Assessment of Family Needs in Neonatal Intensive Care Units

By Cynthia A. Mundy, RN, DNP, NNP-BC, CNL

Background  Limited research has been conducted to assess family needs in neonatal intensive care units. Health care providers often make assumptions about what families need, but these assumptions are unfounded and can lead to inappropriate conclusions. When assessed appropriately, family needs can be incorporated into individualized plans of care, enhancing family-centered care.

Objective  To assess the needs of parents in neonatal intensive care units, we asked the following 3 questions: What are the most and least important needs of families in a level III neonatal intensive care unit? Do parents’ needs differ at admission and discharge? Do the needs of mothers and fathers differ?

Methods  Parents were interviewed by using the Neonatal Intensive Care Unit Family Needs Inventory. Participants rated statements as not important (1), slightly important (2), important (3), very important (4), or not applicable (5).

Results  Fifty-two (93%) of the 56 items were rated as important or very important, and parents rated assurance-type needs highest. Parents at admission rated support needs higher than parents at discharge rated those needs. Needs of mothers and fathers did not differ significantly.

Conclusions  Identifying the needs of parents in neonatal intensive care units can enhance nursing communication and allow nurses to incorporate parents’ needs into families’ plans of care. The family needs inventory can help identify those needs and allows the integration of individualized nursing care to fulfill those needs, providing a positive family-centered experience in the unit for patients and their families. (American Journal of Critical Care. 2010;19:156-163)
A family need is defined as “a requirement, which if supplied, relieves or diminishes their distress or improves their sense of adequacy or well-being.” Improving “well-being” is the role of all health care providers, especially nurses who innately foster health through caring. However, what nurses think are the most important needs of family members differ from what those needs actually are. Therefore, it may be difficult for nurses to correctly identify the needs of parents. Several studies conducted in adult ICUs were focused on the assessment of family needs, but the needs of parents in the NICU are not well defined or documented.

The purpose of this project was to assess the needs of parents in NICUs by using an existing assessment tool. The following 3 questions were addressed in this study: What are the most and least important needs of families in a level III NICU? Do the needs of parents differ at admission and discharge? Do the needs of mothers and fathers of NICU babies differ?

**Literature Review**

**Summary of Literature**

Few studies have been done to assess the needs of parents of infants in the NICU, so studies conducted in the pediatric intensive care unit (PICU) also were reviewed. From this literature review, similarities have emerged.

Several studies used measurement tools that categorized family needs as involving information, communication, assurance, support, or comfort. Parents cited information needs as the most important need in many of these investigations. Assurance needs were also a key finding in several studies. An additional theme that has been identified from the existing body of evidence is that the family needs perceived by nurses differ from what the family needs actually are.

**Specific Investigations**

In one report, researchers studied the differences in the family needs perceived by nurses and the needs reported by families of patients in adult ICUs and NICUs. Using an adapted form of Molter’s Critical Care Needs Inventory (CCFNI), the Norris and Grove Needs Questionnaire, the researchers found that families rated informational needs higher than other needs. Significant differences were noted among families in NICUs and families in adult ICUs, but the differing need statements were not identified in the manuscript. The needs of NICU families perceived by NICU nurses differed from the needs described by the families themselves. Specifically, NICU nurses rated the need to talk about feelings higher than NICU families actually rated the need.

Using the Critical Care Maternal Needs Inventory, another tool adapted from the CCFNI, a group of researchers studied maternal needs and priorities in the NICU. The need for accurate, reliable, and topic-specific information and the need for regular communication were rated the highest in this group of mothers. The researchers concluded that the meaning of maternal needs should be shared between the mother and nurse so that family-centered care can be facilitated.

In another study, the needs of 51 parents in a NICU were examined. Using the NICU Family Needs Inventory (NFNI), Ward found that needs for assurance were rated the most important and support needs were rated the least important in the population studied. Differences were noted in the responses of mothers and fathers, with mothers rating needs for...
that their child was being treated for pain as very important. The need to feel hope was also rated very high. The investigator noted significant differences in the needs of mothers and fathers, with mothers rating needs higher than fathers in 9 individual responses.

**Methods**

This study was conducted in a 36-bed level III NICU at the Medical College of Georgia from January 2006 to May 2006 after approval was received from the internal review board. Participants were given an information sheet that explained the study’s purpose, provided contact information for the primary investigator, and explained that refusal to participate in the study would not affect the care of their child.

