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## Parental Perceptions of Neonatal Intensive Care Unit Discharge Teaching

Virginia A. Passero  
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PARENTAL PERCEPTIONS OF NEONATAL INTENSIVE CARE UNIT  
DISCHARGE TEACHING

by

Virginia A. Passero

A Dissertation  
Submitted to the  
Faculty of The Graduate College  
in partial fulfillment of the  
requirements for the  
Degree of Doctor of Philosophy  
Center for Science Education

Western Michigan University  
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June 1988

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**Parental perceptions of neonatal intensive care unit discharge  
teaching**

**Passero, Virginia A., Ph.D.**  
**Western Michigan University, 1988**

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Virginia A. Passero

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PARENTAL PERCEPTIONS OF NEONATAL INTENSIVE CARE UNIT  
DISCHARGE TEACHING

Virginia A. Passero, Ph.D.

Western Michigan University, 1988

The purpose of the study was to determine parental perceptions of Neonatal Intensive Care Unit (NICU) discharge teaching. Orem's (1985) self-care deficit theory was the conceptual framework. Fifty mothers and 15 fathers were interviewed in their homes following the infant's discharge to determine their perceptions of involvement, recall, need, satisfaction and importance of NICU discharge teaching.

The 50 infants in the sample were hospitalized an average of 41 days with a variety of neonatal diagnoses. The average age of the mothers was 27 years, and the sample of 50 included 82% married women, 42% primiparas, and 52% cesarean deliveries. Forty-two percent had not attended prenatal classes, and 76% had never taken a baby-care class.

Most of the mothers visited their infant daily and had positive relationships with the nurses. Only 30% of the mothers perceived themselves as very involved in planning their discharge teaching. Eighty-four percent of the fathers and 86% of the mothers were very satisfied with the discharge teaching they had received. In some cases the parents perceived no need for the teaching they received. In other cases the parents perceived a need for the teaching, but did not recall being taught. The parents were generally satisfied with the teaching on individual areas, even when they perceived it as



unnneeded.

Parents considered all areas of the discharge planning instrument as important to their care of the infant. Eighty-two percent of the parents had experienced problems since discharge, and had located a source of post-discharge information. The post-discharge problems, parental suggestions for additional teaching, and sources of information are described. Among the recommendations are increased parental involvement in the planning phase, improved assessment of parental teaching needs, and consideration of additional anticipatory teaching for post-discharge problems.

## CHAPTER I

### INTRODUCTION

The hospitalization of an ill or premature infant in the Neonatal Intensive Care Unit (NICU) creates a situational crisis for the family and delays normal parenting activities (Beaton, 1984, Montgomery, 1983, Tarbert, 1985). The specialized care required by the high-risk infant is beyond the capabilities of most parents and requires the skills of the neonatologists and NICU nurses. The parents of a healthy neonate can rapidly take over parenting of their newborn with minimal teaching, whereas the parents of a high-risk neonate must wait until the infant's condition permits involvement. Even simple contact such as touching and holding may be impossible with the very premature or ill infant (VandenBerg, 1985).

While administering nursing care to the high-risk infant, nurses can advise parents on ways to begin their parenting involvement. Initially, this may consist of brief touches and loving words, but gradually, as the infant's condition improves, the parents' involvement increases until they can safely assume full parenting at discharge. The education of these parents is an extensive process requiring thorough assessment, careful planning, gradual implementation, and evaluation (Cagan & Meier, 1983).

### Nursing Conceptual Framework

Orem's (1985) self-care deficit theory of nursing is a useful conceptual framework for examining NICU discharge teaching for parents of high-risk infants. A major premise of Orem's theory is that persons provide self-care through their own abilities, called the self-care agency. If they are unable to meet their own needs, they have a self-care demand that must be met by another person such as a family member or a nurse.

Infants and children who are unable to provide their own self-care, because of their rudimentary developmental stages, are said to have a dependent-care demand. In such cases the parents or guardians attempt to meet the dependent-care demand through their parenting abilities termed the dependent-care agency. Orem (1985) states, "In dependent care situations the limitations of dependent-care givers are associated with the health state and the care requirements of the dependent person" (p. 30). The capacity of the family to meet these needs is termed the dependent-care agency, whereas the professional capacity of the nurse to meet these needs is called the nursing agency.

Orem speaks of a requirement for nursing with a child when there is an "inability of the parent (or guardian) to maintain continuously for the child the amount and quality of care that is therapeutic" (p. 55). Thus the parents of a high-risk infant may wish to provide care (furnish the dependent care agency), but lack the skills or knowledge base to do so. Orem further elaborates,

"human beings have the potential to develop their intellectual and practical skills and the motivation essential for care of dependent family members" (p. 37). Such families may require temporary nursing care for the complex needs of the high-risk infant as well as specialized infant-care education to develop the parental dependent-care agency.

Orem's model describes a complementary relationship between the nurse and the patient, or parents in the case of an infant. Such a cooperative nurse-parent relationship is started at the time of admission and strengthened throughout the infant's hospitalization so that mutual goals direct the nursing care toward the establishment of an adequate dependent-care agency at the time of discharge (Beaton, 1984).

Through Orem's model one can describe the changing types of nursing care used for the family of a sick infant. Initially the nurse gives physical and emotional support to the parents while acting for the parents by providing appropriate infant care. The nurse must also provide a developmental environment that involves the parents in planning and permits the parents to gradually assume parenting through the teaching of appropriate infant-care concepts and skills. The ultimate goal of these nursing actions is to enable the parents to give successful dependent care, at the time of discharge. When the nurse successfully uses the nursing agency, the parents will be involved in planning, will have their needs correctly assessed, their dependent-care agency developed, and will use this agency to assume care of the infant at discharge.

### Statement of the Problem

Parents of infants requiring neonatal intensive care may begin with an information deficit in their dependent-care agency. Those giving birth prematurely to their first child, may miss part, or all, of the infant-care content of prenatal classes (Johnson, 1986; Lissenden, 1984). In addition, parents of high-risk infants may not receive, and may not desire routine postpartum infant-care teaching due to the infant's critical condition, high parental stress, and the anticipated lengthy NICU stay. Since the infant requires special equipment and nursing care, routine infant care could not be practiced by the parents, even if it were taught (Frodi & Lamb, 1980).

During the early phase of NICU hospitalization, parents must relinquish care to the nurses who can implement the complex procedures needed for the infant's survival and recovery (Montgomery, 1983, Sims-Jones, 1986). As the infant's health improves the parents can gradually be included until they are ready for complete infant care at discharge. If their dependent-care agency is inadequately developed, parents may doubt their abilities and experience difficulties with dependent care following discharge (Johnson, 1986). Use of the nursing agency, primarily in the form of parent education, can assist the parents with this development (Barnard, 1978, Sims-Jones, 1986).

With this goal of an adequate parental dependent-care agency, nurses can include the parents in planning and care from the time of

admission (Coward, 1984; Johnson, 1986; Slade, Reidl & Mangurten, 1977). When the infant's condition has been stabilized, full discharge teaching can be initiated using a joint family-staff decision-making process (Beaton, 1984). If the discharge teaching is to be successful in assisting the parents to make the transition to full dependent care, the parents' needs must first be correctly assessed and then adequately met (Cagan & Meier, 1983).

The success of the discharge teaching is influenced by many factors, including parental needs and involvement, the nurse-parent relationship, appropriate teaching content, timing and method. While the full scope of this process has not been detailed in the nursing literature, the literature does describe a discharge planning tool for NICU parents (Cagan & Meier, 1983), and one for the home apnea monitor (Graber & Balas-Stevens, 1984). There are no nationally accepted guidelines for NICU discharge teaching. The assessment of need, selection of timing and method, as well as much of the content are left to the judgments of the nurses working with each family. Whether the resulting discharge teaching facilitates the development of an adequate dependent-care agency at discharge is uncertain and is the focus of this study.

This research study will explore the success of the discharge teaching conducted by the nurses of a regional NICU in which the discharge is coordinated with a planning instrument. The discharge teaching includes information on basic infant care, special care, growth and development and follow-up services. Although there are many ways to evaluate the success of NICU discharge teaching, this

study will determine parental perceptions of the teaching through a post-discharge home interview.

#### The Research Questions

Five research questions are addressed: (1) Were the parents involved in planning their own NICU discharge teaching? (2) Were the parents' needs correctly assessed? (3) Were the parents satisfied with the NICU discharge teaching? (4) Did the parents perceive the NICU discharge teaching as being important to their care of the infant? (5) Did the NICU discharge teaching include the essential areas needed for care of the infant following discharge?

## CHAPTER II

### REVIEW OF RELATED LITERATURE

The nursing literature provided background on both normal and high-risk parenting education. It is assumed that although parents of high-risk infants have special educational needs, they also require basic infant-care information common to all neonates. Research reviewed in this chapter included studies on prenatal parent education; postpartal parent education on maternal tasks, infant care tasks, and infant behavior; parent education programs; parental role transition; and special planning for educating the parents of high-risk neonates.

#### Prenatal Parent Education

Although parent education may begin at several points, a number of authors have advocated prenatal parent education. This is not always possible with the high-risk infant, especially those born prematurely. Snyder, Eyres and Barnard (1979) reported on a longitudinal study of 193 families of healthy first-born children, in which the relationship between the parents' prenatal expectations and the child's actual development through 24 months were compared. Many mothers were not aware of their infants' capabilities. Those who did not understand early infant development, provided a less stimulating environment and had infants with lower mental and



psychomotor scores at 24 months.

