factors that facilitated and obstructed their presence a quantitative descriptive design was used. To get to know the real time and factors of importance for parental presence a form for parental presence and an interview guide were developed and tested at another neonatal unit which included registration of number of hours the parent was with his/her child. The interview guide consisted of three short open questions: 1. What was the reason for your presence with your child at the NICU? 2. What facilitated your presence at the NICU? 3. What obstructed your presence at the NICU? The use of an interview method with open questions provided detailed answers and a chance to ask for clarification. In the analysis, the factors could easily be grouped and quantified (34).

This study was guided by international principles of research ethics outlined in the World Medical Association's Helsinki Declaration (35). Permission to conduct the study was obtained from the heads of the wards, and the Ethical Committee of the Central Ethical Review Board in Gothenburg. The staff and parents were given verbal and written information about the study, and assured that participation was voluntary and that all information would be treated confidentially and locked securely in a fireproof place.

Data collection and participants

Data were collected over a period of four weeks with a two-week period in each unit between August and September 2007. During this period, 43 children were inpatients at the NICUs. The parents of these children (n = 72) were asked to participate in the study, with the exception of one set of parents whose child's life-support treatment was about to be stopped. Of those asked, one father turned down participation. One mother and three fathers were not available during the period in question, though all of their partners took part. In total, 67 parents gave informed consent: 36 mothers (2 single parents) and 31 fathers. The form on parental presence was filled in by each of the parents, by recording in hours and minutes their stay in the NICU together with their child, for a period of one week or during the time that the child was an inpatient at the NICU during the week of the study. The following week, individual interviews were conducted with each parent, based on the interview guide, in an undisturbed location in the hospital (n = 60) or via telephone (n = 7). The answers were noted directly by the interviewer.

Analysis

A descriptive analysis was carried out with the aim of comparing and investigating differences in parental presence based on accommodation (Table 1). Significant tests were performed with the one-way ANOVA (Tukey *post hoc* test) concerning type of accommodation and time of

Table 1 Presence of parents with their child at the neonatal intensive care unit (NICU) according to the accommodation form, number of hours/24 hours

Accommodation form	*Mothers number*	*Mean, h (SD)*	*Median, h (Range)*	*Fathers number*	*Mean, h (SD)*	*Median, h (Range)*
Parent room	13	23.1 (1.9)	24 (17.2–24)	6	22.1 (2.3)	22.6 (18–24)
Family hotel	3	6.8 (0.6)	6.7 (6.6–7.4)	3	6.8 (3.1)	6.2 (4–10.2)
At home	11	5.9 (2)	5.6 (3–9.1)	18	4.9 (3.6)	4.2 (0–11.8)
Maternity ward	15	5.4 (2.2)	5 (1.7–10.6)	10	4.4 (1.7)	4.4 (2.6–8.3)

Table 2 Influencing the presence of parents with their child at the NICU

Main questions	*Categories*	*Number of parents (n = 67)*	*Number of mothers (n = 36)*	*Number of fathers (n = 31)*
Parents' reasons for being present	Wanting to take parental responsibility	47	24	23
	The condition of the child required it	21	11	10
	Wanting to have control	20	7	13
	Wanting to take part	14	9	5
	Mother could not be present	11	0	11
Facilitating parental presence	Good treatment by the staff	36	23	13
	A family-friendly environment	35	17	18
	High quality care	30	18	22
	Coming and going freely	22	9	13
	Getting regular information	18	11	7
	Being invited to participate	16	8	8
Obstructing parental presence	Ill health by parents	39	22	17
	A non-family-friendly environment	27	17	10
	Care of the home	22	10	12
	Children at home	18	10	8
	Lack of information	18	10	8
	A difficult socio-economic situation	14	4	10
	A long distance between the NICU and the maternity ward	12	8	4
	Poor treatment by the staff	9	8	1

presence (36). ANOVA compares the variance within each group with the variance between groups (34). The test was two-tailed and conducted at the 5% significance level. The parents' replies in the interviews were grouped according to five to eight categories considering the same topic (Table 2).

Findings

The mean age of the mothers was 31 (range 19–44) years and of the fathers 34 (22–52) years. There were 22 first-time mothers and 20 first-time fathers, 14 parents had an immigrant background and had lived in Sweden between 1 month and 12 years. All spoke Swedish and/or English. Of the 42 children, there were five sets of twins. The mean birth weight of the children was 2234 (450–4390) grams, the mean gestational age at birth was 34 (25–41) weeks, the median length of time of hospitalization was eight (1–144) days and the three most common medical diagnoses were prematurity, small for gestational age and infection.

