Mothers' experiences of having their newborn child in a neonatal intensive care unit

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Scand J Caring Sci; 2006; 20; 35–41

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Background: From birth the child has an ability to respond to the environment, which influences the interaction between mother and child. If this attachment is interrupted, the child's emotional development is negatively influenced. When the child needs care in a neonatal intensive care unit (NICU) it is difficult to establish contacts between mother and child. Separation from the child is found to be the most difficult aspect for mothers when their newborn child is hospitalized in a NICU.

Aim: The aim of this study was to describe mothers' experiences when their full-term newborn child was cared for in a NICU during the postpartum maternity care period.

Method: A phenomenological hermeneutic interview study was performed. Ten mothers were interviewed once, 6 months to 6 years after the experience.

Results: The essence of the experience is understood as an alternation between two opposite concepts, exclusion and participation, with emphasis on exclusion. A feeling of *exclusion* dominates when the new mother feels a lack of interaction and a sense of not belonging to either the maternity care unit or the NICU. This has a negative effect on her maternal feelings. On the contrary, when a feeling of *participation* dominates, a continuous dialogue exists and the mother is cared for as a unique person with unique needs. This supports her maternal feelings in a positive direction. The implication of the result for nurses is that it is important to decrease mothers' experience of exclusion and to increase their feeling of participation when their child is cared for in a NICU. A return visit to the responsible nurse to go through the treatment and experiences should be offered to all parents whose child has been cared for in a NICU.

Keywords: mother–child, mothers' experience, newborn caring, neonatal intensive care unit, phenomenological hermeneutic method.

Submitted 3 March 2005, Accepted 28 September 2005

Introduction

To become a mother is a transition that includes several overwhelming feelings. In a study by Barclay et al. (1), the mothers described their experience with the term 'drained', i.e. a sense of having given everything, of being emptied out. During pregnancy, an interaction between a mother and her unborn child develops at a cognitive level (2). The woman becomes attached to the idea of being pregnant and gradually develops an attachment for the child inside her. Immediate physical contact between the mother and her newborn child after the delivery promotes the attachment (3). The baby's nature also influences the mother's feelings towards her baby (1).

Most mothers attach to their newborn child during the first week, although for some of them the attachment is delayed until they have returned home (4). This attachment is a process which begins before pregnancy. A woman who has experienced warmth from her own mother develops stronger emotional relations to her unborn child. During pregnancy the attachment develops successively, but is more obvious during the third trimester. If she has attached to her child during pregnancy this continues and develops after the child is born. If the mother's experience of childbirth is harder than expected, the initial feelings for her child may be influenced. This emphasizes the importance of the mother's experience of childbirth for how she might regard her child during the first period of life. Feelings of pride and satisfaction over

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the delivery could have a positive influence on the early perception of the child (5).

The newborn child has a natural instinct to attach to its closest caregiver, most often the mother. This attachment is important for the child's survival during the first period of life (4). From birth the child has an ability to respond to the environment, which influences the interaction between mother and child (4, 6). The child needs to feel safe and secure. When the mother responds to the child's signals an attachment between them is established (7). If this attachment is interrupted the child's emotional development is negatively influenced (8). The effects of separation on the mother–child bonding process have been described by Klaus and Kennell. They found that the critical or sensitive period is the first hours and days after birth when a positive bond can be established between mother and child (6).

When the child is born premature or sick, the parents find themselves in an acute crisis consisting of three components: (i) the mother has feelings of guilt and shame; (ii) sadness over the lost dream of the baby; and (iii) daily worry, hope and satisfaction. Most of the mothers feel guilty about their child. They also feel ashamed in relation to their husband, their own parents and other social contexts because they have been unable to give birth to a healthy, strong baby (9).

When the child needs care in a neonatal intensive care unit (NICU), it is difficult to establish contacts between mother and child. Therefore, it is of utmost importance that the caregivers actively work for the parents' participation in the care of the child (10). Separation from the child was found to be the most difficult aspect for the mothers when their newborn child was hospitalized in a NICU (11, 12). It involves a great deal of emotional strain for the mother. Her essential feeling is to be left outside which is based upon feelings of despair, powerlessness, homelessness and disappointment. Lack of control was another crucial concept (12). When the mother is supported by an individualized approach to care and appropriate communication is used, attachment can be facilitated (13).

