Needs and Perceptions Relative to Emotional Support in Parents With Preterm Infants

Annika Schmöker, MPH; Jenny Ericson, PhD, RN; Renée Flacking, PhD; Camilla Udo, PhD

ABSTRACT

Objectives of this study were to explore parents’ needs for emotional support and how such support could be best delivered during admittance to a neonatal unit. This study took place at 6 neonatal units in Sweden. Forty-two semistructured interviews were analyzed using qualitative content analysis: 26 individual telephone interviews with mothers of preterm infants 6 to 10 months after discharge and 16 face-to-face interviews with parents of preterm infants admitted to neonatal units. The main category to emerge was needs and preferences for emotional support, which consisted of 2 generic categories: emotional needs and preferences for potential support interventions. Emotional needs define the importance of comprehending the new situation, finding meaning, and managing the situation through resources. Preferences for potential support interventions identify possible ways to deliver emotional support in the form of parental PhD group, diary writing, professional counseling, and Internet support. The results highlight the importance of supporting parents’ sense of coherence in their situation and parenthood by offering different interventions according to parent preferences. Parental groups could serve as a keystone for emotional support with the possibility to combine with other support mechanisms.

Key Words: emotional support, neonatal, parental group, support interventions

After the traumatic event of preterm birth, the majority of parents whose infants require neonatal care experience higher levels of emotional distress, anxiety, and depression compared with parents of healthy and full-term infants. Sweden is in the vanguard of neonatal care as to low mortality and morbidity rates, as well as of family-centered practices in neonatal intensive care units (NICUs). In addition, in half of all Swedish neonatal units, both parents have the opportunity to sleep at the unit for the entire hospital stay. The NICUs’ single-family room design welcomes parents to stay with their infant 24 hours, which benefits breastfeeding, bonding, length of hospital stay, and increased staff-parent interaction.

Still, there are factors that entail a challenge to ensure parents’ emotional well-being and a stable parent-infant relationship, including the infant’s health status, stressful birth experience, and insufficient emotional parental support. Although the stressfulness of having a preterm infant needing neonatal care and parents’ experiences and perceptions of hospitalization in a
NICU are well-known, less is known about the parents’ needs for emotional support. Previous research has demonstrated the importance of receiving emotional support from the NICU staff to be able to manage problems associated with preterm birth. Bry and Wigert found that emotional needs are parts of psychosocial aspects, and could be alleviated (e.g., empathetic sensitive treatment by staff). For staff to address psychosocial issues, including emotional aspects, communication training has been shown to be valuable for improving nurses’ ability to respond with empathy to parents’ emotions.

The NICU staff's emotional support to parents is especially crucial during situations and times when there are rigid visitation restrictions, such as during the coronavirus disease-2019 (COVID-19) pandemic. Restrictions for partners and significant others profoundly affect life, living, and social habits for parents. In NICUs with restricted visiting, efforts need to be made by staff to ensure optimal communication even though visits are not possible.

Despite staff support, there is a need for additional emotional support. Several studies emphasize the need for emotional support given by peer supporters who have had similar life experiences. Sharing experiences and challenges with other parents who have been in a similar situation can increase well-being and reduce stress and feelings of loneliness. In a recent review by Treyvaud and colleagues, a multi-layered approach to support parents of infants in the NICU was recommended; individual psychological and psychosocial support, peer-to-peer support, and family centered care were identified as critical and important for parents’ mental health. With physical and emotional parent-infant closeness and improved support, the negative consequences of having a preterm infant in a NICU for parental health and parent-infant relationship may be substantially reduced. Hence, emotional support to parents of preterm infants during and after their infant’s hospitalization is of vital importance and an area for improvement.

Few qualitative studies have reported on parental experiences of emotional support, and little is known about what kind of emotional support is needed, parents' views on potential types of emotional support, and how support approaches could best be delivered. This study therefore aimed to explore parents’ needs for emotional support and how this support could be provided to parents of preterm infants during admittance to a neonatal unit.