The authors recommended junior-high school classes on normal infant capabilities, plus prenatal education dealing with accurate expectations of the infant, especially for parents with low resources. Since many parents of high-risk infants do not have time prior to the birth to attend prenatal classes, NICU parent education would be expected to include anticipatory guidance on growth and development and ways to promote stimulation for the high-risk infant.

Humenick & Bugen (1987) recommended that prenatal childbirth educators teach couples to be mutually supportive, make conscious parenting choices, and help each other deal with discrepancies in expectations. These authors thought that parents who were unable to attend prenatal classes, such as parents of premature infants, would require special teaching and support to overcome the deficit.

#### Postpartal Education on Maternal Tasks

Normal parenting education may be started or reinforced during the postpartum period. Mercer, (1981) described the maternal tasks of the postpartum period as reviewing the childbirth experience, adapting to reality, developing infant care-taking skills, redefining roles, and resuming other responsibilities. She advised nurses to assess the mother's knowledge of infant care-taking skills and build additional teaching on this foundation.

Parents of a high-risk infant may encounter difficulty in fulfilling Mercer's postpartum tasks. They may have undergone a

premature and/or traumatic childbirth experience, far from their ideal expectations. Either the maternity nurse or the NICU nurse can help the mother to review the experience and gain the knowledge to understand and resolve emotional conflicts. Since the prognosis for their infant is uncertain, adaptation to reality is difficult and requires continued support and guidance. The infant usually requires highly technical care, not appropriate for parental involvement. Infant care-taking skills that can be performed by parents may be minimal due to the highly technical nature of the care. Redefining roles may cause confusion as the parents can't assume their full parental role while NICU care is needed.

The nurse can encourage parents to visit, touch, stroke and speak lovingly to the infant, while assuring them of the therapeutic value to the infant. Resuming other tasks may be difficult, if not impossible, due to frequent medical crises, the uncertain future of the infant, and the demands of prolonged hospitalization. As Mercer (1981) states, the educational needs of the parents should be carefully assessed as a foundation for teaching.

#### Postpartal Education on Infant Care

A study conducted by Adams (1963), using three interviews with forty first-time mothers during the first month of infant care, found that mothers had little information on infant care. Although half of the subjects had attended prenatal or postpartal classes, the prenatal classes were of questionable value as pregnancy was not a time of active interest in infant care. Adams concluded the most

effective infant-care teaching was after delivery with the stimulus of the infant present. Although this study casts doubt on the value of prenatal education missed by high-risk parents, such parents cannot begin postpartal education and infant-care practice until an appropriate time in the infant's recovery process.

Adams (1963) found that feeding was the area of greatest concern for all forty mothers, whereas holding, preparing for bathing, crying, care of the navel and circumcision were also frequently expressed concerns. Minor concerns involved sleeping, taking the baby out, hiccups, weight and rashes. As would be expected, the amount of experience the mother had was highly related to the concern expressed. The 20 mothers of premature infants had more questions only when anticipating care at home. Adams's study supports the need for comprehensive discharge teaching for parents of high-risk infants.

A telephone follow-up service for new mothers of healthy infants was described by Haight in 1977. Among the 136 mothers contacted, the most frequently asked questions concerned breastfeeding, jaundice, normal stools, baby baths, circumcision care, umbilical cord care, room temperature for the baby, colic, taking the baby outside, flying with the newborn and sterilizing the baby's equipment. Some of these not included on the discharge tool, such as jaundice, circumcision and cord care, would no longer be problems for the NICU graduate.

Sumner and Fritsch (1977) explored parental concerns in the first six weeks of life, by examining 270 spontaneous phone calls to

a health-care facility by multiparous and primiparous mothers of healthy infants. Peak call rates were 1 to 2 days after discharge, 7 days, and weekly at 14, 21, 28 and 35 days. Mothers of male infants had increased concerns about feeding, especially breastfeeding. The age of the infant appeared to have a great effect on the questions, with the greatest number in the first 2 weeks and a sharp decline at 6 weeks. The single exception, sleep-behavior questions, increased to the end of the fourth week and then sharply decreased. The highest percentage of infant-care questions regarded feeding, especially breastfeeding, followed by questions related to the gastrointestinal tract, the skin, sleeping/crying and miscellaneous problems. Primiparous women called 3 1/2 times more frequently than multiparous women, although the latter asked more questions per call.

Telephone calls appeared to be for validation of maternal action, not for specific information. Sumner & Fritsch concluded all new mothers need access to health-care resources early in the postpartum period. They recommended contact with the pediatric nurse practitioner in group classes during the postpartum period, plus establishment of group classes for new mothers. Parents of high-risk infants have an extensive involvement with NICU nurses and may have had some of these questions answered prior to discharge. They would however, be expected to benefit from a similar professional support system to answer additional questions following discharge.

In their 1985 survey of 78 new mothers with normal neonates,

Bull and Lawrence found a need for information on the tasks of bathing, cord care, genital care, shampooing, spacing feedings, infant formula and infant behavior. Since their study dealt only with mothers of healthy full-term infants, the authors recommended research into the special needs of high-risk mothers.

In the research project described by Brucker and MacMullen (1985), a postpartum nurse clinician visiting clients 48 hours after discharge found many questions regarding infant care, especially newborn behavior, illness, sibling rivalry and breastfeeding. The mothers lacked knowledge about community resources and were bothered by inconsistencies in pediatric recommendations. These concerns would likely be shared by parents of high-risk neonates.

In a study of 23 primigravida mothers participating in a self-help telephone support service, Gosha & Brucker (1986) found that the mothers wanted to discuss breastfeeding, infant-sleeping behavior, day care, and baby-sitting. This illustrates the continuing need for support with post-discharge questions plus referral to self-help groups if available.

In summary, it is anticipated from these studies of mothers of normal infants, that parents of high-risk infants would need appropriately-timed education on growth, development and basic infant care. Anticipatory guidance on preventing or handling common infant and family problems will be helpful. Multiparas as well as primiparas will need teaching and reassurance about their infant-care abilities. These parents will benefit from a support system of personal, family and professional resources.

### Postpartal Education on Infant Behavior

In 1977 Gruis studied the postpartum concerns of mothers and recommended the mother become acquainted with her baby prior to learning infant care. The author suggested informing new mothers about community resources and utilizing the public health nurse for post-discharge home visits. These recommendations, using the unique growth and development characteristics of the high-risk infant, should be implemented for parents of high-risk infants. Obviously community resources and referral to a public health nurse would also benefit the parents of the discharged NICU infant.

Forty first-time mothers with uncomplicated pregnancies and vaginal deliveries were surveyed in 1981 by Bull. She discovered that "a focus on the self and infant persists after one week at home" (p. 394). Infant behavior continued to be of moderate to much concern whereas there was a statistically-significant decrease in concerns with physical care of the infant after the first week. This supports the inclusion of education on growth and development as well as infant care in NICU discharge teaching.

Riesch and Munns' (1984) work supported these findings and recommended the mother be encouraged to take a more active interactional role with her infant. They suggested "information relative to the infant's interactional potential and the maternal behaviors that support and enhance that potential be included in all standard plans of maternal-neonatal nursing care" (p. 276). Obviously the specific potential of the high-risk infant should be

included and parents should be taught to interact appropriately with their infant.

In summary, the literature supports the view that parents need to be educated on infant growth and development as well as infant care tasks in order for successful parent-infant adaptation to occur. Anticipatory guidance on problems at home, plus information on available community resources will benefit mothers of both normal and high-risk infants.

#### Parent Education Programs

Several studies described the content of teaching programs, without research into parental perceptions of need or satisfaction. Since they lack a documented research focus it seems reasonable to assume that these are based on nurses' views of parents' needs.

A program for early postpartum hospital discharge teaching described by Avery, Fournier, Jones and Sipovic (1982), included infant feeding techniques, holding positions, cord care, hygiene and elimination. The service included an infant-schedule record, handouts, informational booklets, a nurse phone contact at 24 hours, and a home visit at 48 hours post-discharge.

The postpartum teaching program described by Brown (1982), included infant nutrition, breastfeeding, formula preparation, feeding positions, burping techniques, infant bathing and integration of the infant into the family.

A teaching program described by Smith (1986), used a parent checklist for requesting teaching on feeding, spitting-up, hiccups,

baby sitters, sleeping, infant schedules, crying, bathing, laundry detergents, circumcision and navel care, rashes, diapers, temperature taking and bowel movements. A separate checklist used by nurses included teaching on sucking needs, normal reflexes, paternal involvement, sibling rivalry, appropriate toys, activities, developmental milestones, car seats, rolling over and safety-proofing the house. It also directed teaching about specific health concerns such as delaying solids, bulb syringe demonstration, thermometer demonstration, fever-control handout, seborrhea, circumcision, navel, congestion, and when and whom to call for help.

In summary, the programs described by these articles included education on infant-care tasks, infant behavior and anticipatory guidance for post-discharge problems. Similar teaching plus the use of nurse telephone calls and home visits would also benefit the parents of high-risk infants.

#### Parental Role Transition

Success with transition to the parental role was studied by several authors. Using an experimental teaching intervention to help new mothers understand their infants' behavior, Golas and Parks (1986), found high levels of maternal satisfaction with the teaching, but failed to find significant alterations in maternal self confidence in interpreting infant behavior cues. The authors noted that satisfaction with the teaching might be related to the time spent with the mothers as well as to the content of the teaching. Although this study casts some doubt on the use of



satisfaction as a single measure of success, it remains a useful component if combined with other measurements. If it reflects nursing time spent with the mother, it also serves as an important measure of the therapeutic nurse-parent relationship that is a basis of parent education.