Presence and accommodation by parents

There were four accommodation alternatives for the parents: the maternity ward, parent rooms at the NICU, the family hotel and their own home. Parents' themselves had limited possibilities to choose what kind of accommodations they preferred. The staff offered what for the moment was available. The accommodation varied during the period of the study, though the most common was for both the mother and the father to stay on the maternity ward for the first few days after the birth of the child. After that, the mother only usually changed to a parent room at the NICU or to her own home. Parents of children who were

cared for at the NICU with only two parent rooms stayed at their homes more often: only 2 mothers stayed in the parent rooms compared with 17 parents at the other NICU unit with 5 parent rooms. According to Table 1, the presence of parents with their child varied and depended in part on the form of accommodation. Parents staying in a parent room at the NICU spent most time with their children and those staying in one of the other three forms of accommodation were present for less time ($p < 0.001$). There was no significant difference between these three types of accommodation.

Parental presence varied over the day and night. Those staying in a parent room carried out much of the care and were often able to take their child around the unit to the day room and kitchen. If they wished to leave the unit, the staff would take care of the child. Parents staying at the family hotel usually visited their child twice a day, a few hours in the morning and a few hours in the evening. Those staying at home usually visited once a day, normally at nine in the morning when it was generally time for the child to eat, and they stayed for a longer, continuous period, often over two of the child's mealtimes. Mothers with other children at home were at the NICU on average 9 hours and fathers 6 hours/24 hours; mothers without children at home spent a mean of 11 hours and fathers 8/24 hours. Parents staying on the maternity ward were present for more but shorter periods, 15–30 minutes, with their child; they came earlier in the morning and were often present later in the evening.

Parents' reasons for being present

Factors that influenced parents' presence with their child are described in Table 2 and are supported below by quotations followed by information of origin of quotation (M = mother. F = father), and type of currant accommodation (MW = maternity ward, PR = parent rooms, FH = the family hotel, H = own home).

Wanting to take parental responsibility was the predominant reason for being with the child. An inner feeling of being a parent made it natural to be with the child. Another factor that explained the parents' presence was that *the condition of the child required it* and included a strong desire to be near their child and give support and emotional comfort.

> Not being here is completely alien to me. I want to take my responsibly like a father. (F, PR)

Wanting to have control was another reason for parental presence at the NICU. It was primarily expressed by fathers and concerned watching the child's care and following its medical condition. Mothers described that they needed control to feel confident.

> We want to be in control of what is happening, know what the staff is doing and why. (M, H)

Wanting to take part in the child's care was another reason for being with their child. There was a desire to learn to care for the child, and presence increased the opportunity to be taught by the staff and to be prepared for the child going home. An inviting attitude by the staff was seen as encouraging parental presence. Sometimes, however, parents who were not quite ready could be pushed.

> I didn't go on about going to the neonatal because I was throwing up and I just wanted to rest, but the midwife who came to get me from the delivery said, ''You do want to see your children don't' you?'' But when I got there I threw up again and had to leave straight away. (M, MW)

A specific reason for the presence of fathers was when *the mother could not be present* with the child because of her own post partum condition. They then wanted to take their parental responsibility, compensating for the mother, though they often felt ambivalence in wanting to be with both the child and the mother.

> The mother needed to sleep but I was there so we acted like parents; one of us was there. (F, MW)

Facilitating parental presence

The most frequently facilitating factor for parents to be present at the NICU was *good treatment by the staff*. One caring act by the health care staff was the effort to create a private sphere around the family on the ward with the help of screens. Another was to be available and help when the parents requested it and to be kind to the child. As important as the staff caring about the child was for the parents to receive attention and support through consolation and being asked how they were feeling.

> I felt welcome, and when I arrived I saw that my child was happy and satisfied with the staff and that made me feel calm. (M, H)

Almost half of the parents expressed that a *family-friendly NICU environment* made their presence easier. This included homely rooms with, for example, a chair for the parent next to the child's bed. Areas such as a day room, kitchen and play area for siblings were also appreciated, especially if the child was staying for a long time. Important, however, was access to a parent room. Being able to stay together allowed the parents to start parenthood together and fathers to support mothers with delivery complications so that they could be with their child.

