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What are the Perceived Needs of Parents of Critically Ill Neonates?

Linda B. Corliss

Grand Valley State University

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WHAT ARE THE PERCEIVED NEEDS OF PARENTS OF
CRITICALLY ILL NEONATES?

By
Linda B. Corliss

A THESIS

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Thesis Committee Members:
Linda Bond, Ph.D., R.N.
Cynthia P. Covia, Ph.D., R.N.
Sandra Portko, Ph.D., R.N.
ABSTRACT

WHAT ARE THE PERCEIVED NEEDS OF PARENTS OF CRITICALLY ILL NEONATES?

By

Linda B. Corliss

The purpose of this study was to identify needs of parents during the hospitalization of their critically ill neonate. Studies indicate that parents of critically ill neonates are under a certain degree of stress and that sources of stress are identifiable by parents and equated to needs and the importance of those needs.

This study used an exploratory, descriptive design to document the needs of parents while also identifying variables that influenced those needs. Parents of 29 critically ill neonates (n=53) were interviewed using a revised version of the Critical Care Family Needs Inventory (CCFNI) designed by Molter (1979). The revised version consisted of parent need statements that were rated on an attitudinal scale.

Results indicated that parents are able to rate needs by importance. Needs that are informational in nature were rated very high. Findings also suggest that older parents may have greater needs than younger parents.
Acknowledgments

I would like to extend deep appreciation for those who have contributed to the success this research project.

I would like to offer a special acknowledgment to Linda Bond, Ph.D., RN, the chairperson of my committee, along with Cynthia P. Coviak, Ph.Dc., RN, and Sandra Portko, Ph.D., RN, for their continued support and guidance.

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Special appreciation to my colleagues at Bronson Methodist Hospital for their assistance and collaboration during pursuit of my educational objectives.

Last, but not least, I would like to thank my family for their patience, understanding, love and support; for without them, I would not have accomplished my goals.
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CHAPTER 1

INTRODUCTION

For most parents the birth of a child is a joyous event. Under normal circumstances, a healthy pregnancy and the delivery of a full-term healthy baby, will often relieve the stress of transition to parenthood through the common practices associated with pregnancy, labor, delivery, hospitalization, and discharge. These practices, such as attending prenatal classes and having the father actively participate in the delivery, serve to relieve parental stress and help parents adapt to the many changes they are experiencing (Shellabarger & Thompson, 1993). When a child is critically ill at birth because of prematurity, congenital defects or disease, or other perinatal problems, the outcome for these parents is often stress and crisis. During this crisis parents must cope with many confusing emotions stemming from an unexpected delivery, concern about their sick infant, grief from the loss of an ideal pregnancy and birth experience, and the realization that they must begin to function in an environment and with people whom are unknown to them.

Theory and research on stress have produced certain propositions that apply to the stress of childbearing. Specifically, events will be more stressful if they are unexpected or uncontrolled, such as premature delivery; or the stress occurs at frequent intervals (i.e., the sequence of pregnancy, labor and delivery and early parenting (Younger, 1991). It is well documented that the birth and hospitalization of
a preterm infant are very distressing for parents. Feelings of disappointment, fears regarding the child's survival, and altered parental experiences; including separation and reduced opportunities to interact with the infant, are all difficult for parents (Miles, Funk, & Kasper, 1992). Other stressful feelings identified by mothers of premature infants include guilt and failure about being able to carry the pregnancy to term, feelings of inadequacy as caregivers compared to the highly skilled nurses in the Neonatal Intensive Care Unit (NICU), confusion about parenting roles, and financial concerns. During this period of stress parents must also redefine their parenting roles to meet the limitations of parenting in the NICU (Steele, 1987).

With the rapid technical advances and requirements for greater knowledge of the pathophysiology of critical illnesses, little attention has been given to the psychosocial aspects of caring for both the child and the family. Fewer than 10% of the articles published in critical care nursing journals have addressed this issue (Philichi, 1988). A child's critical illness represents an acute stress for parents (Kirschbaum, 1990). If the nurse expands the concept of patient from individual in a bed to a participating member of the family, then the nursing role must expand to assist family members to cope with the patient's illness while simultaneously maintaining family function (Molter, 1979). Because the birth of a sick or premature infant presents a challenge to parents, the health care professionals in NICUs have an important role in helping parents to adjust both to the birth of their sick infant and to the environment in which the child is receiving care (Miles, 1989). An important role for neonatal nurses is to help parents cope with this stressful situation to facilitate the development of a healthy parent-child relationship. In order to plan appropriate
nursing interventions, specific sources of parental stress and their intensity need to be identified (Perehudoff, 1990).