**Sample**

Participants were identified from a convenience sample of parents visiting their infants in the NICU during the week of their infant’s admission or the anticipated week of discharge. Parents interviewed at the time of discharge may also have been interviewed on admission, but participation upon admission and discharge was not a requirement. Inclusion criteria consisted of parents whose infants were less than 32 weeks’ gestation or had a serious medical condition for which the length of stay was anticipated to be greater than 30 days. These 2 criteria were used to select the most critically ill patients, not those requiring minor interventions or monitoring for a short duration. For parents who were interviewed during the week of their infant’s discharge, the infant must have been in the NICU for 30 days or more. Parents of infants who were not expected to survive were excluded from the study because the survey was not deemed appropriate for these families.

Sixty-two parents in the NICU were approached for participation and 60 agreed to do so. Forty parents were interviewed during the week of admission and 20 during the week of discharge. Seventy-two percent (n = 43) of the participants were mothers and 28% (n = 17) were fathers. The ages of the parents ranged from 16 to 44 years (mean, 25.78 years; SD, 6.91 years). The hospitalized infant was the first child for 48% of the parents, and 17% of the parents reported having some type of previous experience in a NICU. Table 1 presents further descriptive data related to the parent participants.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Valuea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), y</td>
<td>25.78 (6.91)</td>
</tr>
<tr>
<td>Mothers</td>
<td>25.21 (6.86)</td>
</tr>
<tr>
<td>Fathers</td>
<td>27.25 (7.04)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17 (28)</td>
</tr>
<tr>
<td>Female</td>
<td>43 (72)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>29 (48)</td>
</tr>
<tr>
<td>African American</td>
<td>27 (45)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Asian</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>33 (55)</td>
</tr>
<tr>
<td>Single</td>
<td>25 (42)</td>
</tr>
<tr>
<td>Divorced</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>&lt;12th grade</td>
<td>22 (37)</td>
</tr>
<tr>
<td>12th grade or equivalent</td>
<td>38 (63)</td>
</tr>
<tr>
<td>Some college</td>
<td>27 (45)</td>
</tr>
<tr>
<td>≥4 years of college</td>
<td>11 (18)</td>
</tr>
<tr>
<td>First child</td>
<td>29 (48)</td>
</tr>
<tr>
<td>Previous experience in neonatal intensive care unit</td>
<td>10 (17)</td>
</tr>
</tbody>
</table>

Values are expressed as number (%) of parents unless otherwise indicated.

**Table 1**

Demographics of parents in the study

NICU mothers rated support, assurance, and information needs higher than fathers did.

Three studies from the pediatric ICU literature were reviewed, and all used modified versions of the CCFNI. In a descriptive qualitative report of 15 parents of PICU children, researchers identified 208 individual needs. The most frequent subcategory of needs documented were the needs related to information pertaining to the child. The single most important need was for the parent to be with his or her child in the PICU.

The needs of parents in 2 metropolitan PICUs were investigated and the most important needs were (1) to know how their child was being treated medically, (2) to feel there was hope, and (3) to be assured that the best care possible was being given to their child. The author suggested that incorporation of informational needs into the plan of care and provision of appropriate coping and support mechanisms will improve crisis prevention in parents of children in PICUs.

Another study showed that the most important need of parents in the PICU was to know the prognosis of their child. Parents rated the need to know why things were done for their child and knowing
The mean length of stay was 46.37 days. However, 3 infants died and 5 were still hospitalized at the conclusion of the study and were not included in the analysis of length of stay. Data on the top 4 medical diagnoses of each infant were gathered and are summarized in Table 2.

**Instrument**

The needs of families in adult ICUs have been studied since the late 1970s. Molter10 developed a 45-item tool to “determine the needs of the relatives so that energy of health care professionals is not misdirected and total patient care is accomplished.” In 1986, the tool was adapted by Molter and Leske and resulted in the CCFNI, which has been used in multiple research investigations to date.2,11 The purpose of the CCFNI is to “(1) generate the degree of importance of specific needs of the family member of the critically ill, (2) provide a fairly generic instrument that covers a wide array of needs, and (3) provide a practical and useful instrument for the clinical setting.”

When using the CCFNI, families rate the importance of the needs statement on a Likert-type scale. After a factor analysis, Leske11 determined that the tool addressed 5 subscales of needs: support, comfort, information, proximity, and assurance.