**METHODS**

**Design**

The study applied a qualitative design using semistructured interviews. An interview guide was used throughout the data collection process that included all topics related to the research aim. Open-ended questions and probing were applied to allow the parents to express their thoughts and views and facilitate discussion.

**Setting**

Sweden has 37 hospitals providing neonatal care, of which 21 offer neonatal intensive care. This study took place at 6 NICUs geographically spread throughout Sweden, chosen based on their size and possibility to take part in the study. Two NICUs had single-family rooms and 4 had open-bay rooms, with some rooms providing provisions for parents to stay overnight.

**Participants and data collection**

During 2 phases of data collection, 51 parents were interviewed.

**Phase 1**

During the spring of 2016, 26 mothers of preterm infants, who had previously participated in an randomized controlled trial study regarding a telephone-based breastfeeding support, were interviewed individually via telephone 6 to 10 months after discharge. In all, 26 telephone interviews were conducted. Eligibility criteria were having an infant born at less than 37 gestational weeks, being admitted to one of the participating NICUs for at least 48 hours, and having been discharged. Excluded were mothers with serious illness, those who were not breastfeeding at discharge, mothers of terminally ill infants, and infants who were transferred to another unit or hospital. Additionally, mothers with language problems that could not be resolved were excluded.

**Phase 2**

During the autumn of 2016, 25 parents of preterm infants who were hospitalized in the NICU were individually interviewed or as a couple in a room they preferred. Data collection consisted of 16 face-to-face interviews, 9 with both parents, 6 with mothers, and 1 with a father. Eligible were all parents whose preterm infant was being admitted to 2 of the participating NICUs and who could understand Swedish or English.

This approach was chosen to include a diverse group of parents from different parts of the country who were hospitalized in different NICUs. The strategy also allowed a more in-depth exploration into the insight of parents' needs for emotional support retrospectively after discharge (phase 1) and during hospitalization (phase 2). In both phases the semistructured interview guide was used. The parents were asked about
their needs for emotional support during their hospitalization in the NICU. They were also asked to reflect on how emotional support could best be delivered and their preference for different support approaches suggested by the interviewer (participation in parental group support, diary writing, professional counseling, and Internet-based support). The semistructured interview guide contained questions such as “What support is/was available for you at the NICU?” and “If you were offered different kinds of support here at the NICU, what would you like to have?” The interviews, lasting an average of 30 minutes, were audiotaped with the parents’ permission. The data collection was terminated after the 42nd interview based on the consideration that similar content reoccurred during the interviews. All 42 interviews were transcribed verbatim.

We used the following abbreviations for the interviews: M = mother, F = father, U = at unit, and D = discharged.

Analysis
Qualitative content analysis, as inspired by Elo and Kyngäs, was applied to the transcribed interviews. Qualitative content analysis is a suitable form of analysis for multifaceted and sensitive research areas, including the investigation of emotional experiences in parents of preterm infants. During the analysis, the extracted information was kept close to the parents’ original statements to ensure transparency and outcome trustworthiness.

To gain a sense of the content, the research team read all of the transcribed interviews individually before discussing the first impressions. In the next step the first author organized the data from the interviews by open coding with content summarized in the margins. These codes were then translated into English by the first author and afterward transformed into coding sheets to achieve briefer and more explicit content. The codes were then grouped into subcategories and generic categories according to similarities and patterns (see Figure 1). Based on these generic subcategories, the main category was created, which remained close to the original descriptions. All authors critically reflected on all steps in the analysis process until consensus was reached.

During the analysis process, it became apparent that the results corresponded to Antonovsky’s theoretical framework sense of coherence. Thus, we used this framework for the presentation and interpretation of our results. It is often used to understand more about views and resources in people who manage or do not manage to maintain their well-being and health in challenging life situations. In accordance with this approach, the following components are crucial to well-being: meaningfulness (finding meaning in difficult and distressful situations), comprehensibility (understanding the situation), and manageability (capable of managing the situation).

Ethics
All eligible mothers and fathers who agreed to participate in the study signed a written informed consent after receiving oral and written information about the study and having had the opportunity to ask questions. The participants were told about their right to withdraw at any time and confidentiality of data. If further support was needed after the interviews, the research team could help and guide the parents. The study was approved by the Regional Ethical Review Board in Uppsala (Dnr. 2012/292/4).