Mercer (1985) studied the process of maternal-role attainment in three age groups, (15-19, 20-29, 30-42), and concluded "mothering over the first year presented similar challenges for all age groups, although age groups began with different levels of proficiency" (p. 202). She recommended anticipatory socialization and guidance by nurses working with first-time mothers in preparation for the realities of the maternal role.

Roberts (1983) found that the healthy infant's obligatory behavior, namely that requiring parental action, affected the parents' perception of the infant and ease of transition to parenthood. She recommended prenatal efforts to increase the prospective parents' self-esteem, education to increase parental understanding of infant behavior, and suggestions to new mothers to obtain help at home in order to continue previously satisfying activities. Since parents of high-risk infants are under high stress and must cope with an infant requiring extensive parental action, NICU discharge teaching should include education on specific infant behaviors and ways to promote parental self-esteem and satisfaction.

These studies conclude that the nurse working with parents of high-risk infants should offer anticipatory guidance on parental

role development, increased education on infant behavior plus support to build parents' self-esteem and confidence in parenting activities.

#### Parenting the High-Risk Neonate

The authors of studies dealing with parents of high-risk neonates described the unique problems of this group and the special alterations needed for administering effective nursing care for the parents.

Kennell, in his 1978 article on problems in bonding with the premature infant, noted that lack of preparation for the delivery, the appearance of the premature infant, the tense environment of the NICU, and problems with staff-parent communication were related to the difficulty encountered in parent-infant bonding.

In 1980 Frodi and Lamb described the factors thought to be associated with the high incidence of premature-infant abuse and neglect. The premature infant does not look like the anticipated full-term infant and often has a high-pitched arrhythmic cry. The parents may be poorly prepared for infant care due to the early delivery and may experience bonding difficulty due to separation and isolation. Frodi & Lamb recommended using social supports and counseling to resolve unrealistic parental expectations and beliefs.

Sims-Jones (1986) believe the theory of attachment may not apply to mothers of premature infants. In contrast to fullterm healthy neonates, "their infants are ineffective in initiating maternal contact by crying, sucking, or clinging" (p. 394). Since

the expected factors promoting maternal attachment are absent, it is necessary for the NICU staff to promote attachment by educating mothers on premature-infant behavior. These measures help to prevent the guilt arising when the mother is unable to interact with her sick newborn. It could be anticipated that fathers would need similar assistance to promote attachment to the high-risk infant.

Anxiety and problem-solving ability were studied by Gennaro, (1986). From the 40 mothers of premature infants studied, she found that "just having an infant in a neonatal intensive care unit may result in maternal anxiety", irrespective of actual illness of the neonate (p. 163). Gennaro concluded nurses need to reassure these mothers that anxiety is a normal reaction and assist them to channel anxiety into appropriate responses to family changes necessitated by the premature birth.

These studies illustrate the problems in bonding with the ill or premature infant and recommend education on high-risk infant behavior, ways to respond appropriately to the infant, and methods for dealing with stressful changes accompanying the high-risk birth.

#### Education for Parents of High-Risk Neonates

In contrast to the behavior of the full-term infant, Coward (1984) described the altered behavior of the premature infant and the special teaching needed for the parents. She encouraged the parents' active involvement in infant care and decision-making to decrease feelings of isolation and loss of control. Coward also discovered a deficit in nursing literature on parent education and

discharge planning for high-risk families.

The role of the postpartum follow-up nurse clinician has been described by Donaldson (1981). She outlined the postpartal problems experienced by the mother of a normal healthy infant and the unanticipated stressors associated with the high-risk infant. According to Donaldson, key nursing interventions for postpartum follow-up include help with the existing crisis, methods for ego strengthening, anticipatory guidance and the mobilization of resources.

Censullo (1986) described teaching strategies for the parents of high-risk newborns, that included the educational principles of readiness to learn, level of understanding, perception of the event, individualized learning styles, ability to participate and practice, need for positive feedback and appropriateness of information. She emphasized the need for education on growth and development, especially erratic sleep-wake states, pediatric follow-up care and community resources.

In 1983 Montgomery explored the crisis periods and developmental tasks of the premature infant's family, including preparation for possible loss of the neonate, acceptance of the premature infant, interaction with the premature infant, and clarification of the premature infant's needs. Montgomery advised nurses to teach the parents caretaking tasks and to attempt to promote trust and attachment to the infant. Nurses were advised to give the parents tasks at which they would be successful and to allow at least two days of total infant care prior to discharge.

According to Montgomery's study, discharge arrangements should include medical follow-up, visiting nurse referral, and high-risk follow-up.

In an attempt to promote positive parent-infant interaction, Harrison and Twardosz (1986) studied 30 mothers of premature infants separated into three groups. One group received structured teaching on premature infant characteristics and behavior, a second group had a special question-and-answer session, whereas the third group received routine discharge teaching. Significant differences were not found in maternal perceptions and behaviors at home visits two, four and eight weeks post-discharge. The authors attributed the lack of differences to inadvertent provision of the experimental information to the other two groups. The authors concluded that a single short-term teaching program about preterm infant characteristics does not significantly enhance the support currently provided by NICU nurses. This does not mean that such teaching should be eliminated, but that it may be effectively incorporated into nursing care without the need for a special program.

In the implementation of a model for premature birth, Beaton (1984) advocated continuing evaluation by parents and staff to improve services. She recommended including the parents in decision-making for the infant's hospital care, actively involving parents in the infant's care and using a telephone contact and public-health nurse follow-up visits after discharge of the high-risk infant.

### Discharge Teaching for Parents of High-Risk Neonates

Lissenden (1984) advised nurses working with mothers of premature infants to ensure care-giving skills by praising care-giving, building parental confidence to cope with the baby at home, actively preparing parents for the homecoming, and including information on counseling and follow-up resources.

In a 1983 study, Cagan and Meier compared 35 sets of parents receiving unsystematic discharge teaching with a group of 40 parents whose discharge teaching was directed by a discharge-planning instrument. The instrument coordinated parent teaching on bathing, diapering, cord care, circumcision care, axillary temperature, reading the thermometer, discussing medications and medication schedules, and special treatments or procedures. During a home visit two to four days post-discharge, parents who had received the coordinated discharge teaching judged themselves more capable of caring for their high-risk infants. The authors noted a lack of discharge planning literature for high-risk infants and concluded, "Nurses must realize that discharge planning is a process, not just a procedure, and must plan care around this process" (p. 280).

Teaching principles for high-risk parents were described by Graber and Balas-Stevens (1984). Their home apnea monitor teaching tool was "designed to address concerns and to allow parents time to express their fears while taking steps toward developing their cognitive and psychomotor skills" (p. 178). They assessed the

parents' knowledge level and comprehension, described the teaching tool to the parents seven days in advance, and taught infant cardiopulmonary resuscitation (CPR) at least four days prior to discharge. During this time the family made home plans and reported their progress to the nurse. The actual monitor was explained by company representatives and the parents were given an opportunity to respond to the alarms with supervision until they gained confidence.

Arenson (1988) states, "The key to providing continuity of care is appropriate and comprehensive standards for discharge teaching" (p. 29). Among the risk factors leading to rehospitalization of sick infants cited by this author is incomplete discharge teaching. She recommends that each family have a discharge coordinator and that the parents be part of the NICU team from the day of admission. She states that, "community health nurses are vital in making a good transition to home care" (p. 49). Arenson cites a need for research on the effects of different discharge teaching methods on patient and family outcomes.

The articles and reports summarized here recommend including parents early in planning, employing appropriate teaching principles, encouraging an active parental role in infant care, and teaching about the special physical and behavioral characteristics and needs of each infant. Parents need to practice total infant care prior to discharge and the discharge should be coordinated with a planning instrument. Anticipatory guidance, appropriate referrals and the mobilization of special supports are recommended.

## CHAPTER III

### DESIGN AND METHODOLOGY

#### The Research Design

The research design was a non-experimental exploratory study of parental perceptions of Neonatal Intensive Care Unit (NICU) discharge teaching. It consisted of interviews with a sample of 50 mothers and 15 fathers selected from the population of parents of infants discharged from a midwestern regional neonatal intensive care unit.

The interview method was selected in order to maximize parental cooperation at a time when the family is adapting to the recently discharged infant. Such a personal interview was thought to encourage the expression of special feelings and problems related to discharge teaching that might not be shared through a questionnaire.

The interviews were conducted in the parents' home or a place of their preference, 10 days to 19 weeks following the infant's discharge from NICU. An interview schedule was used to collect demographic data, to validate sample selection criteria and to determine the parents' involvement in planning and perceptions of the discharge teaching. The interview also included questions on major problems since discharge, parental suggestions for nurses and the major source of infant-care information since discharge.



### The Sample

Since it was difficult to arrange interviews with both parents following discharge, the study involved interviews with mothers, or both parents. A non-probability sample of the parents of fifty infants was selected from the population of all infants discharged between November 1, 1986 and August 15, 1987, meeting the following criteria:

#### Parent Criteria

1. A parent who is at least 18 years of age
2. Parents who are maintaining their own place of residence, separate from the extended family
3. Parents who are the main infant care providers
4. Parents with no previous children discharged from a neonatal intensive care nursery

#### Infant Criteria

1. Infants admitted to NICU within 24 hours after birth.
2. Infants with a minimal stay of five days in NICU
3. Infants discharged directly from the study hospital's Neonatal Intensive Care Unit or associated Convalescent Care Nursery

#### Rationale for Criteria

A parent must be at least 18 years of age to sign the informed consent. Those parents maintaining their own place of residence are

less likely to have infant care performed by extended family members. Those who are the main infant-care providers are better able to judge the importance of the teaching and give their perceptions of the discharge teaching. Excluding parents with previous neonates in NICU is important as they would be more comfortable with care for the high-risk infant.