The purpose of this study was to identify the perceived needs of parents and the importance of those needs during hospitalization of their critically ill neonate. A critical care nurse’s perception of the parents’ needs often determines which needs are addressed. In reality these needs may not be viewed as the most important by parents. It is important to be able to identify parental needs in an objective manner. It is crucial that critical care nurses recognize that despite the environment, nurses can influence family members and are able to meet their needs (Kleinpell & Powers, 1992). To devise strategies that are effective and minimize parental stress as well as to enhance adaptive coping during their child’s stay in the NICU, it is important to be able to identify and understand both the stressors and the needs experienced by parents. Critical care nurses in NICU are uniquely positioned to support the parents during the critical illness of their child.
CHAPTER 2
CONCEPTUAL FRAMEWORK AND REVIEW OF THE LITERATURE

Conceptual Framework

Anything that elicits distress is defined as a stressor. A conceptual framework that was designed by Miles and Carter (1983) for assessing parental stress was used for this study. It is based on stress theory and proposes that the parent’s cognitive appraisal of the situation, coping responses, and resources available to assist them to cope, all interact to influence how parents will respond to the stressors. Sources of parental stress are: (a) environmental stimuli, or the physical and psychosocial environment, (b) situational conditions, and (c) personal or family factors. These three sources of stress are mediated by cognitive appraisal of the situation, coping responses, and available resources. The parents’ response to stress is viewed as a changing phenomenon being influenced by alterations in the variables and in turn influencing the parents’ perception of the stressors. The overall stress response may be adaptive or maladaptive (Miles & Carter, 1983).

Magnusson (1982) viewed stress as an individual’s reaction to demands that approach or exceed the limits of coping resources. He defined stressors as physical and psychosocial elements of a situation that impose demands and that lead to stress reactions. The term "situation" was defined as both the actual situation and the
perceived situation (the perception, interpretation, and cognitive representation of an actual situation).

The serious illness of a child is usually viewed as a crisis situation. A crisis is a period in an individual’s life when an extremely stressful event or series of events significantly tax the individual’s coping abilities (Burgess, 1978). When an individual can adapt constructively to a crisis, the individual becomes stronger with the development of new coping and problem solving skills that can be used in future stressful situations. Parents who experience hospitalization of their neonate are in a crisis situation. Their coping may already be compromised. When their needs are unmet in the crisis situation, stress can increase and coping skills can decrease further.

Review of the Literature

Affonso et al. (1992) recruited a convenience sample of 36 mothers from high-risk pregnancy subgroups to study maternal perceptions of frequency and intensity of stressors between the initial period of the infant’s hospitalization and later periods of hospitalization. Separation was the highest negative stress at the first and second assessment. Factors interfering with a mother’s visitation, especially lack of adequate transportation, childcare, or economic resources, were reported to intensify the negative stress associated with separation from the infant. Limitation of the study include small sample size, a high attrition rate across interview periods, and limited generalization of the study because of the nonrandom sample that was primarily skewed toward well-educated women.
A list of needs statements, originally designed by Molter (1979), and later modified by Kirschbaum (1990), was used to determine the needs of families of critically ill pediatric and adult patients and the importance of those needs. Need statements were rated on a four point scale from "not important" to "very important". In Molter's (1979) study, relatives of critically ill patients were interviewed and the top needs identified were the need to feel that there was hope and that hospital personnel cared about the patient. Age and socioeconomic status were examined to determine if they had an influence on the needs, but the sample size (n=40) was too small to determine statistical differences. There were indications, however, that these variables did influence the needs. A difference in mean degree of importance more than 1.0 was considered an indication. Rating the needs using three different methods was used to test responder bias. No appreciable difference in rate was noted among the three methods.

Kirschbaum's study (1990), using Molter's (1979) attitudinal scale, examined the responses of 41 parents whose children were hospitalized in two separate institutions. Once again, the need to feel hope was found to be important for the parents. Additionally, feeling that the best medical care was being given and knowledge of that care was rated high.

Kirschbaum also modified Molter's (1979) tool adding eight needs specific to the Pediatric Intensive Care Unit (PICU). These needs were rated based on median values. The highest ranked need of these added pediatric items was that of being recognized as important to the ill child's recovery. In conjunction, assisting with their child's physical care was also a priority. Limitations of this study include a small
sample size that consisted predominantly of mothers. Furthermore, the parents were married rather than unpartnered, therefore the results cannot be generalized to single parent families.

Kleinpell & Powers (1992) used a convenience sample of family members of patients in an Intensive Care Unit (ICU) (n=64), and nurses employed in the ICU (n=58), in a study to identify important needs of families of critically ill patients, and the degree to which these needs were being met. Family members and nurses completed the modified form of the CCFNI (Molter, 1979) and identified many similar important needs. However, some family members indicated that some needs were both more important and less satisfactorily met than the nurses perceived. The need to know the occupational identity of staff members, the need to have directions as to what to do at the patient’s bedside, and the need to have friends for support were identified as more important to family members. Both groups rated importance of needs higher that satisfaction which indicated needs not being met. Possible limitations of this study included the non-random sample and the generalization of the study. Almost two-thirds of these family members had previously visited another person in the ICU and over half of these family members stated that the hospitalization was expected.