> The parent room is a landing place where you can be on your own. (M, PR). The fact that the father had a bed and was able to stay the night here was a condition of me being able to be here. (M, PR)

High quality care, medical as well as nursing, also facilitated parental presence. A feeling of trust was obtained by the fact that the child received professional care by experts who were seen as having full control of their child's conditions trough constant monitoring. This facilitated

parents' possibility to relax with their child and reduced their need to control the child's condition themselves.

> The staff looked after his needs, checked his condition and could make the right decisions; that was not my responsibility. (M, MW)

Coming and going freely was described by a third of the parents as facilitating their presence. The family's social situation, such as taking care of children at home, became easier if the parents could decide the time of visiting their child. Nonetheless, the parents often had a bad conscience when they were unable or did not have the energy to be with the child. This feeling was alleviated a little by an affirmative attitude from the staff.

> The staff said, ''come when you like,'' and I don't have a bad conscience because I know the children are well looked after. I don't need to worry; that's a nice feeling. (M, MW)

Getting regular information also facilitated parental presence at the NICU. This included receiving answers to questions and being informed about the condition and care of their child.

> The staffs always have time to explain and if they're busy, they make time later. (F, H)

Being invited to participate in the care of the child was mentioned by a quarter of the parents as a factor that made their presence easier. Caring for their child themselves with the help of the staff but without being forced was described as strengthening the identity as a parent. This helped them to overcome their fear of touching the child and included feeding the child and changing nappies.

> As a parent, you are subordinate to the staff somehow, but I felt that I was able to be a mother and bond with my child. (M, MW)

Obstructing parental presence

Ill health by parent was the predominant factor that made it more difficult for parents to be at the NICU. They needed to recover from tiredness after the often dramatic birth of their child, and some mothers needed care after a complicated delivery. Sometimes the parents also needed to leave the NICU to gather the strength to be with their child, but the mothers had less opportunity to do so.

> I do all the practical things, so I have a natural break when I carry out my errands. I can distance myself from the event and reflect on everything that has happened, but the mother she is here in NICU all the time. (F, PR)

A non-family-friendly environment at the NICU was described as a hindering factor by just over a third of the parents. This included factors such as a high level of noise on the wards with alarms on technical equipment and, at times, many staff, children and parents. A quieter care environment that would give children and parents more peace was desired. The parents missed a private sphere for the family on the ward. As many children were cared for on the same ward, parents sometimes had to take part, involuntarily, in other families' situations, and this could be seen as obstructing their presence on the ward with their child.

> We were affected. There was a child on the ward who didn't make it and it was the last time the parents were with their child. They said goodbye to their child behind a screen and we were on the other side happily bathing our child, unaware until later. Of course there is secrecy, but we would have appreciated knowing, so that we could have kept the noise down a bit and bathed our child later. (M, H)

Parents who did not have access to parent rooms often sat beside their child on the ward and then needed a comfortable chair, which was not always available. If they wanted to be on their own it was possible to book a private room for a few hours, though these were often occupied.

> Sometimes you were sad and wanted to be on your own but the rooms were occupied, you hadn't booked a room for just the time when you were going to be sad. (M, H)

Care of the home and *children at home* were also described as preventing presence. This was also clear from the amount of time the parents were present, and it applied regardless of the accommodation form. Parents who stayed at home, more often had siblings to the sick newborn at home (15 of 29) than parents staying on the maternity ward (6 of 25) and parents staying in parent rooms (6 of 19). None of the parents staying at family hotels had children at home.

Lack of information also had a negative impact on presence. It was important for parents to be informed about which nurse was the responsible nurse for their child during the hospital stays, as well as which physician was in charge so they knew to whom they could turn with questions. Many felt that it was left to them to find out the information about their child's medical condition, though they really considered this to be the health care staff's responsibility.

> After three months here, we still meet new staff every day, but now in the last month, we have a responsible nurse, which we should have had from the beginning when the need is greatest. (M, FH)

A long distance between the NICU and the maternity ward sometimes obstructed mothers on the maternity ward from seeing their child. For some mothers, the presence of their partner was a condition of them going to the NICU, especially at the hospital where the NICU and maternity ward were far apart. Times for examinations, rounds, specimen taking, etc. on the maternity ward could also hinder them.