Using infants admitted within 24 hours after birth decreased the likelihood that parents had received infant-care teaching from nurses other than the NICU staff. The five-day minimum stay in NICU increased the possibility of the infant being truly high-risk and decreased the chance of infant-care teaching being done by maternity nurses. Using infants discharged directly from the NICU or associated Convalescent Care Nursery eliminated those parents whose infant-care teaching was done by back-transfer hospitals or the normal newborn-nursery staff.

#### The Variables

The purpose of this study was to gain insight into parental perceptions of NICU discharge teaching by addressing the following questions. (1) Were the parents involved in planning their NICU discharge teaching? (2) Were the parents' needs correctly assessed? (3) Were the parents satisfied with the NICU discharge teaching? (4) Did the parents perceive the NICU discharge teaching as being important to their care of the infant? (5) Did the discharge teaching include the essential areas needed for care of the infant following discharge?

Thus the major variables of the study were the NICU discharge-teaching content and parental perceptions of involvement, need, satisfaction, importance and adequacy of that teaching.

#### The Interview Instrument

A search of the literature failed to yield an appropriate instrument for the interview, and consequently the "Parental Perceptions of NICU Discharge Teaching" instrument was constructed (see Appendix A). The instrument incorporated teaching categories of the NICU discharge teaching tool, "Discharge Referral/Parent Education Sheet" that serves as the written basis for all NICU and Convalescent Care Nursery (CCN) discharge teaching (see Appendix B).

The instrument consisted of three-pages with 69 items. These included demographic data; criterion data; parental perceptions of involvement in planning, recall, need, practice, satisfaction, importance; and comments on the discharge teaching. The background data were obtained from the NICU nursing staff and parents. Charting of the discharge teaching was obtained from examination of the "Discharge Referral/Parent Education Sheet" completed by the nurses.

The parents were asked each question regarding their perceptions of discharge teaching by the nurse researcher, who recorded the answer on the interview schedule. Involvement in planning the discharge teaching was judged from a single question (Item 34), answered on a three-point scaled response of 0=not involved, 1=somewhat involved, 2=very involved. Recall was based on

the parent's memory of receiving an area of teaching without necessarily recalling the content and was judged "Yes" or "No." Need for the teaching was based on the parent's perception, again using a yes/no dichotomous response. For those items that could be reinforced by practice, the opportunity to practice was based on the parent's recall of the approximate number of times practice took place.

Satisfaction with the teaching was judged by parents on a three-point satisfaction-dissatisfaction scale of 0=not satisfied, 1=neutral, 2=very satisfied. Importance of the teaching to care of the infant at home also used a three-point importance scale of 0=not important, 1=somewhat important, 2=very important. Each participant was given a card with the satisfaction/importance codes to facilitate selection. Parental comments were appropriately recorded on the interview instrument.

The instrument also contained specific items that may be related to satisfaction including demographic items, fulfillment of subject criteria, use of prenatal classes, frequency of NICU visitation, satisfaction with maternity unit teaching, use of and satisfaction with the overnight stay in NICU, presence of an especially helpful nurse, involvement in discharge planning, and overall satisfaction with the discharge teaching. Infant-care categories used were those of the discharge-planning tool. Since some interviews involved only the mother, questions were included regarding the father's involvement and satisfaction with discharge teaching. The latter questions were answered directly by the

father, if interviewed, or reflected the mother's perception when the father was not available for interview. No interviews were conducted with the father as the single subject.

Four open-ended items completed the interview. These explored parental views on: major problems since discharge; content that might have prevented or helped with these problems; other baby-care information that should have been included; and the major source of infant-care information since discharge.

#### Evaluation of the Instrument

Since this is a newly constructed interview instrument, it was examined by four NICU nurses involved in discharge teaching for appropriateness of wording. The face content validity was judged and approved by six NICU nurses regularly involved in discharge planning.

#### Human Subjects Considerations

Since the interviews involved parents and infants associated with one hospital, the specific guidelines of that hospital, as well as Western Michigan University Human Subjects Institutional Review Board were used to construct the consent form (see Appendix C).

Prior to initiation, the research study was examined and approved by the appropriate committees of the study hospital and Western Michigan University Human Subjects Institutional Review Board.

### Procedure

The nurse researcher was denied direct access to NICU clients due to human-subjects concerns for confidentiality, thus potential subjects were selected by the NICU Unit Supervisor on the basis of the parent and infant selection criteria (see Appendix D). The process was facilitated by having the researcher accompany the Unit Supervisor on nursing rounds twice each week. As infants were selected, a preconsent letter from the Unit Director asking for the parent's signed permission to be contacted was left at the bedside (see Appendix E).

The signed letters of interested parents were collected by the Unit Supervisor and relayed to the researcher for subsequent parental phone contact to explain the project. After receiving a verbal description of the project, those who wished to participate had two consent forms left at the infant's bedside. This gave the parents time to read the consent, have their signature witnessed by the infant's nurse and also to receive a copy of the consent for their own records.

A current list of infants involved in the project was given to the NICU Unit Supervisor, the NICU Unit Clerks and the OCN Charge Nurse each week. As a study infant was to be discharged, the researcher was notified and the parents were contacted by telephone to remind them of the project and the probable date of the interview. In some cases this took up to 17 telephone calls and 16 weeks to arrange. The day of the scheduled home visit, another call

was made for confirmation and appropriate changes as needed. The busy schedules of these families, particularly in the case of working mothers, often necessitated delays and rescheduling.

#### Operationalization of the Variables

In this study, content was operationalized as the individual categories of discharge teaching listed on the interview instrument. Involvement was operationalized as a score on a three-point involvement scale. Recall was operationalized as an answer of "Yes" by the parents on the "Teaching Recalled" section of the interview instrument. Need was operationalized as a "Yes" for the "Teaching Needed" column of the interview, whereas practice was operationalized as a score in the "Times Practiced" column. Satisfaction was operationalized as a score on a three-point satisfaction-dissatisfaction scale for the column "Satisfaction". Importance was operationalized as a score on a three-point importance scale listed under the column "Importance". Completeness was judged from answers to the question regarding additional information that would have been helpful.

#### Analysis of the Interview Results

The results of the closed-ended items were analyzed via the Statistical Package for the Social Sciences (SPSS-X) to yield means for interval data and frequencies/percentages for the ordinal data such as recall, need, satisfaction and importance scores. The open-ended items were examined individually for trends in major problems,

sources of infant-care information, suggestions and supplemental educational needs.

Kendall's tau was selected as the appropriate test for correlations between non-parametric variables. The overall-need score for infant-care items 36-61, was correlated with maternal age, marital status, parity, attending prenatal classes and involvement in discharge planning. The amount of practice was correlated with the satisfaction for individual items. The 15 individual father's scores were correlated with that mother's scores on need, recall, satisfaction and importance. The overall-satisfaction score (item 35) was correlated with mean-satisfaction for specific infant-care items 36-61. The mean satisfaction score was also correlated with maternal age, marital status, parity, delivery type, gestational age of the infant, involvement in discharge planning, staying overnight in NICU, presence of an especially helpful NICU nurse, number of days in NICU, CCN, and number of days home.

The open-ended items were examined for categories of problems following discharge, additional teaching needed, suggestions for maternity and NICU nurses and major source of infant-care information following discharge.



## CHAPTER IV

### RESULTS

The research questions in the present study included the following: (1) Were the parents involved in planning their own NICU discharge teaching? (2) Were the parents' needs correctly assessed? (3) Were the parents satisfied with the NICU discharge teaching? (4) Did the parents perceive the NICU discharge teaching as being important to their care of the infant? (5) Did the NICU discharge teaching include the essential areas needed for care of the infant following discharge?

In order to examine these questions, a non-experimental exploratory design was used. Fifty mothers and 15 fathers of infants discharged from the Neonatal Intensive Care Unit (NICU) of a midwestern regional medical center, were interviewed about their perceptions of discharge teaching. The interviews took place in the home in 49 cases and in the pediatrician's office in one case. The length of time following discharge of the infant ranged from 10 days to 137 days with a mean of 54 days.

All infants and parents fit the criteria for subjects (see Appendix D). The infants had been admitted to NICU within 24 hours after birth, had remained there for a minimum of 5 days, and were discharged from NICU or the associated Convalescent Care Nursery (CCN) to their home. All parents were at least 18 years of age,

maintaining their own residence, were the major infant-care providers and had no previous children discharged from a neonatal intensive care unit.

#### Infant Characteristics

Infants ranged from 25 weeks gestation to 42 weeks with a mean gestational age of 34 weeks. They had multiple diagnoses of prematurity (72%), respiratory distress syndrome (54%), apnea (38%), jaundice (22%), sepsis (18%) and miscellaneous problems (58%), including meconium aspiration syndrome, pulmonary hypertension, pneumonia, blood incompatibilities, hypoglycemia, and congenital anomalies. The infants' total hospitalizations (NICU + CCN) lasted 6 to 255 days averaging 41 days. The average stay in NICU was 37 days, with a range of 5-255 days. The mean stay in CCN was 15 days, with a range of 1-26 days.