In a descriptive design by Perehudoff (1990) a Neonatal Intensive Care Parental Stress Scale (NICUPSS) was used to measure parental perception of stressors arising from the physical and psychosocial environment of the NICU. Mother and father participants (n=31) perceived that, overall, the NICU environment caused them a relatively low level of stress. Parental role alteration caused the highest stress for
mothers, followed by sights and sounds, the infant's appearance and behaviors, and staff communications and relations. Fathers' scores indicated that sights and sounds caused the highest stress, then parental role alteration, the infant's appearance and behavior, and staff communications and relations. The difference between the mothers' and fathers' scores for the dimension of staff communications and relations was not statistically significant. Generalization was limited in this study by the nonrandom sample. Variables that could have potentially skewed the results include a sample of primarily well educated women, a high attrition rate due to infant transfers and more than one half of the parents had no other children at home.

In a study conducted by Miles (1989), parents of hospitalized infants (n=53) in the NICU were interviewed close to the time of discharge using a Parental Stress Scale and a personal-situational questionnaire. Results suggested that the greatest sources of stress for the parents were the appearance of the fragile, sick infant and the altered parent-child relationship. Sights and sounds of the physical environment were not rated as highly stressful. This sample was small and there was no reference to the personal-situation questionnaire and how it might have influenced outcomes.

Summary and Indication for Study

The previous studies propose that parents of hospitalized infants are under stress. Because these parents are dealing with a crisis situation their coping mechanisms may be compromised and their perceived unmet needs may lead to increased stress. The source of these stresses are identifiable by parents and equated to needs and the importance of those needs. By identifying those needs the critical care nurse is able to facilitate interventions that will begin to decrease stress and
enhance coping skills.

The purpose of this research was to examine the relationship between certain variables and the importance of needs of parents of critically ill neonates. This research replicated studies by Molter (1979) and Kirschbaum (1990) to explore the importance of needs, as well as to look at other relationships. Age, household income, educational level, gestational age of the infant at birth, distance from the hospital and existence of other children at home, were examined to see if these factors influenced the parents' needs. Marital status, paternal involvement, support systems, maternal health problems, method of delivery, and visitation practices were identified. Differences of total need scores between mothers and fathers were investigated.

**Key Terms.** The theoretical and operational definitions employed in this study were:

- **perceived needs** - a sensed necessary requirement.

- **critically ill neonate** - a seriously ill newborn requiring immediate and continuous care by specially trained health professionals.

- **parents** - female acting in the mother role of the infant, male acting in the father role of the infant. These roles may be self defined.
CHAPTER 3
METHODOLOGY

Design
This study employed an exploratory, descriptive research design. This design was chosen to document the needs of parents while also identifying variables that may influence those needs. This study also explored the importance of needs related to certain demographic characteristics.

Sample
The subjects of this study were parents of critically ill neonates hospitalized at a tertiary-level NICU in the Midwest. Four inclusion criteria for parents were: a) they would only be interviewed if their child was living, b) they must have visited their child during hospitalization, c) they must have the ability to read and understand English, and d) they must be at least 17 years old. The method used to recruit subjects was a convenience sample and included parents of 29 critically ill neonates. A designated staff person was asked to identify the subjects for the researcher. The interview took place between the first and second week of hospitalization. Subjects included both mothers and fathers of the newborn.

Instrument
The needs of parents were assessed using the Critical Care Family Needs Inventory (CCFNI) (Molter, 1979). This was a survey composed of statements of
parent need using an attitudinal rating scale. Permission was obtained to use and modify the tool (Appendix A). The modification was the elimination of the second part of the assessment tool that dealt with whether the need was met. This study focused on the identification and importance of needs only. Importance of needs was established by a scoring format which rated each item on a four point scale from "not important" to "very important". Parents were also asked whether they had experienced needs other than those in the instrument.

The reliability and construct validity of the tool was established in the research conducted by Leske (1991) when exploratory stepwise factor analysis was used to summarize the interrelationships among items on the CCFNI. The internal consistency alpha coefficient of the total CCFNI determined by Leske (1991) was 0.92. Internal consistency for this study was established at 0.90. Reliability coefficients of 0.70 or greater are sufficient in making group comparisons (Polit & Hungler, 1991).