RESULTS
Sociodemographic characteristics of the study participants and their infants are shown in Table 1.

In the interviews parents described their need for emotional support during hospitalization in the NICU and how it could best be delivered. Needs and preferences for emotional support emerged as the main category, which comprised 2 generic categories: emotional needs and preferences for potential support interventions. Emotional needs refer to the importance of comprehending the new situation, finding meaning, and managing the situation through resources. Preferences for potential support interventions denote ways to provide emotional support (eg, participation in parental group support, diary writing, professional counseling, and support through the Internet). The Figure shows the flowchart of the 3-category classification: main

Figure 1. Main category, generic categories, and subcategories. This figure is available in color online (www.jpnnjournal.com).
Table 1. Characteristics of participating mothers, fathers, and their preterm infants

<table>
<thead>
<tr>
<th>Demographic variables</th>
<th>Total All interviews Participants (n = 51)</th>
<th>Phase 1 Telephone interviews Participants (n = 26)</th>
<th>Phase 2 Face-to-face interviews Participants (n = 25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), y</td>
<td>30 (5.1)</td>
<td>30 (4.7)</td>
<td>30 (5.5)</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher education</td>
<td>26 (51)</td>
<td>15 (58)</td>
<td>11 (44)</td>
</tr>
<tr>
<td>Upper secondary school or less</td>
<td>25 (49)</td>
<td>11 (42)</td>
<td>14 (56)</td>
</tr>
<tr>
<td>Parity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First-time parents</td>
<td>33 (65)</td>
<td>16 (61)</td>
<td>17 (68)</td>
</tr>
<tr>
<td>Parents with more than 1 child</td>
<td>18 (35)</td>
<td>10 (39)</td>
<td>8 (32)</td>
</tr>
<tr>
<td>Multiple birth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Singleton</td>
<td>41 (80)</td>
<td>20 (77)</td>
<td>21 (84)</td>
</tr>
<tr>
<td>Multiple</td>
<td>10 (20)</td>
<td>6 (23)</td>
<td>4 (16)</td>
</tr>
<tr>
<td>Infant gestational age at birth, median (IQR), wk</td>
<td>33 (3)</td>
<td>34 (1)</td>
<td>33 (3)</td>
</tr>
</tbody>
</table>

Abbreviations: IQR, interquartile range; SD, standard deviation.

category, generic categories, and subcategories. The results are further elaborated later and illustrated by verbatim quotations from the parents.

Emotional needs
The generic category of emotional needs corresponds to Antonovsky’s theoretical formulation sense of coherence. According to this framework, to be able to emotionally handle a situation, the parents had to comprehend the situation, find meaning, and be able to manage the situation.

Comprehending the new situation
Comprehending the new situation was vital for the parents’ emotional well-being. For the parents, understanding the situation was closely related to receiving clear information about why their infant was born preterm and the infant’s current health status. Several parents wished for more distinct and proactive information without having to ask for it, as they sometimes did not have a clear idea of what they needed. The parents wanted information to be repeated because it was difficult to process all the details at once. However, many parents felt that they were not given enough information, or they received contradictory advice, which caused confusion and frustration, hindering them from comprehending all that was happening.

The only thing I felt was negative and that there was no common thread, but that everyone had their own way. And then there were vague things. But then there might be others who maybe have a completely different opinion. One evening, things were done in a certain way. And then during the night someone would come and say, uh-huh, did you do it that way? No, you must do it differently. Therefore, it became a little like, how are we supposed to do? (PU35)

One suggestion from the parents was to have a contact person within the NICU during the entire hospital stay to achieve continuity in care contact and in whom they could turn to with questions and in times of distress. From the parents’ perspective, a contact person was especially important if the family needed to stay in the NICU for a longer time.

Finding meaning
Finding meaning in their situation after preterm birth was important for the parents to deal with their emotional crisis. To see their role as a parent and bond with their infant were crucial. Being and feeling like a parent was portrayed as difficult because of insecurity about their responsibility and NICU staff expectations. Many parents perceived the staff to act as their infant’s primary caregiver and felt as though they borrowed the infant from the staff and needed to ask for permission when they wanted to be with their infant.