Twenty infants had been discharged from the Convalescent Care Nursery, whereas 30 were discharged directly from the NICU. Thirty-six (72%) of the infants had post-discharge problems including 19 on apnea monitors, 8 requiring oxygen due to lung problems, and others with urinary tract abnormalities, feeding problems, hypertension, congenital and genetic problems. Several infants had a combination of problems.

#### Maternal Characteristics

Twenty-six mothers (52%) had delivered by cesarean section and 24 (48%) vaginally. Mothers were 18 to 42 years of age with a mean

age of 27 years and included 29 (58%) multiparas (one or more previous live births) and 21 (42%) primiparas (no previous live births). The multiparous mothers had 1 (24%) to 5 (2%) other children, (mean of 1.8), with ages from 14 months to 19 years, (mean 5.6 years). None of the siblings had been hospitalized in a neonatal intensive care unit after birth.

Seven mothers (14%) were non-white (6 black, 1 oriental). Nine (18%) were single parents and 41 (82%) were married. Two of the single mothers were living with the father of the infant at the time of the interview. Although there were no formal questions regarding employment status, 18 mothers (36%) volunteered that they were working or planned to return to work soon.

Thirty-four percent of the multiparas and 33% of the primiparas had attended prenatal classes at some time. Two of the primiparas had attended only two classes prior to the premature delivery of the infant. Twenty-one (42%) had never attended prenatal classes, and gave the following reasons: early delivery (48%); unneeded classes (24%); maternal illness/possible fetal demise (19%); unavailable classes/family relocation (9%).

Only 6 multiparas (21%) and 6 primiparas (29%) had attended a baby-care class at some time. Seven of these were prenatal baby-care classes, but 5 were community or high-school baby-sitting classes. Of those not attending baby-care classes, thirty-five percent of the multiparas and 48% of the primiparas would like to have taken such a class prenatally. In total, 38 (76%) had never taken a baby-care class, but 40% of these would like to have taken

such a class.

Thirty-three mothers (66%) had experienced serious health problems that affected their pregnancy. According to the mothers, these problems included premature labor (36%), prolonged rupture of membranes (30%), pregnancy-induced hypertension (18%), placenta previa or abruptio (18%), uterine abnormalities (6%), twin pregnancy (6%), incompetent cervix (6%), blood incompatibility (6%), diabetes (3%), and pneumonia (3%). Some mothers had a combination of problems, and others were not familiar with the exact nature of their pregnancy-related problems.

#### Satisfaction with Maternity Unit Teaching

Thirty-three mothers (66%) had been hospitalized on the maternity unit of the regional hospital. Eighteen (55%) were very satisfied, 9 (27%) were neutral on satisfaction and 6 (18%) were not satisfied with the maternity-unit teaching (see Table 1, p. 36). Nearly all stated that the teaching had not included basic baby care. Two had benefited from watching the closed-circuit channel on baby care; however, another cautioned that such teaching would be too stressful with the infant in NICU. Those who were not satisfied gave the following reasons: inadequate help with breastfeeding, a sense of physical and emotional isolation, inadequate teaching on premature birth and the infant's condition.

Of the mothers who were neutral on satisfaction, 56% had received no baby-care teaching from the maternity nurses. Although these mothers verbalized their appreciation for the special care and

Table 1  
Parental Perceptions of Recall, Need, Satisfaction

Discharge Teaching Content Areas	Teaching Recalled	Recalled & Needed	Needed but Not Recalled	Satisfaction		
(n=50 unless specified)				Not	Neutral	Very
Maternity Unit (n=33)				18%	27%	55%
Overnight Stay in NICU (n=24)				13%	20%	67%
Overall Satisfaction				0%	14%	86%
Bathing baby	76%	68%	8%	18%	27%	55%
Feeding:						
Tube Feeding (n=36)	100%	97%	0%	6%	3%	91%
Breastfed Babies: (n=21)						
How to Breastfeed	38%	88%	10%	13%	24%	63%
Amt/Frequency	29%	19%	24%	0%	33%	67%
Pumping/Storing	53%	82%	10%	0%	45%	55%
Formula Supplement	24%	40%	6%	0%	40%	60%
Bottlefed Babies: (n=29)						
How to Bottlefeed	48%	50%	6%	7%	22%	71%
Making Formula	28%	25%	4%	13%	12%	75%
Temperature:						
Use of Thermometer	86%	53%	29%	2%	19%	79%
Normal/Abnormal	70%	66%	73%	6%	5%	89%
Bulb syringe:						
How/When to Use	70%	63%	20%	0%	14%	86%

Table 1--Continued

Discharge Teaching Content Areas	Teaching Recalled	Recalled & Needed	Needed but Not Recalled	Satisfaction		
(n=50 unless specified)				Not	Neutral	Very
CPR/Safety:						
CPR Slide-Tape	98%	86%	0%	0%	8%	92%
CPR Demonstration	96%	92%	0%	0%	9%	91%
Car Seats	22%	9%	28%	0%	27%	73%
Poison Control	35%	24%	42%	0%	35%	65%
Comfort Measures:						
Swing/Rock/Bundle	63%	58%	28%	0%	26%	74%
Infant Stimulation/Play	49%	54%	32%	0%	33%	67%
Normal Growth/Development	38%	63%	42%	5%	48%	47%
Medications at Home: (n=18)						
Type/Reason	84%	100%	67%	0%	12%	88%
When/How to Give	84%	100%	67%	0%	12%	88%
Reactions/Side Effects	68%	100%	67%	0%	8%	92%
Apnea Monitor (n=24)	100%	100%	0%	4%	9%	87%
Follow-Up Care:						
Progress Clinic (n=42)	60%	100%	41%	17%	33%	50%
Pediatric Care	82%	63%	44%	0%	27%	73%
Eye Examination (n=37)	66%	97%	44%	7%	29%	64%

support of the maternity nurses, they expected more teaching, and more discussion of the infant's condition. One mother perceived the maternity nurses as being too busy, but wished they had taken time to accompany her to NICU for the first few visits. Of the 18 (55%) that were very satisfied, 8 (44%) said they received no teaching on infant care, 2 were taught only about breastfeeding, and 1 had been given a pre-delivery NICU tour. In all, 58% of the 33 mothers who were patients on the maternity unit of the study hospital, received no teaching on infant care. Their suggestions for maternity nurses were: obtain the infant's photo, show slide-tapes about high-risk infants and discuss the infant's condition. They also suggested making a special effort to get sick mothers to NICU to visit their infant. As one mother expressed it, "I felt miserable having to get up, but going to the NICU each day made me get well faster!"

#### Parental Visitation

Forty-two mothers (84%) had visited their infants in NICU every day, whereas 7 (14%) visited three times each week, and 1 mother (2%) visited weekly. The latter was a multipara whose home demands prevented more frequent visits. Nineteen of these mothers (38%) had visited primarily between the hours of 6 and 9 pm, whereas 13 (26%) had visited at random times, including 11 pm to 7 am. Several parents commented on the helpfulness of the NICU Watts telephone line. Parents drove as far as 175 miles round trip to visit and the average round-trip distance traveled was 56 miles.

### Recall of an Especially Helpful Nurse

Thirty-seven subjects (74%) recalled one especially helpful NICU nurse, and 30 could recall her by name. The comments about this special nurse were extremely positive and complimentary. Many parents voluntarily identified one special nurse on each shift. Although 13 mothers could not recall one special nurse, 2 of these stated that all NICU nurses fit this description.

The comments about NICU nurses were generally positive. Representative comments were, "They really cared about my baby and were as happy as I was when she improved." "They were so patient and repeated the teaching over and over for me." "He couldn't have been in better hands!"

### Overnight Stay in NICU

Twenty-four mothers (48%) had stayed overnight in NICU with their infant and 16 (67%) were very satisfied with the experience, five were neutral, and 3 (13%) not satisfied (see Table 1). The dissatisfaction was related to lack of clear expectations, monitor problems, lack of comfort, and infant procedures and teaching that delayed bedtime. In one case, the parents were not satisfied because they thought the experience was required but not needed. Even some who were very satisfied, called it "a horrible experience" and also described problems with unclear expectations, inappropriate timing of teaching, lack of sleep and privacy.

Of the 26 mothers who had not stayed overnight with their



infant, 11 (42%) would like to have had the experience. Thus 58% would have rejected the overnight stay if offered. Twenty-seven mothers (54%) stated that all parents should be given the opportunity to stay overnight with the infant. Suggestions made by parents included clarifying expectations, avoiding extensive teaching prior to sleep, increasing privacy, making available a phone, private bath and comfortable bed, and setting off the monitor alarm only once during the night.

#### Factors Correlated With Parental Need for Teaching

To determine which factors showed statistically significant correlations with the mother's need for teaching, the overall need score for infant-care items 36-61 was correlated with maternal age, marital status, parity, attending prenatal classes, and involvement in discharge planning. The overall need for teaching was slightly negatively correlated with attending prenatal classes ( $-0.1895$ ), and slightly positively correlated with age of the mother ( $0.0308$ ), marital status ( $0.1331$ ), parity ( $0.1801$ ) and involvement in planning ( $0.2415$ ). None of the correlations attained high levels of significance.

#### Maternal Involvement in Discharge Planning

Fifteen mothers (30%) judged themselves very involved, 16 (32%) somewhat involved and 19 (38%) not involved in planning their discharge teaching. Most of the "not involved" mothers viewed the discharge teaching as a mandatory program controlled by the nurses

and guided by the discharge-planning tool. They did not view themselves as having input into or control of the process. Several of the "very involved" mothers commented that they had been encouraged or felt free to tell the nurses about their own special teaching needs.