Procedure

Permission and human subject approval was obtained from the agency where data collection took place (Appendix B) and from Grand Valley State University (Appendix C). After selection of potential subjects by the designated staff person, interviews were scheduled in the appropriate time frame. Questionnaires were given out between the first and second week of hospitalization, after informed consent was obtained (Appendix D). Parents were asked to fill out a demographic information sheet (Appendix E) and the investigator provided an explanation and a copy of the questionnaire. The questionnaires were returned to the investigator to record the
relative importance of each need. Anonymity and confidentiality was maintained by using identification numbers instead of the participant’s names. To deal with the possibility of emotional upset during the interview process, the consent form included information to provide resources available for counseling.
CHAPTER 4
DATA ANALYSIS

The data for this study was collected during the first and second week after admission to the hospital over a six month period and included a total of 53 parents and 29 neonates. The parent sample consisted of 29 mothers and 24 fathers. The mean age of parents was 30.3 years (s.d. = 6.98). The range of age for the mothers was between 17 years to 43 years old, with a mean age of 29. The fathers ranged in age from 18 years to 46 years old, with a mean age of 32.

The majority of the respondents were married (74%). There was almost an equal distribution of parents with other children (49%) as those without (51%). The fathers of the critically ill neonates were involved in 96% of the cases and were the major support persons in 87% of the cases.

The mode household income level was between $10,000 and $20,000. The majority of parents (89%) had a high school education or greater. Seventy percent of the parents lived greater than 20 miles from the hospital. Eighty-eight percent of the parents visited their neonate every day and 70% of the parents stated that they called daily.

Most mothers of the critically ill neonates reported no significant health problems after delivery, with 15% indicating a problem. Sixty-two percent of the deliveries were by cesarean section and 38% were vaginal deliveries. The mean
gestational age of the neonates was 33 weeks (s.d. = 4.87).

The research questions were answered by summing the rating of the needs from the scale of most important to least important (Appendix F). A maximum score of 180 was possible on the importance section of the CCFNI. The overall mean importance rating for mothers and fathers was 143 (s.d. = 14.475), with a mean of 145 (s.d. = 13.606) for mothers and 143 (s.d. = 15.716) for fathers. T-tests were used to further substantiate that there was no significant difference between the total needs scores of mothers and fathers.

Existence of other children in the home also did not show a significant difference in the ranked needs of parents. Correlation coefficients were used to determine if the parents’ age, gestational age of the neonate, or distance from the hospital influenced the importance of needs. Only age indicated a statistical significance (r = .2665; n=49; p = .032). This correlation indicated that needs were greater as parental age increased. Distance from the hospital (r = -.1066; n=49; p = .233) and gestational age of the neonate ( r= -.0263; n=49; p = .429) were not related to the perceived importance of needs. Income and education variables were examined for their relation to perceived needs using a Spearman’s rho correlation coefficient and were not significant (income: p = .28; education: p = .55).

A evaluation of highest rated perceived needs between mothers and fathers was completed as shown in Table 1 and Table 2. All of the fathers identified four needs as being very important at 100%. However, there was not a need that was recognized by 100% of the mothers as very important.
Table 1

Highest Rated Needs of Fathers

<table>
<thead>
<tr>
<th>Need Statement</th>
<th>Percentage</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To see my baby frequently.</td>
<td>100.0%</td>
<td>4.000</td>
<td>0</td>
</tr>
<tr>
<td>2. To be called at home about changes in my baby’s condition.</td>
<td>100.0%</td>
<td>4.000</td>
<td>0</td>
</tr>
<tr>
<td>3. To have questions answered honestly.</td>
<td>100.0%</td>
<td>4.000</td>
<td>0</td>
</tr>
<tr>
<td>4. To receive information about my baby at least once a day.</td>
<td>100.0%</td>
<td>4.000</td>
<td>0</td>
</tr>
<tr>
<td>5. To know how my baby is being treated medically.</td>
<td>95.8%</td>
<td>3.958</td>
<td>0.204</td>
</tr>
<tr>
<td>6. To be assured that the best care possible is being given to my baby.</td>
<td>95.8%</td>
<td>3.958</td>
<td>0.204</td>
</tr>
<tr>
<td>7. To know exactly what is being done for my baby.</td>
<td>95.8%</td>
<td>3.958</td>
<td>0.204</td>
</tr>
<tr>
<td>8. To have explanations given that are understandable.</td>
<td>95.8%</td>
<td>3.958</td>
<td>0.204</td>
</tr>
<tr>
<td>9. To feel that hospital personnel care about my baby.</td>
<td>95.8%</td>
<td>3.958</td>
<td>0.204</td>
</tr>
<tr>
<td>10. Knowing specific facts about my baby’s progress.</td>
<td>91.7%</td>
<td>3.917</td>
<td>0.282</td>
</tr>
<tr>
<td>11. To visit at any time.</td>
<td>91.7%</td>
<td>3.917</td>
<td>0.282</td>
</tr>
<tr>
<td>12. To know why things were done for my baby.</td>
<td>91.7%</td>
<td>3.917</td>
<td>0.282</td>
</tr>
<tr>
<td>13. To feel there is hope.</td>
<td>91.7%</td>
<td>3.917</td>
<td>0.282</td>
</tr>
<tr>
<td>14. To be told about transfer plans while they are being made.</td>
<td>87.5%</td>
<td>3.875</td>
<td>0.338</td>
</tr>
<tr>
<td>15. To know the expected outcome.</td>
<td>83.3%</td>
<td>3.833</td>
<td>0.381</td>
</tr>
<tr>
<td>16. To help with my baby's physical care.</td>
<td>83.3%</td>
<td>3.833</td>
<td>0.381</td>
</tr>
</tbody>
</table>
Table 2