It feels a bit like we need to have their permission to do things. So, it becomes a little as though they were not my children. I can borrow them a little. And the staff is out there, sleeping next to them, coming in with food, so we do not need to fix so much ourselves. (MD3)

Some parents recounted their inadequacy to feel and act as a parent until they could come home with their infant. They wished for a more active role in taking care of their infant, having a voice as a parent, and being part of the decision-making process, but found it difficult to take an active role without the staff initiating a relationship with equal collaboration. The parents stated that
an active involvement would help in developing their role as a parent, and by that, establishing meaning in being a parent.

Managing through resources
The parents reported that previous life experiences had significant impact on how they managed and were either empowering or aggravating. For example, a former preterm birth could be experienced as either helpful or impairing. Other ways to manage and cope included discussing issues with their partner and receiving support from other family members and close friends.

The staff's behavior and availability were crucial to the parents in managing their distressful situation and had a substantial impact on their overall well-being. Some parents pointed out the desire for more proactive emotional support, whereas others were highly satisfied with the emotional support they received. When staff regularly paid attention to the family's well-being or when there was a staff member present whom they felt they could trust and could turn to, it made them feel not only cared for but also seen and heard as an individual.

It was one of the nurses whom I really liked. After a while she came in and sat with me, twice sometimes. She sat with me and helped me and pushed me a little and gave me a boost. But this works very well. So, it felt terrific. // She made me feel a little calmer. (MD2)

Preferences for potential support interventions
Within the generic category of preferences for potential support interventions, parents were asked about their thoughts on how emotional support could best be delivered and thereafter about their preference for different support approaches suggested by the interviewer. They also mentioned barriers for taking part in the support interventions and emphasized their individual needs in what kind of support might be most beneficial. Moreover, several parents stated that a combination of the different support approaches would be most efficient to meet their diverse needs.

Parental group
Many parents claimed they only rarely met other parents at the NICU and that no conversations between parents occurred in the common areas, as they returned to their infant as soon as possible. Spending so much time in their room without any contact with other parents created a feeling of loneliness; however, they appreciated being able to be with their infant 24 hours a day. Many parents emphasized that parental groups would allow them to meet other parents in a similar situation, which would perhaps contribute to a feeling of normality and community, as well as help in the processing of inner thoughts. The parents wished for advice about how other parents handled certain situations, both practically and emotionally. They reasoned that sharing experiences, expressing their feelings, and being acknowledged as a parent would help them to deal with the emotional rollercoaster of being a parent of a preterm infant.

Talking to others in a similar situation is always good, I think. That you can get some advice about how to handle it or to see how others are feeling ... so that you would talk a little. Because you become quite isolated here. To get a bit more social life here. (MU32)

According to most of the parents, parental groups should be optional and led by a member of the staff who could provide information and practical advice in a relaxed and positive atmosphere. Some parents of relatively healthy infants specified that they were apprehensive about joining a parental group that included parents in a much worse situation. Other parents mentioned barriers for joining a parental group, such as an unwillingness to leave the infant or a lack of time and energy.

Diary writing
Many parents favored the idea of writing down their thoughts and emotions in a diary. They wanted the staff to take the initiative of arranging a diary at the beginning of their NICU stay, as they did not have the energy to organize one because of the chaos they experienced when arriving at the NICU. The parents felt that diary writing would probably be a form of therapy, help them to process the event of preterm birth, and clear their mind. Several parents also stated that writing a diary would serve as an external memory device that could be helpful in the future because it provides a written account of what happened, their innermost feelings and fears, and the progress in their infant's development.

With diary writing, you document everything, all feelings that arise and so you process what you are going through at the same time. That I believe is important. If there were a diary ready with empty pages where you can just write in because mostly everything is so challenging when you arrive at the neonatal unit. You cannot manage to organise things by yourself. And a diary is like a little therapy. Maybe you can go back and see how it was then. How far did we come? Because sometimes you get stuck and do not see the children's progress. (MD16)

Some parents felt no need to keep a diary because of lack of time or energy, but other parents might
benefit who were less comfortable in talking about their feelings and problems directly with others.