#### Factors Correlated With Maternal Satisfaction

There was a statistically significant positive correlation between the item on overall satisfaction (item #35) and the mean satisfaction for items 36-61 on infant care (Kendall's tau B 0.383, significance 0.0037). The mean satisfaction of mothers was not strongly correlated with maternal age (-0.1523), marital status (0.0222), parity (-0.0166), delivery type (0.0148), gestational age of the infant (-0.038), involvement in discharge planning (-0.1005), staying overnight in NICU (0.138), having an especially helpful nurse (-0.0617), number of days in NICU (0.0177), number of days in CCN (-0.0503), or number of days home (-0.0302). None of these correlations were significant at the 0.05 or higher level.

#### General Maternal Satisfaction

Seven of the mothers (14%) were neutral on satisfaction and 43 (86%) were very satisfied with the overall NICU discharge teaching (Table 1).

### Maternal Perceptions of Infant-Care Teaching

The reader is referred to Table 1 p. 36 for recall, need and satisfaction information, Table 2, p. 43 for information on practice and satisfaction, and Table 3, p. 45 for importance of teaching items.

#### Bathing Techniques

Of the 12 mothers who were not taught to bathe their baby, 8% actually needed the teaching. Thirty-eight mothers (76%) were taught to bathe their baby, but only 68% thought they needed the teaching. Of the 38 mothers who were taught, all had practiced bathing the baby, and 47% had practiced 10 or more times (see Table 2). Thirty-two mothers (84%) were very satisfied; 5% were not satisfied (see Table 2). Of the entire group, one mother (2%) thought this teaching was not important, 18% judged it somewhat important and 80% thought it was very important (see Table 3).

The comments of the mothers were enlightening. Four multiparas felt they needed help with bathing because, "A premie is different." "Premies are scary!" "I was afraid of hurting him." Suggestions ranged from making the teaching less stressful, to advising parents on bathing products for use after discharge.

#### Feeding Techniques

Thirty-six mothers were taught to tube-feed their infant, and 97% said this teaching was needed (see Table 1). All had practiced,

Table 2  
Parental Perceptions of Practice and Satisfaction

Discharge Teaching (n=50 unless specified)	Practice			Satisfaction		
	None	Once	Ten +	Not	Neutral	Very
Maternity Unit (n=33)				18%	27%	55%
Overnight in NICU (n=24)				13%	20%	67%
Mothers' Overall Satisfaction				0%	14%	86%
Fathers' Overall Satisfaction by Mother				3%	18%	79%
Fathers' Overall Satisfaction (n=15)				0%	7%	93%
Bathing baby	0%	13%	47%	5%	11%	84%
Feeding:						
Tube Feeding (n=36)	0%	6%	58%	6%	3%	91%
Breastfed Babies: (n=21)						
How to Breastfeed	14%	0%	57%	13%	24%	63%
Amt/Frequency	NA	NA	NA	0%	33%	67%
Pumping/Storing	25%	0%	0%	0%	45%	55%
Formula Supplement				0%	40%	60%
Bottlefed Babies: (n=29)						
How to Bottlefeed	0%	0%	92%	7%	22%	71%
Making Formula	100%	0%	0%	13%	12%	75%
Temperature:						
Use of Thermometer	6%	11%	43%	2%	19%	79%
Normal/Abnormal	20%	20%	0%	6%	5%	89%

Table 2--Continued

Discharge Teaching (n=50 unless specified)	Practice			Satisfaction		
	None	Once	Ten +	Not	Neutral	Very
Bulb syringe:						
How/When to Use	20%	17%	20%	0%	14%	86%
CPR/Safety:						
CPR Slide-Tape	NA	NA	NA	0%	8%	92%
CPR Demonstration	4%	77%	0%	0%	9%	91%
Car Seats	NA	NA	NA	0%	27%	73%
Poison Control	NA	NA	NA	0%	35%	65%
Comfort Measures:						
Swing/Rock/Bundle	0%	0%	67%	0%	26%	74%
Infant Stimulation/Play	0%	0%	100%	0%	33%	67%
Normal Growth/Development	NA	NA	NA	5%	48%	47%
Medications at Home: (n=18)						
Type/Reason	NA	NA	NA	0%	12%	88%
When/How to Give	33%	25%	8%	0%	12%	88%
Reactions/Side Effects	NA	NA	NA	0%	8%	92%
Apnea Monitor (n=24)	0%	33%	20%	4%	9%	87%
Follow-Up Care:						
Progress Clinic (n=42)	NA	NA	NA	17%	33%	50%
Pediatric Care	NA	NA	NA	0%	27%	73%
Eye Examination (n=37)	NA	NA	NA	7%	29%	64%
VNA Visit (n=15)	NA	NA	NA	0%	13%	87%
SIDS/Apnea Program (n=6)	NA	NA	NA	0%	33%	67%

Table 3  
Parental Perceptions of Importance

Discharge Teaching	Importance					
	Recall Group*			Entire Group**		
	Not	Somewhat	Very	Not	Somewhat	Very
Bathing baby	3%	18%	79%	2%	18%	80%
Feeding:						
Tube Feeding (n=36)	3%	0%	97%	2%	5%	93%
Breastfed Babies: (n=21)						
How to Breastfeed	0%	0%	100%	9%	5%	86%
Amt/Frequency	0%	0%	100%	13%	7%	80%
Pumping/Storing	9%	0%	91%	10%	9%	81%
Formula Supplements	40%	0%	60%	24%	14%	62%
Bottlefed Babies: (n=29)						
How to Bottlefeed	0%	21%	79%	0%	24%	76%
Making Formula	0%	12%	88%	14%	24%	62%
Temperature:						
Use of Thermometer	0%	12%	88%	0%	12%	88%
Normal/Abnormal	0%	9%	91%	0%	10%	90%
Bulb syringe:						
How/When to Use	3%	14%	83%	4%	22%	74%
CPR/Safety:						
CPR Slide-Tape	0%	0%	100%	0%	0%	100%
CPR Demonstration	0%	0%	100%	0%	0%	100%
Car Seats	9%	9%	82%	6%	22%	72%
Poison Control	6%	5%	89%	4%	16%	80%

Table 3—Continued

Discharge Teaching	Importance					
	Recall Group*			Entire Group**		
	Not	Somewhat	Very	Not	Somewhat	Very
Comfort Measures:						
Swing/Rock/Bundle	0%	16%	84%	4%	24%	72%
Infant Stimulation/Play	0%	12%	88%	2%	30%	68%
Normal Growth/Development	0%	10%	90%	4%	14%	82%
Medications at Home: (n=18)						
Type/Reason	0%	0%	100%	0%	0%	100%
When/How to Give	0%	0%	100%	0%	0%	100%
Reactions/Side Effects	0%	0%	100%	0%	6%	94%
Apnea Monitor (n=24)	0%	0%	100%	0%	0%	100%
Follow-Up Care:						
Progress Clinic (n=42)	0%	8%	92%	0%	5%	95%
Pediatric Care	2%	5%	93%	4%	6%	90%
Eye Examination (n=37)	0%	3%	97%	0%	5%	95%
P.H. Nurse Call (n= 14)	36%	21%	43%	NA	NA	NA
P.H. Nurse Visit (n= 21)	43%	28%	29%	NA	NA	NA
VNA Visit (n=15)	7%	6%	87%	NA	NA	NA
SIDS/Apnea Program (n=6)	0%	33%	67%	NA	NA	NA
OT/PT (n=2)	0%	0%	100%	NA	NA	NA
Respite Care (n=1)	100%	0%	0%	NA	NA	NA

\* Recall Group received teaching or referral

\*\*Entire Group contains subjects with and without teaching

and 58% had practiced ten or more times (see Table 2). Ninety-one percent of these were very satisfied with the teaching, 6% were not satisfied (see Table 1), although 93% thought it was very important (see Table 3). Of the 2 mothers who were not satisfied, 1 wanted more involvement in tube-feeding her infant, and the other was concerned about the lack of consistency in teaching about tube-feeding.

Of the 21 mothers who were breastfeeding their infant, 38% recalled being taught by NICU nurses to breastfeed, and 88% of these needed the teaching (see Table 1). Two others (10%) were not taught but thought they needed the teaching. One mother (13%) was not satisfied with the teaching; 63% were very satisfied. All 8 mothers (100%) who were taught, rated it very important (see Table 3). Eighteen (86%) of the 21 breastfeeding mothers rated this teaching as very important, 1 (5%) somewhat, 2 (9%) not important to care of the infant (see Table 3). Although 1 mother had not practiced breastfeeding prior to discharge, 50% of the mothers had practiced 10 or more times.

Fifty-three percent of the nursing mothers were taught by NICU nurses to pump and store their breastmilk. Eighty-two percent of these needed the teaching, 91% thought it was very important (see Table 3), and 55% were very satisfied with the teaching (see Table 1). Eighty-one percent of the 21 nursing mothers thought this teaching was very important for care of the infant, whereas 10% thought it was not important (see Table 3). Of the 29% who were taught amount and frequency of nursing, 19% needed the teaching.



Twenty-four percent of the nursing mothers who were not taught about this aspect, said they needed the information (see Table 1).

Twenty-four percent of the breastfeeding mothers were also taught to use formula supplements, and of these, 40% needed the teaching. One (6%) who didn't receive teaching, thought she needed it. Sixty-two percent of the 21 breastfeeding mothers believed it was very important, whereas 24% said it was not important to teach about formula supplementation (see Table 3).

The area of breastfeeding caused problems for several mothers. They wanted more privacy with breastfeeding, and additional help with the breastfeeding procedure, especially for weak infants. Several mothers had planned to breastfeed, but were not given this option with the sick infant. One was put on an antilactation drug without her agreement.