Nursing staff can alleviate the mothers' anxiety by inviting them to participate in the care of their child. By maintaining a dialogue and motivating the mothers to develop a relationship with their child, their stress and anxiety is alleviated (14). Research shows that active parent participation in the care of the child promotes the bonding of the parent to the child. The mother in NICU develops from outsider to engaged parent and her psychological stress and anxiety for the child is diminished (15, 16). Parental participation in the care of the child can include social activities such as talking to the child, holding, stroking, washing and feeding the child at NICU (15).

In Sweden, the mean period of postnatal care after a normal childbirth is 3 days (17). When the newborn child requires care in a NICU it is not always possible for the mother to be there in the hospital during the whole period. The parents are encouraged to be with their child and participate in their care whenever possible, without any formal restrictions, 24 hours a day. When the mothers are discharged from the maternity care unit practical problems emerge as there are no beds, food or space in the NICU for the mothers/parents who have a child expected to recover quickly.

Previous studies (12, 14, 16) describe the mother's experience of having their child cared for at NICU while the child is still in the NICU or up to 6 months after the birth of the child. There is a lack of knowledge concerning the mother's experience after a longer period of time such as several years after the birth of the child.

The study

Aim

As care in a NICU may influence the attachment between mother and child, the aim of this research was to study mothers' experiences when their full-term newborn child was cared for in a NICU during the postpartum maternity care period.

Method

A phenomenological hermeneutic method was performed to understand the meaning of the phenomenon of mothers' experiences when their newborn child needed care in a NICU during the postpartum maternity care period.

Humans and their living conditions can never be completely understood if they are not studied as living wholes (18). Therefore the everyday world of experience prior to any theories has to be studied (19, 20). Experiences are always mediated by the subject's anchorage in history, in a social environment and in a special language (20, 21). Thus, pre-understanding, historicity and interpretation are viewed as necessary conditions for an understanding of phenomena in the world (21–23). A phenomenological hermeneutic method takes as its starting point the everyday lived experience of human beings. The statements are true as seen from the individual's life world. When the life experiences are written down, a text which has its own meaning is automatically produced (24). Interpretation presupposes understanding and is used in text analysis to see explanations and symbols, put together available information to enable a new pattern which is not totally visible for the interviewee. To capture the phenomenon which can be seen in the text, it is important as a researcher to be open and allow the text to speak for itself, see the parts and bring them together as a whole. The method of choice for this study was based on Ricoeur's philosophy (23) for analysis of text and contained three main steps: a

naive reading of the text, followed by one more structural analyses and finally an interpreted whole (24).

The researchers' pre-understandings within this area are based on clinical experience in maternity care and neonatal care in their roles as paediatric nurse and midwife.

Participants

Nurses at a primary healthcare centre for children arranged contact with the mothers. Informed consent from the mothers was obtained. Inclusion criteria were: (i) mothers with children cared for in a NICU; (ii) primiparous or multiparous; (iii) children born in gestation week 37 or later without deformities; (iv) children aged 6 months to 6 years; and (v) good knowledge of the Swedish language. In total, 10 mothers were interviewed once in 2002. The children stayed in a NICU for 1–14 days, due to different reasons. Three of them were observed after emergency Caesarean section: one was observed on account of spasm during sleep, two were treated for meconium aspiration and four were treated for convulsions. The mothers' age range varied between 27 and 45, the median age was 34. One woman was single and nine were living with the child's father. Six mothers were primiparous and four multiparous. Two of the mothers had earlier given birth to a child who had been cared for in a NICU. At the time of the interview the children's age varied between 6 months and 6 years.