**Professional counseling**

Parents desire more professional counseling at the NICU and some suggested one-to-one support with a medical social worker. Some parents had been offered contact with a medical social worker and others had not. Many parents who were offered this support were satisfied and thankful to have the opportunity to talk to someone outside the family soon after the preterm birth and who had specialized knowledge and understanding of their situation.

It was nice to talk to a medical social worker at an early stage. It lightened [the situation] a lot to talk to an outside person who still has insight because that is something difficult. That your loved ones do not understand how life is here. We made contact with a medical social worker almost immediately. We talked to the medical social worker two days after our child was born. (MU36)

Other parents wanted information focused on a more proactive approach about the existing support and the offer of professional counseling as a routine, regardless of whether the parents seemed to need it.

**Internet**

The parents held that Internet-based support did not necessarily need to be organized by the NICU staff, given that the parents already used the Internet to search for information and receive emotional support through sharing and reading other parents’ experiences. According to the parents, it was helpful to receive information from the staff about available groups of parents with preterm infants on social media outlets. The parents appreciated the Internet-based support because of its 24-hour accessibility.

There are excellent forums on Facebook, especially for premature children. And it is also something we need to be informed of by the staff at the neonatal unit. There are people from all over Sweden. Then I believe it is easy to end up sitting on your own. And I experience that communication with other parents is of great importance. (MD20)

However, not all parents liked the idea of Internet-based support, arguing the importance of meeting other parents face-to-face instead.

**DISCUSSION**

To our knowledge, no studies have focused on parents’ views and preferences for emotional support interventions in the NICU. The main findings showed how Antonovsky’s theory of sense of coherence can be used to identify emotional needs in NICU parents and how to provide emotional support consistent with the parents’ preferences. These findings will now be discussed in detail.

Corresponding to previous findings, parents characterized their emotional needs during their infant's hospitalization in a NICU, including the need for parental involvement in infant care and receiving information and emotional support from the staff. Many parents in our study called for a more active role in caregiving of their infant, as they often felt they just borrowed the infant from the staff, which made them not feel as a parent. This loss of the parental role can make it difficult for the parents to bond with their infant. Hence, becoming more involved and empowered as a parent in the NICU might help the parents find meaning and their parental identity despite their difficult situation. Meaningfulness has been depicted as the most important component within the theory of sense of coherence. Besides meaning, our study observed that comprehending why the preterm birth occurred appears to be an essential precondition for determining the parental role and bonding to the infant, which has been shown to be important for feeling emotionally close. Our results showed that lack of information could result in stress and confusion and that many parents had a wish for more proactive emotional support from the staff. This need for a more proactive approach is in line with several studies. Additional to the support from family and friends, the staff’s behavior and emotional support can be crucial in terms of the manageability of the parents’ difficult situation. The sense of coherence could guide staff on how to provide emotional support to parents at the NICU, as well as parents in their transition to parenthood and bonding with their infant. For staff to apply theory in practice requires education and communication training. Hall et al have shown that educating staff for enhancing psychosocial support can help the communication process and improve parents’ functioning and the parent-child relationship. To acknowledge and address aspects such as meaning, comprehension is complex and needs an individualized approach. Individually adapted sensitive and responsive communication has previously been suggested as a strategy to support parents at the NICU. With a more responsive communication strategy, perhaps mothers would feel treated and supported as the main caregiver, instead of feeling as borrowing the child from the staff. Feeling empowered as a parent is most likely even more important now in times of the COVID-19 pandemic considering they are alone with their infant at the NICU due to the visitation restraints.
The parents in this study were asked about how emotional support could best be delivered. Many parents perceived the emotional support they received from staff, family, and friends as insufficient. The emotional support did not meet their needs entirely, asserting that only other parents of preterm infants would fully understand their feelings. When different support approaches were suggested, most parents preferred to attend a professionally led parental group at the NICU. Since the parents in our study also wished for peer support, a suggestion could be for the parental group to be led by a staff and a “senior” parent (ie, a parent with previous experiences from being hospitalized at the NICU with their preterm infant). This approach has been suggested to provide unique and useful means to support NICU parents. 38