**Highest Rated Needs of Mothers**

<table>
<thead>
<tr>
<th>Need Statement</th>
<th>Percentage</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To see my baby frequently.</td>
<td>96.6%</td>
<td>3.966</td>
<td>0.186</td>
</tr>
<tr>
<td>2. To be called at home about changes in my baby's condition.</td>
<td>96.6%</td>
<td>3.966</td>
<td>0.186</td>
</tr>
<tr>
<td>3. To have questions answered honestly.</td>
<td>96.6%</td>
<td>3.966</td>
<td>0.186</td>
</tr>
<tr>
<td>4. To visit at any time.</td>
<td>96.6%</td>
<td>3.966</td>
<td>0.186</td>
</tr>
<tr>
<td>5. To feel there is hope.</td>
<td>96.6%</td>
<td>3.966</td>
<td>0.186</td>
</tr>
<tr>
<td>6. To know how my baby is being treated medically.</td>
<td>96.6%</td>
<td>3.966</td>
<td>0.186</td>
</tr>
<tr>
<td>7. To be assured that the best care possible is being given to my baby.</td>
<td>96.6%</td>
<td>3.966</td>
<td>0.186</td>
</tr>
<tr>
<td>8. To receive information about my baby at least once a day.</td>
<td>93.1%</td>
<td>3.931</td>
<td>0.258</td>
</tr>
<tr>
<td>9. To know the expected outcome.</td>
<td>93.1%</td>
<td>3.931</td>
<td>0.258</td>
</tr>
<tr>
<td>10. To know why things were done for my baby.</td>
<td>93.1%</td>
<td>3.931</td>
<td>0.258</td>
</tr>
<tr>
<td>11. To know exactly what is being done for my baby.</td>
<td>93.1%</td>
<td>3.931</td>
<td>0.258</td>
</tr>
<tr>
<td>12. To feel that hospital personnel care about my baby.</td>
<td>93.1%</td>
<td>3.931</td>
<td>0.258</td>
</tr>
<tr>
<td>13. Knowing specific facts about my baby's progress.</td>
<td>93.1%</td>
<td>3.931</td>
<td>0.258</td>
</tr>
<tr>
<td>14. To have explanations given that are understandable.</td>
<td>82.8%</td>
<td>3.828</td>
<td>0.384</td>
</tr>
<tr>
<td>15. To help with my baby's physical care.</td>
<td>79.3%</td>
<td>3.793</td>
<td>0.412</td>
</tr>
<tr>
<td>16. To be told about transfer plans while they are being made.</td>
<td>79.3%</td>
<td>3.759</td>
<td>0.511</td>
</tr>
</tbody>
</table>
CHAPTER 5
DISCUSSION AND IMPLICATIONS

This study, as did Molter's (1979) and Kirschbaum's (1990) identified needs of relatives of critically ill patients. This study and Kirschbaum's specifically identified needs of parents of critically ill children. All these studies found that those needs that were informational in nature were rated the highest. Informational needs included the desire to have questions answered honestly and to be kept informed of patient status were consistently rated most important.

The result of this study indicate the ability to visit and/or see the neonate frequently as a priority, which would indicate a possible correlation with increased stress. Separation was the highest negative stress in the study that reported maternal perceptions of frequency and intensity of stressors (Affonso et al, 1992). However, separation from the infant immediately after birth may also be related to the emotional needs of the parents to bond with their newborn as a primary caregiver.

The conceptual framework used for this study is based on stress theory (Miles and Carter, 1983), and proposes that the parent's cognitive appraisal of the situation will influence their perceptions and how they respond to the stressors. The need for honest information about the status of the critically ill infant congruent with this framework. The provision of honest and frequent information should facilitate an increased understanding and realistic perception of the critical event.

The physical and psychosocial environment questions did not rate high on the
importance of needs, however specific questions were not asked about the immediate environment at the baby's bedside and the activities that happened there. This would warrant further research investigation. Parents were not concerned with their own health or of being told about available resources and in this respect did not fit into the framework's indication that stress is mediated by available resources. However it's possible that their own support systems may have been interpreted as sufficient at this time. This may be because the study was conducted early in the hospitalization and these factors had not yet become important. As length of stay increases or as families prepare to take the infant home, the need for additional support systems may change.