Interviews

Tape-recorded open interviews were conducted in the mothers' homes by two of the authors (H.W, R.J). The introductive questions were: Please, describe your experiences when your newborn child was cared for in a NICU during the postpartum maternity care period? Attendant questions were posed: What do you mean? Could you tell us more? How did it feel then? The interviewed mothers were encouraged to describe their experience as vividly and deeply as possible. The duration of the interviews varied between 60 and 90 minutes.

Ethical considerations

Ethical approval and permission to undertake the study was obtained from the local Research Ethics Committee at the University of Göteborg. The invited mothers were given written information and informed that all participation was voluntary and all information would be treated confidentially. Counselling was offered after the interview; however, none of the mothers requested this.

Analysis

Each interview was given a letter code from A to K, where the letter J was left out to avoid confusion with the letter I. The tape-recorded narrative interviews were transcribed verbatim to text by the interviewers (H.W, R.J). A phenomenological hermeneutic text analysis inspired by Ricoeur's philosophy was performed (23, 24). To guarantee validity, all four authors worked jointly in the data analysis process. During analysis of the text we exchanged understanding and explaining. First the entire text was read through several times to obtain a sense of the whole. A structural step followed which included reading the whole text again while searching for meaningful units, i.e. units which described the phenomenon. The research context was balanced by considering the parts and the whole. All meaningful units were extracted, read through as a whole and sorted into groups. During further reading, the groups were clustered together into three constituents. Finally, an interpreted whole of the phenomenon was formulated. An example of this procedure follows: the statement, 'I had no idea where my child was or who was caring for him. No, nobody told me and perhaps it would have been better if I had known', was placed in the group 'information'. The groups 'information', 'communication' and 'trust' together made up the constituent 'feeling of interaction'. The same procedure was used for groups in the constituents 'feeling of belonging or not belonging' and 'maternal feelings'.

Results

The essence of mothers' experience when their newborn child was cared for in a NICU during the postpartum maternity care period is understood as an alternation between exclusion and participation with emphasis on exclusion. The phenomenon is expressed in three constituents: feeling of interaction, feeling of belonging or not belonging and maternal feelings.

Feeling of interaction

In the constituent *feeling of interaction* the mother's need for communication, information and trust, was expressed. The character of the interaction between the mother and the caregivers was influenced by the experience of being separated from her child. The verbal information was an important part of the interaction. To understand her situation, the mother needed continuous information. However, there was often a lack of information: *I had no idea where my child was or who was caring for him. No, nobody told me and perhaps it would have been better if I had known* (B). Lack of interaction led to speculation about what the carers were doing with the child in the mother's absence. A feeling of exclusion evolved: … *then I don't know much about them, what they did to her when I wasn't there, if you see what I mean. If they were with her or not* (C). *Nobody knew the reason, didn't want to say anything, almost everybody said nothing about the reason, always saying that I should talk to the doctor*… it felt as if the caregivers never really had enough time (F).

The text gives several examples of how the mothers had to get information about their child themselves. They wanted to have a conversation with the carers and even evolved their own strategy to be informed: …I learnt that the coffee room was at the end of the neonatal corridor, and that the doctor took a coffee break every morning at 9 o'clock. So that's when I showed up: Ha, Ha! Then he couldn't go past without saying something, giving details (G).

On the contrary, when continuous information existed, confidence for the caregivers developed. Their knowledge and treatment, as well as their affirmation of the mother as a unique person were of great importance. Then it might even be pleasant to be liberated from responsibility: … *had no energy at all to hold infants so I thought it was a relief when she was returned to the cot. Then they took me back to the ward. It was nice not having responsibility for a child as I was in great pain* (K). Confidence included a feeling of being understood and treated as a unique person with unique needs: …they know how to deal with me, to keep me calm…the people who worked there (the maternity ward) also knew the neonatal ward so I received very good support, they took care of me (G). When their child finally left hospital they felt in control of the situation: *When we left we knew what to do as we had asked so many times, had been sitting and talking about everything so much* (I).