> It is easy to have a bad conscience when you haven't got the energy to get there (NICU). You feel pressurised to go there but it's so far and you're so tired. (M, MW)

A difficult socio-economic situation could also obstruct parents from being present, such as having to work, a long distance between the hospital and home and /or the lack of a car.

Poor treatment by staff in some cases made parental presence more difficult. Some felt at a disadvantage against the decision-making staff, having to ask for permission before doing anything with their child.

> I felt in the way. I wanted to hold my children but the staff thought we were disturbing the children and that we shouldn't hold them. (M, MW)

Experiences of staff with unexpressed expectations on parental presence were also described, and this led to questions such as: how often and how long are we as parents expected to be here? Clearer guidelines on the expectations on parents were requested.

Discussion

This study provides new information on parental presence at NICUs. The results show that parental presence varied depending on the type of accommodation. Parents who were offered to stay in the unit's parent rooms were with their child day and night, which was not possible for parents staying in a family hotel, on a maternity ward, or at home. The total time spent with the child was considerably lower for those who did not have a parent room.

The two NICUs had limited choices of accommodation forms and there was an uneven distribution in the four accommodation groups. In particular, few participants in the parent group stayed at a family hotel as may be considering as a weakness of the study. A study aimed at comparing different forms of accommodation among parents with children cared for in a NICU could have been carried out with, for example, groups of the same size and a stratified sample of participants. This study, however, was designed to tell us the actual time these parents spent at the NICU during one week and to analyse and compare this against the accommodation forms.

The first days after birth, the child often needed intensive medical care connected to medical-technical equipment. Most of the parents were then still staying on the maternity ward and had a lower presence than parents in other forms of accommodation. This could be due to ill health by the parent, but also to the long distance between the NICU and the maternity ward. It is notable, and hardly reasonable, that the mothers had difficulties with transport to see their child at the NICU. By not offering parents a real chance to stay near their child at the hospital, the health care system hinders parents from taking parental responsibility.

One motivating reason for parents to be present was that they felt responsible for making sure their child was looked after and that its needs were met. This is completely in accordance with the Swedish Children and Parent Code (26). Previous research results showed that if the parents not feel control in the situation or if the relation with the staff is not good, they could feel powerless (37). Our result echoes earlier research showing that mothers and children should not be separated during the newborn period (38) and that time together by parents and child should be prioritised as it develops the relationship between them (3–5). This result should contribute to the design and organisation of future NICUs. Locating the delivery ward, maternity ward and NICU next to each other facilitate parents' moving between the units, and a ward where the mother and child could be cared for together, or alternatively more parent rooms, would facilitate presence by all parents. This is however above all an organizational health care matter of a financial nature. Rebuilding wards and rooms requires huge economic resources, but it would be interesting to study its effects in terms of health economics, as earlier research shows that increased participation by parents in the care of their child reduces the period of care for the child at the NICU (39).

The study also shows that ill health and tiredness was the primary obstructing factor for parental presence. By offering parents a parent room, they can both rest and spend more time with their child. Another benefit would be that fewer common areas would be needed for talking, breast pumping and rest, as all these activities could be carried out in the parent room. Research findings from the United States (40) has shown that caring for children in a single room at a NICU has many benefits; mothers were able to breastfeed in a comfortable environment, parents could talk undisturbed to the health care staff and were able to bring siblings from home without disturbing other families. Our study confirms results from a previous study (30), showing parents with other children at home found it more difficult to be with their child at the NICU.

An important factor for the presence of parents with their child was good treatment by the staff. Good treatment is an important value of caring. The caring of the child and their parents involves respect for the dignity of human beings and responsibility for others' lives (41). Thoughtfulness and confirmation of the parents meant that they felt welcome at the NICU. This result is in accordance with earlier studies (37, 42). Support for parental presence through an inviting attitude is not dependent on any economic or organizational resources. It is also important for staff to be understanding and supportive of parents when they find it difficult to be present with their child. These parents should be able to feel part of the care of their child even if they are not physically present, for example, through a diary, photos and video communication.

Conclusions

This study highlights that there is a need to develop a family-friendly environment and tangible strategies that provides optimal conditions for parents to be with their child in a NICU. The result has provided greater knowledge and understanding of parental presence and the factors that facilitate or obstruct this presence. This knowledge

and understanding can help the staff to consider the parent's own reason for being or not being present.

Author contributions

All the authors contributed to all the stages of the research, from planning to the final manuscript, except the data collection, which was performed by HW.

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