A qualitative research method was used to allow the parents to identify additional need statements on the questionnaire. Two needs were identified by the parents that were already included in the CCFNI; the ability to call and visit anytime, and to be able to have at least two other people with them when visiting. Since these needs were evaluated in the CCFNI, this may be indicative of a greater need fulfillment in these areas. Furthermore, the parents identified the desire for a private place to grieve, especially during the first few days after admission. These needs may indicate an even greater need for personal support systems, more frequent information and updates on the infant's condition. The request for a private place to grieve may be an indication of the added stress in the intensive care environment, with its bright lights and monitor alarms.

**Application to Practice**

This study furthers substantiates the need for nursing staff to provide honest and accurate information in a timely manner to the families of critically ill patients as
did those studies by Molter (1979) and Kirschbaum (1990). Informational needs were rated the highest in this and the other two studies and must be given priority by the caregiver. Critical care nurses and family members have identified many similar important needs, such as the need to have questions answered honestly, the need to be called at home about changes in the patient’s condition, and the need to know why things were done for the patient (Kleinpell & Powers, 1992). The parental needs identified by nurses often determine which needs will be addressed. Parents of critically ill infants should be encouraged to ask questions and should be helped to identify the kinds of information that would be most helpful to them. Specific times should be scheduled for a conference between the primary nurses, physicians, and parents to discuss the prognosis, and plan of care for the infant. Nursing careplans should include interventions that address the parents' needs.

Nurses should speak in a language that parents understand, and assess their understanding by questioning in a nonthreatening manner, while also facilitating communication between physicians and other involved medical personnel (Hickey & Rykerson, 1992). As patient advocates, nurses can update parents at least daily and arrange mutually agreeable times to talk with physicians. Parents and infants should be treated as a family unit, not as separate entities, realizing that one member influences the health and wellbeing of the other. This study indicates that fathers and mothers have similar needs and that nurses should not assume that the fathers’ needs may be of less importance than the needs of the mothers.

Consistency of the caregiver did not rate high in this study with 14% of the mother and 8% of the fathers rating the need as very important. Honest and accurate
information was rated more important than the person who gave it. Knowledge of the type of staff person providing care, and assurance that the best care was being given rated very high in importance. Nursing staff should provide opportunities to discuss the care of the infant at frequent intervals with the parents and be able to answer their questions honestly. Private rooms close to the NICU should be available for parents to use for discussions concerning their critically ill neonate. Providing parents an opportunity to discuss their infant in private, as well as a place to have private time in a quiet environment may help alleviate stress.

Parents of different age groups have different needs which may impact their level of understanding. Parents who had children later in life had higher rated needs in this study. In conjunction, parents that conceive their first child later in life may have additional stressors related to the possibility of limited length of childbearing years. Nurses may assume older parents have a better level of understanding and effective coping mechanisms, which may not be accurate. Even though older parents may have increased life experience and the ability to comprehend the seriousness of the situation, an older parent can still experience a higher degree of stress than a younger parent. Nursing assessments need to focus on identifying these needs and develop interventions to meet them.

Critical care nurses in the NICU are in a unique position to facilitate meeting the needs of parents of critically ill neonates. By exercising the ability to identify parental needs and their importance, the nurses will have a better understanding of the interventions required to meet these needs.
Limitations

The limitations of this study include the small sample size and the limited generalization related to the nonrandom sample. Data collection was limited to one hospital in a specific geographical area.

Suggestions for Further Research

Identification of needs by parents of critically ill children has been established in this and previous research. Further study needs to be done to test interventions utilized to meet the needs of parents. Longitudinal studies at different intervals during hospitalization should be examined to assess how needs may change over time.

Specific needs of older parents and the types of interventions that are effective with varying age groups need to be explored. Also, parental needs and the relation to cultural differences should be investigated. The results of this study did not support that consistency of care was a concern. Reassurance that the best care was being given and that information was given honestly and frequently was identified as priorities. Therefore, is the concept of a primary caregiver for a patient as important as indicated by some delivery care models? Perhaps, primary care is more important to the caregiver than it is to family members. It is crucial for nurses to explore this issue further and develop delivery models grounded in research.

This research study suggested that needs can be identified by parents of critically ill neonates in the NICU and categorized by their importance. The next step is to create and examine interventions to meet those needs.
Appendices
APPENDIX A

Permission To Use Needs Assessment Tool
APPENDIX A

Permission To Use Needs Assessment Tool

I, Nancy Molter, R.N., Captain, ANC, give permission to Linda Corliss to use my Needs Assessment Tool for her research in completing her thesis work to obtain her MSN at Grand Valley State University. I give permission to her to alter the tool for her specific area of focus if need be.

Signed,

[Signature]
APPENDIX B

Human Use Committee Approval
APPENDIX B

Human Use Committee Approval

BMHS40 What Are the Perceived Needs of Parents of Critically Ill Neonates

At the August 2, 1994 Meeting of the Bronson Methodist Hospital Human Use Committee, BMHS40 and the informed consent were approved as submitted.