The CCFNI is specific to adult critical care. Ward6 adapted the tool for use in the NICU, resulting in the NFNI, a 56-item tool. Permission for use of the NFNI in this study was granted by developers of the tool. A test of internal consistency was completed after data collection; the Cronbach \( \alpha \) was 0.94.

**Study Design**

A descriptive correlational design was used for this study. After agreeing to participate, parents were interviewed separately by using the NFNI tool. Interviews were conducted by the principal investigator or by 1 of 4 staff nurses who were trained in the use of the NFNI by the principal investigator. Conference rooms within the NICU were used to interview parents in an effort to avoid distractions from the NICU.

Items were read aloud to participants, and participants rated the statement as not important (1), slightly important (2), important (3), very important (4), or not applicable (5). Clarification of statements or examples were given as necessary, but interviewers were instructed not to alter the meaning of the statement. Parents were asked an open-ended question at the end of the survey to determine if they had any specific needs that were not covered by the NFNI.

Demographic variables were collected on parents and their infants after the survey was completed. The interviews took from 5 to 30 minutes to complete (mean, 10.98 minutes; SD, 5.56 minutes). An interpreter, provided by the Culturally and Linguistically Appropriate Services of the hospital, was necessary for 1 interview.

**Statistical Analysis**

The Statistical Package for the Social Sciences 13.0 for Windows (SPSS, Inc, Chicago, Illinois) and Microsoft Excel 2003 (Microsoft Corp, Redmond, Washington) were used for data analysis. Descriptive statistics were used to identify the most and least important needs among families in the NICU and to analyze the demographic data of parents and infants. Independent t tests were used to determine if responses of parents differed between the time of admission and the time of discharge or between mothers and fathers. One-way analysis of variance was used to determine if such differences in responses were apparent between the 5 subscales. Confidence intervals were set at 95%.

**Results**

**General Needs**

Frequency distributions and rating of means for each question were used to determine the most important and least important needs of the families interviewed (Tables 3 and 4). Fifty-two (93%) of the

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Table 2: Demographics of infants in the study

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Valuea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gestational age, mean (SD), weeks</td>
<td>32.15 (4.73)</td>
</tr>
<tr>
<td>Birthweight, mean (SD), g</td>
<td>1883.13 (982.51)</td>
</tr>
<tr>
<td>Length of stay, mean (SD), d</td>
<td>46.37 (35.14)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Prematurity</td>
<td>27 (71)</td>
</tr>
<tr>
<td>Respiratory distress syndrome</td>
<td>16 (42)</td>
</tr>
<tr>
<td>Respiratory failure</td>
<td>4 (11)</td>
</tr>
<tr>
<td>Congenital heart disease</td>
<td>3 (8)</td>
</tr>
<tr>
<td>Patent ductus arteriosus</td>
<td>3 (8)</td>
</tr>
<tr>
<td>Persistent pulmonary hypertension of the newborn</td>
<td>3 (8)</td>
</tr>
<tr>
<td>Gastroesophageal reflux disease</td>
<td>2 (58)</td>
</tr>
<tr>
<td>Infant of diabetic mother</td>
<td>2 (58)</td>
</tr>
<tr>
<td>Intraventricular hemorrhage</td>
<td>2 (58)</td>
</tr>
<tr>
<td>Extracorporeal membrane oxygenation</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Gastrochisis</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Group B streptococcus pneumonia</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Meconium aspiration syndrome</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Other</td>
<td>19 (50)</td>
</tr>
</tbody>
</table>

a Values are expressed as number (%) of infants unless otherwise indicated.
56 items were rated as important to very important. Twenty-six items (46%) were rated as not important by at least 1 respondent. By subscales, parents rated assurance needs highest (mean, 3.89) and support needs lowest (mean, 3.33). The Figure gives a summary of subscale responses.

**Admission and Discharge Needs**

The demographics of the admission and discharge groups did not differ significantly. The total number of responses about needs at the time of admission and at discharge were not significantly different ($P = .12$).

Analysis of subscale differences indicated that parents at admission rated support needs as significantly more important than parents at the time of discharge rated support needs (admission mean, 3.37; discharge mean, 3.24; $P = .02$).

Two individual questions were significantly different between the admission parent group and the discharge parent group. Parents during the week of discharge rated the need “To have someone to help with transportation” higher than parents at the time of admission rated it (admission mean, 3.32; discharge mean, 3.39; $P = .003$). Admission parents rated the need statement “To feel there is hope” higher than discharge parents rated it (admission mean, 4; discharge mean, 3.89; $P = .03$). The need “To feel accepted by the hospital staff” approached significance, with admission parents rating this need higher than discharge parents rated it (admission mean, 3.8; discharge mean, 3.42; $P = .07$).