Based on previous studies, peer support (eg a parental group) is one of the core factors for the development and support of the parental role. 21,39 Parents in our study often felt alone and uncertain of their situation and the future. The present results suggest that meeting other parents who experience a similar life event may contribute to the feeling of being a “normal” parent among other parents. Being confirmed, sharing experiences and expressing emotions might be of help in reducing feelings of stress and loneliness, gaining hope for the future, and promoting the parental role. 18,39,40 We suggest that feeling ensured as a parent may help parents become more active and confident in the caregiving of their infant. Moreover, a parental group could serve as an important source of information, involving both staff and parents in regular dialogue. Parents in our study wished for a contact person from the staff to ensure continuity in care contact by offering proactive support and information. However, this might not be feasible in many contexts, as rotating shift work, different levels of experience of the staff, and acute illness of an infant may be obstacles preventing this continuity in care contact. Thus, a parental group might partly fulfill this role and ensure that the staff members are even more aware of the emotional needs and how to support the parents in the best way, which, in turn, might strengthen the relationship between staff and parents. Thus, meeting other NICU parents might serve as a powerful catalyst and incentive to foster the parents’ sense of coherence and, by that, facilitate their transition to parenthood. It would also normalize the emotional crisis many parents face during their infant’s hospitalization.

Although the parental group was the primary means of support that most parents preferred, such an approach was not equally relevant for all parents. Every family’s situation is unique, with parents having different external and internal resources for managing their stay in the NICU. Diary writing, professional counseling, and Internet-based support were other support interventions suggested to the parents. Diary writing may be beneficial for the parents in terms of emotional relief, especially for those who do not feel comfortable in a group setting. It also has the advantage of being available around the clock without having to leave the infant. Some parents preferred contact with a medical social worker and did not want to be confronted with parents who were in a worse situation than them. Just a few parents expressed interest in professionally led Internet-based support, probably because most parents already used the Internet for information and support. Therefore, a professionally led parental group at the NICU meets the needs and preferences for emotional support for many parents. However, the parents also mentioned barriers that might prevent them from taking part in a parental group, such as lack of time and energy and the unwillingness to leave the infant. 29 Therefore, it is vital to offer a range of different types of support intervention based on the theory of sense of coherence. Parental groups could serve as a cornerstone for emotional support with the possibility to combine with other means of support (eg, diary writing). This central support mechanism could make it possible for all parents to receive the emotional support they need to be able to develop their parental identity, bond with their infant, and manage their infant’s hospitalization.

A strength of this study is that the interviews were conducted at different time points, both during the parents’ admission to different NICUs and retrospectively after discharge. The different room designs of the participating NICUs and that both mothers and fathers were interviewed provide a broad and multifaceted perspective. A limitation of the study is the exclusion criteria used in both phases of data collection. Vulnerable groups, such as parents of terminally ill infants or parents with depression, might have other emotional needs and preferences of support interventions than those included. Thus, our findings may not be generalizable to the whole population of parents of preterm infants in Sweden. Another limitation is that some of the interviews were relatively short. These short interviews, however, were compensated by the large number of interviews, which continued until similar content reoccurred during the interviews.

Still, the study provides insight into parents’ emotional needs and preferences of potential support interventions, which could play a prominent role in designing future studies. To achieve trustworthiness, several aspects were considered throughout the research process including reflexive and critical joint discussions among the authors. The rigorous and systematic data collection and analysis process strengthened credibility.
and dependability. Finally, confirmability was achieved by the illustration of the verbatim quotes.]

The main results in this study were related to parents’ preferences of how to deliver parental emotional support at the NICUs. Peer support along the lines of professionally led parental groups was preferred by many parents, either as a single support system or together with other means of support. Clinical implications include the development, testing, and evaluation of emotional support interventions where, according to our study, the sense of coherence theory could help guide the designing of content.

References