Feeling of belonging or not belonging

Another crucial constituent of the experience was the feeling of *belonging or not belonging*. The text expressed that the mothers belonged neither to the maternity care unit nor to the NICU. Most children were in hospital for more than a week. The mothers received care in the maternity unit but they felt that they did not belong to that ward. They had an intensive desire to stay at the hospital as long as their child – to be nearby, to breastfeed and to care for their child. Instead, they felt that they took a bed that another mother needed more in an already overcrowded maternity care unit: *It was a bit stressful with such overcrowding and it felt that I couldn't stay as long as I wanted. I felt that the staff wanted me to leave. Now and again they asked: 'when do you feel you can go home?' They probably didn't know that one of the others had already been in and asked the same question* (B). It was difficult to come in contact with the midwives and other caregivers: *I never met any of the staff (the maternity ward), no I don't think I have spoken to anybody down there (the maternity ward), maybe one or two perhaps* (C).

The mothers felt that they had nothing in common with other mothers who had their child with them and it was emotionally difficult to meet them: *Then I had the feeling that it was completely crazy that I was in the maternity ward with all those happy mothers in happy situations with their babies* (H). *It was difficult when they all sat beside their cots and their newborns and I had nobody – it was terrible* (G). Instead it was with other mothers, who were in a similar situation, they found fellowship: *I wasn't unique; there were several others who sat there with their children upstairs. I felt that we were all in the same situation* (F).

In the NICU there was no bed or place for the mothers and there was a feeling of not being welcome. When the child was asleep the mothers felt superfluous, as they had nothing to do. The rooms and surroundings were not welcoming. Often it was impossible to find a place to be alone with their child: *It was very important not to disturb them. That gave a feeling that I was governed by times there. They (the neonatal ward) did not want me to visit in-between times. There was little space, only a few chairs* (H). *It didn't feel right being there (the neonatal ward) either. Nobody sent me away but when he was asleep, well, I felt that I was intruding* (I).

Maternal feelings

The maternal feelings were crucial in the mothers' narratives. The child was a confirmation of being a whole woman, which fortified her identity as a mother. If there was something wrong with the child, the mother's self-confidence wavered and there was a frequent questioning of her own motherhood and whose child it really was. The first meeting with the child, immediately after childbirth or after several hours, was a crucial experience for the mothers: *I started thinking; here I am looking at my son for the first time – in an incubator. I hadn't even held him. Of course it felt terrible* (A).

When the NICU caregivers, separated from the mother, cared for the child feelings of powerlessness were frequent. She was both tired after a difficult childbirth and filled with a guilty conscience for not taking care of one's own child: … lying down at the post operation ward and the only thought I had was, for goodness sake I can't lie down here. I have a child up there (B). The guilty conscience continued to follow the mothers. A feeling of insufficiency arose when they could not take care of the child by themselves: *I also had a guilty conscience about not being able to cope, that I was not always with him. If he had been in the ward I would have been able to be with him* (E). However, the desire to have the child at their side and nurture them was subordinated to the most essential feelings, i.e. that the child had survived and felt well: …*thankful for all the help she received, I felt that it was not too bad that she wasn't with me. That was not the most important thing* (F).

During the separation several mothers experienced a feeling of not being a mother. Intellectually they knew that they were mothers but the feeling was denied them: …it didn't come at once in the hospital because I didn't feel that I had given birth to a child. It was not until he disappeared, and he was only up and turned over on my stomach, and then he was gone (E). The child was experienced as belonging, more to the caregivers in the

NICU than to the mothers themselves. As the caregivers were experts, the new mother felt unwanted. Even the care the mother was capable of giving was taken over by the caregivers: …they are experts in some way. You feel superfluous, they change (nappies) him, they are a lot more skilled, that was the feeling I had…they are real specialists of course but it's perhaps unnecessary. Perhaps I am not needed as a mother as they do it so much better (I). Every mother remembered exactly the moment when they experienced that the child was theirs. It happened when they were alone with their child, in the NICU, during the time they were allowed to leave the neonatal ward, or after they were discharged: *The first time I was allowed to have her with me. We were sitting in my room; I have a mental picture of it. She turned her head, looked at me and suddenly it was the first time I had a feeling of, Oh! This is my baby* (H).