Even mothers who had successfully nursed before, encountered difficulties with the premature or sick infant. They needed clearer directions on when and how to begin nursing the recovering infant. Their frustrations were expressed vividly by their statements: "You take for granted it will work." "Breastfeeding is the hardest part of all!" "I finally gave up because of his poor suck."

Twenty-nine mothers were bottlefeeding their infant. NICU nurses had taught this procedure to 14 (48%) of this group; however, only 50% of these needed the teaching (see Table 1). All had practiced at least twice prior to discharge and 92% had practiced ten or more times (see Table 2). One mother (7%) was not satisfied, and 71% were very satisfied with the teaching. Twenty-four percent

of the mothers viewed the teaching of bottlefeeding as somewhat important and 76% judged it very important (see Table 3).

Twenty-eight percent of the nursing mothers were also taught to prepare infant formula; however, only 25% of these needed the teaching (see Table 1). Four percent of those not taught, thought they needed the information. Sixty-two percent of the mothers thought formula preparation was very important; 14% viewed it as not important. Seventy-five percent were very satisfied with formula preparation teaching; 13% were not satisfied (see Table 2). None of the nursing mothers had practiced formula preparation prior to discharge.

#### Thermometer Use

Of the 43 mothers (86%) who were taught to take axillary temperatures, 53% needed the teaching (see Table 1). Twenty-nine percent of those not taught, actually thought they needed the teaching. Two had never practiced and 35% had practiced ten or more times (see Table 2). Seventy-nine percent were very satisfied, and one (2%) was not satisfied. The latter mother said she needed additional help with reading a mercury thermometer. One mother was using a digital thermometer at home, and thought teaching should be included for it. Eighty-eight percent of the entire group thought it was very important and no one judged it not important. Three mothers cautioned nurses to make certain parents were actually reading the thermometer correctly.

Seventy percent of the mothers were taught to judge abnormal

versus normal temperatures. Sixty-six percent of these mothers needed the teaching, 89% were very satisfied and 6% were not satisfied with the teaching. Seventy-three percent of those not taught, thought they needed the information. Ninety percent of the mothers viewed this teaching as very important (see Table 3). No one practiced this skill. Three mothers suggested giving a pamphlet with abnormal temperatures and appropriate parental action.

#### Bulb Syringe Use

Seventy percent of the mothers were taught to use the bulb syringe, but only 63% of these needed the teaching (see Table 1). Twenty percent of those who were not taught, needed the teaching. Seventeen percent had never practiced, whereas 17% had practiced ten or more times prior to discharge. Fourteen percent were neutral and 86% were very satisfied with the teaching (see Table 1). Of the entire group, 74% judged it very important; 4% thought it was not important.

#### CPR Instruction

Forty-nine mothers saw the infant cardiopulmonary resuscitation (CPR) slide tape and 86% of those who recalled the teaching also needed it (see Table 1). Ninety-six percent had seen the demonstration on a resusci-baby model, 92% of those taught, said they needed the demonstration, and 96% had practiced CPR on the mannequin. Both mothers who had not practiced on the doll stated they were already well-prepared in CPR use.

Ninety-two percent of the mothers were very satisfied with the CPR slide-tape, 91% with the demonstration, and all mothers said the CPR tape and demonstration were very important to care for the infant at home. The teaching had been used in two cases where the infant was successfully resuscitated by the parents at home. The mothers who were neutral in satisfaction with the teaching had experienced problems in locating a CPR teacher at a time convenient for the family.

Comments on improving the CPR teaching included giving the teaching earlier in the hospital stay, allowing more time for questions, practicing until the parents are confident, offering a yearly refresher course, and requiring CPR for all parents of newborn infants. Two mothers suggested making the CPR practice more realistic by stressing the seriousness, and using a more life-like mannequin plus a working telephone.

#### Car Seats

Twenty-two percent of the mothers had been taught about car seats; only 9% needed the teaching (see Table 1). Twenty-eight percent of those who were not taught, expressed a need for this information. Twenty-seven percent were neutral and 73% were very satisfied with the teaching. When all parents were asked about this item, 6% viewed it as not important, and 72% thought it was very important (see Table 3). Parents thought this teaching could be improved by special advice on positioning the small infant and using the car seat with an apnea monitor.

### Poison Control

Thirty-five percent of the mothers recalled being taught about poison control in the home, and 24% of these needed the teaching (see Table 1). Forty-two percent of those who were not taught, thought they needed the teaching. Sixty-five percent were very satisfied with the teaching. Only 4% of the mothers believed this teaching was not important, whereas 80% of the entire group, viewed it as very important (see Table 3). One mother who thought it was not important, commented that the teaching was inappropriate for NICU nurses as too much time would elapse prior to use of the information. Mothers frequently commented that they had received written information on poison-control, and those who had not requested such information.

### Infant Comforting Measures

Thirty-one mothers (63%) recalled teaching on infant comforting measures, and 58% of these needed the teaching (see Table 1). Twenty-eight percent of those who did not receive the teaching needed it. Sixty-seven percent had practiced ten or more times, and 74% were very satisfied with the teaching (see Table 2). When all were asked, 2 mothers (4%) thought such teaching was not important, and 72% viewed it as very important (see Table 3). Several parents commented that the slide-tape "Prematurely Yours" had been very helpful with this teaching, and suggested showing it earlier in the hospitalization. One mother urged the nurses to advise parents of

small infants to use a beanbag pillow for improving the infant's comfort and rest.

#### Infant Stimulation and Play

Forty-nine percent of the mothers recalled, but only 54% believed they needed the teaching on infant stimulation and play (see Table 1). Thirty-two percent of those who did not receive the teaching, needed it. Thirty-three percent were neutral; 67% were very satisfied with the teaching (see Table 1). When all were asked about importance, one mother (2%) felt such teaching was not important, whereas 68% viewed it as very important (see Table 3). Two parents were very satisfied with the individualized teaching done by the occupational and physical therapists. One mother suggested a group session for this teaching and another thought the babies needed more play time incorporated into their care.

#### Growth and Development

Thirty-eight percent of the mothers had received teaching on growth and development, and 63% said they needed this teaching. Forty-two percent of those who didn't receive it, actually needed the teaching (see Table 1). One (5%) was not satisfied, but 47% were very satisfied. When all were asked, 4% judged growth and development teaching as not important and 82% said it was very important (see Table 3). One mother, who said it was not important, thought that it was more appropriate for the pediatrician to include this teaching with well-child care. Five mothers wanted a special

book or newsletter on premature development.

#### Medication Administration

Eighteen infants were taking medications at home and 84% of their mothers had received teaching on the type of medication, reason for medication, and how and when to give the medication (see Table 1). All the mothers who were taught, thought they needed the teaching. Of these mothers, 33% had not practiced, but 8% had practiced ten or more times. Eighty-eight percent were very satisfied with the teaching.

Sixty-eight percent recalled teaching on the medication's side effects or problems and all needed this teaching. Ninety-two percent were very satisfied with the teaching on side effects or problems, and 94% viewed the teaching as very important. Of the group that did not recall the teaching on side effects or problems, 67% thought they needed the information. Thirty-three percent of the mothers had not practiced giving medications prior to discharge, but 3 of these were still very satisfied with the teaching.

Their suggestions for improvement included using informational handouts for each medication, contacting the pharmacy in advance to make certain the medication is available, and emphasizing side effects and dangers of overdose. Two parents stated they needed more complete teaching at the time of discharge, as they had not understood basic principles such as 1 cc = 1 ml.

### Apnea Monitor Teaching

Twenty-three mothers needed and had received apnea monitor teaching. One who didn't receive the teaching, needed it. All had practiced and 20% had practiced ten or more times. Eighty-seven percent were very satisfied and only one (4%) was not satisfied, as the teaching could not be arranged at a convenient time for the family. All of the mothers with infants using a home monitor, thought the teaching was very important.

### Follow-Up Services

#### Progress Clinic

Sixty percent of those mothers whose infant would be returning to the Progress Clinic, were given information on the Clinic and all thought they needed the teaching. Forty-one percent of those who didn't receive the teaching, thought they needed it. Fifty percent of the 25 who received teaching were very satisfied, whereas 17% were not satisfied. Ninety-five percent of the mothers who received the teaching thought this teaching was very important. Many mothers were not clear as to whether their infant would be returning to the Progress Clinic and several suggested a booklet on the service.

#### Pediatric Follow-Up

Eighty-two percent of the mothers had been given information on pediatric follow-up, but only 63% needed the teaching. Seventy-three percent were very satisfied and 90% believed that it was very



important to include this teaching. A few parents had not been prepared for the transition to private pediatric care and one mother said discharge made her feel as if she were, "put out in the cold."

#### Eye Examinations

Sixty-six percent of the mothers were given information on infant follow-up eye examinations and 97% of these needed the teaching. Forty-four percent of those who did not recall the teaching, believed they needed it. Sixty-four percent of the mothers were very satisfied; whereas 7% were not satisfied. Ninety-seven percent of the mothers who received the teaching, thought the information on eye examinations was very important to care of the infant. The reason for the eye examination was unclear to many mothers, even those expressing a high degree of satisfaction with the teaching.

#### Discharge Procedure

Four mothers (8%) had problems with the discharge procedure itself. They thought that the discharge process seemed hectic with extensive teaching being done at the last minute, when the nurses seemed rushed and unsure of information. For these four mothers, there appeared to be little coordination between the physician writing the discharge and the nurses doing the discharge. One of the four, a multipara who was generally very satisfied with the teaching, stated she needed more advanced notice of discharge in order to be prepared for the infant at home.