1. It was recommended that the study investigator increase the study sample size.

Robert H. Hume, M.D., Chairman
Bronson Methodist Hospital
Human Use Committee
252 East Lovell Street
Kalamazoo, MI 49007
(616) 341-7988

cc: LBCorliss
APPENDIX C

Permission to Conduct Research by

Grand Valley State University
APPENDIX C

Permission to Conduct Research by

Grand Valley State University

August 9, 1994

Linda Corliss
2928 Travis
Kalamazoo, MI 49004

Dear Linda:

Your proposed project entitled "What Are the Perceived Needs of Parents of Critically Ill Neonates" has been reviewed. It has been approved as a study which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,

[Signature]

Paul Huizenga, Chair
Human Research Review Committee
APPENDIX D

Consent Form
APPENDIX D

Consent Form

You are being asked to take part in a nursing research study. The purpose of this study is to find out the needs of parents when their baby is in the hospital. By being involved in this study, you will help nurses identify and meet those needs.

You will be asked to answer questions about your needs on a questionnaire. This should take approximately thirty minutes. An I.D. number will be placed on your questionnaire to assure confidentiality. Your name will not be placed on the questionnaire.

It is not anticipated that you will be harmed in any way by participating in this study, however some of the questions asked may raise concerns. Should this occur, the researcher will be available to answer these concerns or refer you to an appropriate resource. In the event of harm or injury from this study the researcher (Linda Corliss), Bronson Methodist Hospital, and Grand Valley State University will not be responsible for any free medical care or compensation to you. You may withdraw from this study at any time without any change in treatment your baby may receive in the future.

This study is conducted by Linda Corliss. She is a Master's student at Grand Valley State University and a registered nurse at Bronson Methodist Hospital. If you have any questions she can be contacted at the following number, (616) 341-6475. If you have any additional concerns regarding this research you may direct your questions to Jo Ulrich at the Bronson Methodist Hospital research committee at 341-7831.

I have read and understand the information presented above. I consent, of my free will, to be involved in this study.

Participant ____________________ Witness ____________________

____________________________
Date
APPENDIX E

Demographics
APPENDIX E

Demographics

Please answer the following questions:

1. What is your age? _____

2. How many miles do you live from the hospital? _____

3. Do you have other children at home? _____ Yes _____ No

4. What is your average household income?
   _____ Less than $10,000  _____ $10,001 to $20,000
   _____ $20,001 to $30,000  _____ $30,001 to $40,000
   _____ Over $40,000

5. What is your level of education?
   _____ Less than 12th grade  _____ High school graduate
   _____ Some college  _____ College graduate

6. What was the gestational age of your baby? _____ weeks

7. What is your marital status?
   _____ Married  _____ Single  _____ Divorced  _____ Separated

8. Is the baby’s father involved? _____ Yes _____ No

9. Who is your main support person?
   _____ Spouse or significant other  _____ Parent(s)  _____ Friend
   _____ Grandparent(s)  _____ Other
10. How often do you visit your baby? _____ Everyday
    _____ 2 or 3 times a week _____ Once a week

11. How often do you call to inquire about your baby?
    _____ Everyday _____ 2 or 3 times a week _____ Once a week

12. Was your baby born by vaginal birth or C-section?
    _____ Vaginal _____ C-section

13. Has the baby’s mother had health problems since the birth of the baby?
    _____ Yes _____ No
APPENDIX F

Table 3:

Rating of Most Important Needs of Parents (n = 53)
APPENDIX F

Table 3
Rating of Most Important Needs of Parents (n=53)

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1. To have questions answered honestly.</td>
<td></td>
<td></td>
<td>1</td>
<td>52</td>
</tr>
<tr>
<td>2. To see my baby frequently.</td>
<td></td>
<td></td>
<td>1</td>
<td>52</td>
</tr>
<tr>
<td>3. To be called at home about changes in my baby's condition.</td>
<td></td>
<td></td>
<td>1</td>
<td>52</td>
</tr>
<tr>
<td>4. To know how my baby is being treated medically.</td>
<td></td>
<td></td>
<td>2</td>
<td>51</td>
</tr>
<tr>
<td>5. To know about the types of staff members taking care of my baby.</td>
<td></td>
<td></td>
<td>2</td>
<td>51</td>
</tr>
<tr>
<td>6. To be assured that the best care possible is being given to my baby.</td>
<td></td>
<td></td>
<td>2</td>
<td>51</td>
</tr>
<tr>
<td>7. To receive information about my baby at least once a day.</td>
<td></td>
<td></td>
<td>2</td>
<td>51</td>
</tr>
<tr>
<td>8. To feel that hospital personnel care about my baby.</td>
<td></td>
<td></td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>9. To visit at any time.</td>
<td></td>
<td></td>
<td>3</td>
<td>50</td>
</tr>
</tbody>
</table>
### Table 3 (continued)