Since early pregnancy the mothers were informed repeatedly at the antenatal clinic that the first contact with the child after childbirth was essential. A crucial question was if this early separation could influence their relationship with their child: …it always says that the first contact with the child is very important. Obviously, I wondered, and still wonder, if there is anything in my child's and my relationship that would have been different if this hadn't happened (A).

When the mothers got help and support, their confidence in taking care of their child successively developed and by time of the child's discharge from hospital they felt in control of the situation: *The period up there (the neonatal ward) was very positive. They helped me, I learnt how to breast-feed properly and was not afraid to do a lot with him, to handle it* (A).

Interpretation of the whole phenomenon

During the pregnancy, a relationship between the woman and her child develops. She prepares for motherhood and imagines how the first encounter with her child should be. When her newborn child needs extra care in a NICU, the new mother finds herself in a situation for which she is unprepared. She is filled with different kinds of feelings during the separation, such as fear, guilt, anxiety, loneliness and a sense of not belonging. The feeling of interaction between the mother and the caregiver is important for her understanding of what is happening to her child. When a feeling of insecurity occurs, belonging neither to the maternity care unit nor to the NICU, the feeling of *exclusion* evolves. It is natural that the care in the NICU focuses on the child's needs, but when the mother is not seen as part of this care, the mother's feeling of *exclusion* is strengthened. When the mother is nearby, breastfeeds and takes care of her child's daily care she has a feeling of *participation*. The difficulty in receiving care from the caregivers in the maternity care unit, as well as having the other mothers with a child at side, further strengthens the feeling of *exclusion*. The maternal feeling is negatively influenced. To not acknowledge the mother, including her needs, is understood to be uncaring, leading to suffering where the mother's dignity is insulted. The opposite, *participation*, is an essential core of the phenomenon, when the mother is seen as a natural part of care, no matter whether she is in the maternity care unit or the NICU. Here the new mother is seen as a unique person with unique needs, supported in her motherhood, both in the maternity care and in the NICU. A feeling of *participation* influences the maternal feelings in a positive direction.

Discussion

The use of a phenomenological hermeneutic method offered good possibilities to describe the studied phenomena, 'mothers' experience of having their newborn child in a Neonatal Intensive Care Unit'. The mothers' stories were strongly expressed emotionally. No matter when the child was born, 6 months or 6 years ago, the experience of the separation was still very alive and some of the mothers cried during the interview. Once the interviews started the narratives just flowed, told with great detail and enthusiasm. Despite two of the mothers having previously had children in the NICU, they could separate the events. This illustrates how important the experience was and that it remains with the mothers for a long period of time.

Although the 10 narratives had many variations, there was a common essence in the experience of being separated from the newborn child. The oscillation between *exclusion* and *participation* was present in every story. There are many examples of how the mothers struggled to be acknowledged, to get detailed information about their child's health and, like other mothers, to take care of their own child. There is also a domination of *exclusion*, feeling excluded both from the care in the maternity care unit and in the NICU. Viewed from an existentialistic perspective, this may contribute to a feeling of not being a mother or an insufficient mother. To experience *exclusion* gives a deep sense of loneliness. An exclusive mode of care, where the mother is not seen and met in her needs, insults a mother's dignity, being an expression of uncaring which leads to unnecessary suffering from care. According to Eriksson (25), the most profound suffering related to care involves the patient's perception of having been deprived his or her dignity, of not being understood, of not being taken seriously. As nursing personnel to not see the patient is a form of power abuse which can make the possibility of participation in their own care impossible. Caring, on the contrary, means communion between patient and caregiver. The caregivers must have courage and take responsibility for the mother of the child to ensure that this suffering does not arise and that *participation* dominates the care (25).

The feeling of exclusion was also crucial in another study (12). In that study, exclusion included a feeling of 'being

left outside' based upon feelings of despair, powerlessness, homelessness and disappointment. The similarity between the findings strengthens the reliability of our study and that the essence of the feelings persists for as long as 6 years after the event.