**Mothers’ and Fathers’ Needs**

Demographics did not differ significantly between the group of mothers and fathers. The total numbers of responses about the needs of mothers and fathers were not significantly different ($P = .11$). Subscale responses did not differ significantly between mothers and fathers, although mothers rated support needs slightly higher than fathers rated support needs (mothers’ mean, 3.36; fathers’ mean, 3.26; $P = .08$). When individual statements were analyzed, the need “To receive information about my infant at least once a day” was more important to mothers than to fathers (mothers’ mean, 3.86; fathers’ mean, 3.78; $P = .04$). Two additional questions approached significance. Mothers rated “To be allowed to have my infant’s siblings visit” and “To feel it is alright to cry” as more important than fathers rated those needs (mothers’ mean, 3.36; fathers’ mean, 2.83; $P = .06$; mothers’ mean, 3.52; fathers’ mean, 3.06; $P = .07$).

**Other Variables Related to Needs Assessment**

Age. Parents who were more than 30 years old rated total needs as more important than their younger counterparts (<20 years old: mean, 3.56; 20-30 years old: mean, 3.59; >30 years old: mean, 3.7; $P = .002$). Parents more than 30 years old also rated the subscales of support and comfort as significantly more important than younger participants.
rated those subscales (support, $P = .04$; comfort, $P = .05$). Participants more than 30 years old rated the following individual items significantly more important than the younger groups did: “To have a pastor, clergy, or other person from my church to visit” ($P = .009$); “To help make decisions about my infant’s plan of care” ($P = .03$); “To have a support group of other families available” ($P = .04$); and “To have classes about premature infants and their special care needs” ($P = .04$).

**Marital Status.** Single parents rated “To be recognized as important in my infant’s recovery” ($P = .001$) and “To have a place to be alone while in the hospital” ($P = .03$) as more important than married or divorced individuals rated those needs. Other conclusions about marital status were difficult to ascertain because only 1 participant reported being divorced.

**Race.** Total responses differed significantly between racial groups ($P < .001$). Individuals classified as “other” and African American parents rated the overall need statements as more important than whites or Hispanics rated those statements. They also rated the subscales of support, assurance, and comfort as significantly more important than did whites or Hispanics (support, $P < .001$; assurance, $P = .004$; comfort, $P = .006$). Nine individual needs statements were rated significantly differently between racial groups.

**Education.** To correlate education and the importance of the needs statements, parents were assigned to 1 of 3 groups: those with less than a 12th-grade education, those with a 12th-grade education or the equivalent, and those with some college. Parents who had a 12th-grade education rated the overall needs as more important than the other groups rated them ($P = .001$). Those with a 12th-grade education also rated the subscales of support and information as more important than the other groups rated them (support, $P = .01$; information, $P = .01$). When individual questions were analyzed according to education level, parents with some college rated the needs statement “To have a pastor with me when visiting the NICU” as more important than did parents with less education ($P = .003$).

**First Child.** Total, subscale, and individual-item responses did not differ significantly between parents who already had children and first-time parents.

**NICU Experience.** Parents who had previous experience in the NICU before the birth of the current child rated the overall need statements higher than did parents who had never been in a NICU before (experience mean, 3.68; no experience mean, 3.60; $P = .009$). These parents also rated the subscales of comfort and support more important (comfort, $P = .03$; support, $P = .05$). One needs statement, “To be assured that the best care possible is being given to my infant,” was significantly more important to parents with no NICU experience (experience mean, 3.9; no experience mean, 4.0; $P = .02$).

**Open-Ended Question**

Ten parents responded to the open-ended question at the end of the interview. Of these, half were comments of appreciation toward the staff and the others were specific to the institution (eg, visiting policy, communication between nurses).

**Discussion**

Our results describe the needs of a small sampled population of families of babies in a NICU and indicate that the most important needs for this group were assurance needs. Other studies have shown similar results. However, information needs were reported as the most important need in several studies. Parents interviewed in this study rated information needs as the third most important need. However, the mean for this subscale was 3.77, suggesting that this need is still very important.

Parents in this surveyed group rated support needs as the least important subscale need. These findings are similar to those found by Ward. Specifically, the support need statements “To have a pastor, clergy member, or other person from my church to visit,” “To have a support group of other families available,” and “To be able to talk to other parents whose infant is in the NICU or has had a similar situation” had the lowest mean scores (Table 4).