**Rating of Most Important Needs of Parents (n=53)**

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>10. To feel there is hope.</td>
<td>3</td>
<td>50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. To know exactly what is being done for my baby.</td>
<td>3</td>
<td>50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. To know specific facts concerning my baby's progress.</td>
<td>4</td>
<td>49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. To know why things were done for my baby.</td>
<td>4</td>
<td>49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. To know the expected outcome.</td>
<td>6</td>
<td>47</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. To have explanations given that are understandable.</td>
<td>6</td>
<td>47</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. To be told about transfer plans while they are being made.</td>
<td>1</td>
<td>8</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>17. To help with my baby's physical care.</td>
<td>10</td>
<td>43</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. To have directions as to what to do at the bedside.*</td>
<td>3</td>
<td>13</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>19. To have explanations of the environment before going into the critical care unit.</td>
<td>1</td>
<td>6</td>
<td>22</td>
<td>24</td>
</tr>
<tr>
<td>20. To feel accepted by the hospital staff.*</td>
<td>3</td>
<td>7</td>
<td>18</td>
<td>24</td>
</tr>
<tr>
<td>21. To talk to the doctor everyday.</td>
<td>7</td>
<td>23</td>
<td>23</td>
<td></td>
</tr>
</tbody>
</table>
Table 3 (continued)

Rating of Most Important Needs of Parents (n=53)

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>To have a specific person to call at the hospital when unable to visit.</td>
<td>2</td>
<td>10</td>
<td>19</td>
<td>22</td>
</tr>
<tr>
<td>To have visiting hours changed for special conditions.</td>
<td>3</td>
<td>8</td>
<td>20</td>
<td>22</td>
</tr>
<tr>
<td>To be assured it is alright to leave the hospital for awhile.*</td>
<td>5</td>
<td>6</td>
<td>19</td>
<td>21</td>
</tr>
<tr>
<td>To have visiting hours start on time.</td>
<td>6</td>
<td>7</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>To talk about the possibility of my baby's death.*</td>
<td>6</td>
<td>8</td>
<td>19</td>
<td>18</td>
</tr>
<tr>
<td>To have someone to help with financial problems.*</td>
<td>8</td>
<td>10</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>To have the waiting room near my baby's room.*</td>
<td>7</td>
<td>13</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td>To know which staff members could give what type of information.</td>
<td>2</td>
<td>10</td>
<td>26</td>
<td>15</td>
</tr>
<tr>
<td>To have friends nearby for support.</td>
<td>5</td>
<td>15</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td>To have a place to be alone while in the hospital.*</td>
<td>4</td>
<td>14</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td>To talk about feelings about what has happened.</td>
<td>2</td>
<td>15</td>
<td>22</td>
<td>14</td>
</tr>
</tbody>
</table>
Table 3 (continued)

Rating of Most Important Needs of Parents (n=53)

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<tr>
<th></th>
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<tbody>
<tr>
<td>33. To have a telephone near the waiting room.</td>
<td>5</td>
<td>16</td>
<td>18</td>
<td>14</td>
</tr>
<tr>
<td>34. To feel it is alright to cry when I want to.*</td>
<td>7</td>
<td>11</td>
<td>21</td>
<td>12</td>
</tr>
<tr>
<td>35. To be told about other people that could help with problems.*</td>
<td>4</td>
<td>9</td>
<td>27</td>
<td>11</td>
</tr>
<tr>
<td>36. To have a bathroom near the waiting room.</td>
<td>10</td>
<td>15</td>
<td>17</td>
<td>11</td>
</tr>
<tr>
<td>37. To have a pastor visit.</td>
<td>10</td>
<td>17</td>
<td>16</td>
<td>10</td>
</tr>
<tr>
<td>38. To have good food available in the hospital.</td>
<td>7</td>
<td>19</td>
<td>19</td>
<td>8</td>
</tr>
<tr>
<td>39. To have another person with me when visiting the critical care unit.*</td>
<td>16</td>
<td>14</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>40. To have comfortable furniture in the waiting room.</td>
<td>9</td>
<td>23</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td>41. To talk to the same nurse everyday.</td>
<td>13</td>
<td>13</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>42. To be alone when I want.</td>
<td>9</td>
<td>25</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>43. To have someone be concerned with my health.*</td>
<td>11</td>
<td>20</td>
<td>17</td>
<td>3</td>
</tr>
<tr>
<td>44. To be told about someone to help with family problems.</td>
<td>13</td>
<td>27</td>
<td>10</td>
<td>3</td>
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</table>
Table 3 (continued)

Rating of Most Important Needs of Parents (n=53)

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<tr>
<td>45. To be told about chaplain services.*</td>
<td>9</td>
<td>21</td>
<td>18</td>
<td>3</td>
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</tbody>
</table>

Note. * = missing data.
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