A mother's need of information was shown to be essential in another study performed in Sweden some years earlier (26) highlighting the importance of listening to and seeing the unique mother, and involving her in the care. It is also shown that the caregivers' behaviour affects parents' experience of the care in the NICU. Clearly, it is important to keep up a continuous communication with the parents, to diminish their stress and worries about their child (13, 14).

The woman creates contact with her child during the pregnancy and the desire to be a mother promotes the beginning of a maternal–child relationship. To experience early contact during babyhood promotes the attachment to the child. Fortunately, this attachment is not just developed during the first week; it progresses throughout the whole first year (5, 8). However, to start motherhood with a sick child is a difficult task. The mother's anxiety about the child's health makes the attachment process more complicated. The interaction between mother and child becomes subordinated to the child's health. The mothers often turn off their emotions as a strategy to handle the situation and to protect themselves against a possible loss (27). Parents whose children are in the NICU are often in a critical state of mind. The hospital environment is unfamiliar and the meeting with their sick child can be terrifying. The delivery has often been traumatic and the parents have often missed the early skin-to-skin contact with their child (26). When the child is given care for in the NICU, the mother experiences difficulties in establishing a close relationship with her child. The natural behaviour of the mother ceases. When the child is cared for by 'experts' the mother's self-esteem may be undermined. A feeling that the child belongs to the hospital arises (28). It is essential to stress that support and conversation therapy could help the parents overcome emotional problems, which may occur during the separation (8, 28). Research has shown that a mother who is denied the opportunity to mother her child is left feeling confused and anxious (29). Negative effects arising from the separation of mother and child can be counteracted. When the mother receives extra contact with her child, she shows greater commitment. This gives her higher self-esteem in the caring of her child and greater knowledge in the interpretation of the child's signals (30). When the mother is given responsibility for the daily care of her child, she feels more secure in her maternal identity (31).

The findings highlight that the mother has a struggle within herself. She alters between exclusion and participation. The mother has a desire to demand her right to be with her child, but does not dare, feeling she should deny this need in gratitude for the lifesaving care the child is receiving. She shows a great understanding of the caregivers' behaviour. Perhaps it is difficult to criticize the people who have saved one's child? An essential question to pose here is who is the 'owner' of the child? An interpretation of the present findings shows that the caregivers 'own' the child. To deny the mother's right to her own child is, according to Eriksson's descriptions, uncaring and an expression of suffering (25). For mothers there is no official document which supports their right to be with their child 24 hours a day when being cared for in the NICU. However, children's rights are documented. NOBAB (Nordic standard for care of children in hospital and medical care) (32) which is based upon the United Nations Convention for Children (33) emphasizes that all children, independent of age, have the right to have their parents with them during the whole period in hospital. The children in this study were born at full term without malformations. Compared with other children cared for in the NICU, they were at less medical risk, despite this the mothers' experience was strong. The new study shows that the experience of having a child cared for in NICU, is still very strong within the mother even 6 years after the birth of the child. This illustrates the importance of different forms of care strategies which ease the contact between mother and child, and contributes to caring for both mother and child together being prioritized to a greater degree.

Conclusion

The essence of mothers' experience when their newborn child was cared for in a NICU during the postpartum maternity care period is understood as an alternation between exclusion and participation with emphasis on exclusion. That this strong feeling still exists several years after the experience is new knowledge. This fact increases our knowledge and understanding of the mother's situation and stresses the importance of developing strategies which support the maternal feelings of participation in the care of the child. Furthermore, a return visit to the responsible nurse to go through the treatment and experiences should be offered to all parents who had their child cared for in a NICU.

Acknowledgements

This study is part of a larger ongoing research programme, 'The Value of Caring' at the Department of Nursing, The Sahlgrenska Academy at Göteborg University, Sweden.

Author contribution

Helena Wigert and Renée Johansson were responsible for the conception and design of the study. Helena Wigert and Renée Johansson collected the data. All authors were responsible for data analysis. Helena Wigert and Renée Johansson drafted the manuscript. Marie Berg and Anna

Lena Hellström carried out critical revisions and supervised the study and writing of the paper.

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