These findings disagree with findings from Dobbins et al, who stated that 73.7% of participants in their study indicated a desire to speak with another parent who had a similar situation and
54% desired a family support group. Participants were surveyed after their child had been discharged home, when support needs may be valued more.

Parents and Andersen qualitative evaluated a parent support program and found that the group helped parents to overcome obstacles of being a new parent and to develop positive parenting skills. Parents who participated in the current study may have reported the need for support groups and talking with other families with similar situations as low because programs are not in place at this institution for these activities to take place. Parents participating in such groups may experience the value of such programs and rate them as more important after the experience.

Although the subgroups of parents interviewed had unequal numbers (eg, mothers vs fathers, age, admission vs discharge, differences in infants), the statistical analyses showed some differences. Parents at the time of admission rated support needs and the need to feel hope higher than parents at discharge rated those needs. This difference may be related to the critical health of the infant shortly after birth or the perception of parents who were not anticipating complications with their delivery process. Parents at the time of discharge rated transportation needs higher than admission parents rated those needs, possibly demonstrating that the parent is anticipating the needs for the infant at discharge.

The responses of mothers and fathers in this study were similar. Ward demonstrated that mothers rated support, information, and assurance needs significantly higher than fathers rated those needs. This study showed that mothers rated support and information needs slightly higher than fathers; however, this difference was not statistically significant.

Parents who were older than 30 years old or had previous NICU experience rated comfort and support needs higher than other groups rated those needs. These groups may interpret the experience of having a child in the NICU as more serious than the developmental stage or maturity of the infant, so parents who did not visit often or at times when the interviewers were present were not included. To lessen the effects of this limitation, the 4 nurses trained by the principal investigator to interview families worked on different shifts. Telephone interviews might have recruited parents who were unable to visit, but this technique also has limitations and was not used in this study. Additional limitations included the inequalities in the numbers of mothers and fathers interviewed and in the numbers of parents interviewed at admission and discharge. Finally, a major limitation that could have influenced parents’ response was the variability in the acuity level of the infant's (diagnosis, birth weight, and gestational age).

Having only 1 setting, a level III regional referral NICU, limits generalization of these results. Repeating the study within a different population or in a variety of settings would start to resolve this issue.

Parents of infants in the NICU were the only persons interviewed in this survey. However, the term “family” no longer consists of a nuclear family. This concept should be addressed by including all family members in the survey who are key players in the care of the child.

**Implications for Clinical Practice and Future Research**

Identifying the needs of parents in the NICU can enhance nursing communication and allow nurses to incorporate families’ needs into the plan of care. For example, nurses can provide more support services to families during the week of admission, knowing that this is an important need for families during this time. Family-child interactions and inclusion in infant care activities can be based on family needs to promote individualized holistic family-centered care.

The NFNI is an excellent tool that is easy to use and takes only a few minutes to complete. Nursing actions to enhance family-centered care should include early identification of family needs and incorporation of these needs into an admission database for rapid response in nursing care. Proper referrals can be made to support services as indicated by the responses of parents. Determining the most and least important needs of parents allows nurses to objectively define actual needs instead of placing subjective assumptions on family needs.

Because the NFNI has been used in only 2 studies to date, further studies would enhance the validity of this tool and add to the growing pool of information on experiences of families in the NICU. The tool should be used in a variety of settings and...
across different geographical regions to determine if needs differ in various environments. In addition to interviewing the mother and father of the infant, researchers should include other family members because they are an integral part of the child’s life and a support system to the family unit.

**Conclusion**

This study documented the needs of parents of infants in a level III NICU and examined the differences in needs of particular groups of parents. Nurses cannot assume that they know the needs of families from previous experiences. Health care providers must look at each family as an individual group with specific needs. The NFNI can be used to identify those needs and allows the integration of individualized nursing care to fulfill those needs and promote a more positive family-centered experience in the NICU for patients and their families.

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**FINANCIAL DISCLOSURES**
None reported.

**REFERENCES**


**SEE ALSO**

For more about family needs and critical illness, visit the *Critical Care Nurse* Web site, [www.ccnonline.org](http://www.ccnonline.org), and read the article by Davidson, “Family-Centered Care: Meeting the Needs of Patients’ Families and Helping Families Adapt to Critical Illness” (June 2009).

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