## Discharge Referrals

### Agency Home Visits

Fourteen mothers (28%) had received calls from and 21 (42%) had been visited by their county Public Health Nurse. Five (36%) of these judged the phone call not important; whereas 6 (43%) judged it very important (see Table 3). Nine mothers (43%) viewed the visit as not important, whereas 6 (29%) viewed the home visit as very important. Two wanted, but did not receive a Public Health Nurse visit. One of these had been charted as refusing the referral. The Public Health Nurse referrals caused confusion for some mothers due to incorrect expectations. These mothers were disappointed in the lack of hands-on nursing care and the nurse's inability to answer questions related to the high-risk infant.

There were 15 Visiting Nurse Association (VNA) referrals with 13 mothers (87%) being very satisfied (see Table 2) and judging the visit as very important (see Table 3). Two mothers were neutral and one of these thought the VNA nurse needed more information on her infant's specific problems.

### Other Referrals

Six mothers stated they were involved in the SIDS (Sudden Infant Death Syndrome)/APNEA Support Group. Four of these were very satisfied and thought it was very important to care. Two mothers had occupational/physical therapy referrals and both viewed these as very important. The one mother who had a referral to Respite Care,

was not satisfied with the service as they had no help available for her.

#### Special Parental Concerns

Four families expressed concerns about the rotation of nurses, the use of orientees and float nurses, and periods of short staffing. Two sets of parents stated they had actually stayed an entire shift until a nurse they trusted could care for their infant. These parents commented on a lack of communication between the regular nursing staff and the float or orientee nurse, leaving her unfamiliar with the infant's special care. The parents who were concerned about occasional short staffing, especially on the 11-7 shift, expressed the belief that even very conscientious nurses could not give comprehensive care under such conditions. Two sets of parents said they lost trust in a few nurses who appeared to turn off or ignore cardio-respiratory and oxygen monitors.

Three other parents were concerned with a lack of consistent teaching and thought that the nurses were contradicting each other. This caused parents to lose confidence in the teaching as they wanted to "Do everything the right way." All parents who made critical comments emphasized that they represented exceptions to the generally excellent care their infant had received in NICU.

#### Major Problems Since Discharge

Although 9 (18%) of the mothers denied problems, 41 mothers (82%) had experienced problems since discharge. These included

specific infant health problems (20%), difficulty with feeding or G.I.tract (20%), crying or colic (18%), stress or lack of a predictable infant schedule (14%), real or false apnea alarms (12%), parental lack of sleep (10%), sibling adjustment (4%), and problems with follow-up care and referrals (2%).

#### Additional Teaching Needed

Several mothers had suggestions for maternity nurses on ways to improve care. Three mothers wanted more teaching about the infant's condition and appearance, and 1 asked for explanation of the mother's role in the infant's problems. Seven suggested use of videotapes about the premature/high-risk infant. Three suggested having maternity nurses accompany mothers on the first visit to NICU. Eight needed more teaching on breastfeeding, use of breast pumps, and the correct use of Syntocinon. One mother recommended that the study hospital do more outreach education for maternity nurses on premature infant care. Two mothers commented on the severity of postpartum blues and depression, and the need for anticipatory guidance on coping with post-discharge stress. Two wanted more teaching about self-care and 2 asked for more active comfort and not to be left alone. Two suggested watching closed-circuit programs on normal infant care, but another warned that such teaching would be too stressful when the future of the infant was uncertain.

The mothers had a variety of suggestions on ways the NICU nurses could help during the hospitalization and in preparation for

discharge. Suggestions centering around the NICU unit were: a parent-support group, special activities and sitters for siblings, booklets for the grandparents and extended family, no restrictions on visiting during shift change, clearer and better enforced policies on visitation. One couple suggested making a special effort to introduce the parents to the neonatologists. One mother suggested a special group to hold and comfort those infants whose parents can't visit frequently. Many mothers appreciated the snapshots of the infant, but two mothers wanted more information on baby photographs prior to or following discharge.

There were several ideas for improving family support such as teaching nurses to be more comfortable with parents, having open discussions with other parents when neonatal deaths have occurred, and using more pictures and discussion of fully-recovered infants. Many mothers wanted more referrals, a list of specific referrals and their services, plus a follow-up on the effectiveness of those referrals.

Many comments centered around anticipatory teaching to prevent the problems arising from normal infant care: methods for calming a crying baby, promoting sleep, solving breastfeeding/bottlefeeding problems, types of formula, relieving spitting-up, cleaning bottles, starting solids, normal stools, taking the baby out, and care of the nails and ears.

Mothers would like advice on immunizations, giving medications, safe home remedies for minor problems like nasal congestion, rashes and constipation, plus guidelines on when and whom to call for more

serious problems.

There was a desire for more information on infant stimulation and growth and development, such as a monthly flyer on the premature infant and altered development. Those parents whose infants had congenital anomalies or genetic defects suggested more written information on the problems and ways parents could cope.

Two parents described major problems with sibling adjustment and would have liked anticipatory guidance on preventing and managing these. Several other parents commented on sibling problems but did not consider them major problems. Several of the 18 mothers (36%) who were employed, wanted guidance on returning to work and making appropriate plans for the infant during work.

#### Major Source of Post-Discharge Information

When asked who or what had been their major source of information on baby care since discharge, 34% of the mothers cited their pediatrician, 18% relied on family members, 16% had called NICU, 14% used a nurse (Public Health Nurse, Visiting Nurse and Pediatric Nurse Practitioner), 6% used a baby-care book, and 4% called friends. Eight percent of the mothers said they had not needed any help since the infant's discharge.

#### Paternal Perceptions of Discharge Teaching

When the 35 mothers interviewed without the infant's father, were asked to judge the father's involvement in discharge teaching, 17% were rated as not involved, 23% were somewhat involved and 60%

were viewed as being very involved. Of the 29 fathers who were involved, 3% were judged not satisfied, and 79% were judged very satisfied with the NICU discharge teaching. According to his wife, the father judged "not satisfied" had been forced into involvement in infant care before he was ready and still felt resentment.

Fifteen fathers (30%) had made a special effort to participate in the interview, usually at their own insistence. Of the 15 fathers who gave their own perceptions, 5 (33%) were somewhat involved and 10 (67%) very involved in the discharge teaching. One of the 15 was neutral, whereas 14 (93%) were very satisfied with the teaching received. Thus 84% of all fathers who were involved in discharge teaching were very satisfied with the teaching.

Correlations of the 15 father's actual responses with the infant's mother's responses were highly positive, ranging from a low of 0.40825 for desire to attend baby-care classes, to 1.000 for need for CPR demonstration. Their suggestions were to assess the father's needs and desired information separately from the mother's, and to repeat the teaching for fathers who cannot accompany the mother.

## CHAPTER V

### DISCUSSION AND CONCLUSIONS

The purpose of the research study was to determine parental perceptions of Neonatal Intensive Care Unit (NICU) discharge teaching. Five research questions guided the collection and analysis of information. These questions are: 1. Were the parents involved in planning their own NICU discharge teaching? 2. Were the parents' needs correctly assessed? 3. Were the parents satisfied with the NICU discharge teaching? 4. Did the parents perceive the NICU discharge teaching as being important to their care of the infant? 5. Did the NICU discharge teaching include the essential areas needed for care of the infant following discharge?

#### Subject Backgrounds

Infants in the sample included 72% premature and 28% full-term infants with a variety of high-risk neonatal diagnoses. Hospital stays averaged 41 days (range of 6-255) and 72% of the infants had post-discharge problems.

The sample of 50 mothers consisted of 82% married, 86% Caucasian and 42% primiparous women. The mean age of the mothers was 27 with a range of 18 to 42 years. Fifty-two percent had delivered by cesarean section and 48% had vaginal deliveries. Thirty-three percent had experienced serious pregnancy-related



health problems. There were 1-5 other children in the families of the multiparas, with an age range of 1 to 19 years.

Approximately one-third of the primiparas and multiparas had attended prenatal classes. The major reason given by the primiparas for not attending was premature delivery of the infant.

Only 29% of the primiparas and 21% of the multiparas had attended a baby-care class. Forty-eight percent of the primiparas and 35% of the multiparas would like to have taken such a class. Although the multiparous mothers had infant-care experience from previous children, 76% of all the mothers had no formal infant-care teaching prior to that given by NICU staff nurses. None had experience with previous children discharged from a neonatal intensive care unit.

#### Parental Involvement

The first research question was: Were the parents involved in planning their own NICU discharge teaching? In order to answer this question it was necessary to consider the amount of time the parents were present in the nursery, the relationship with the nurses, and the parents' perceptions of involvement.

Mothers in this study visited their infants frequently, with 84% visiting once to several times daily, and 14% visiting 3 times per week. Since the infants were hospitalized from 6 to 255 days and families traveled as far as 175 miles round-trip to the hospital, the visits represented an extensive investment in time, money and personal energy. The frequent visits should have provided

ample time for parental involvement in planning, to facilitate assessment and teaching to build the dependent-care agency.

There was a great deal of parental gratitude expressed toward the staff and a positive relationship was built in a majority of cases. In fact, 74% of the mothers recalled one especially helpful NICU nurse. This special nurse-parent relationship should facilitate the involvement of parents in the planning process and serve as a strong foundation for parental needs assessment and education.

The interest of the parents and their willingness to be involved is further documented by the high percentage of parents (48%) who had stayed overnight in NICU. In fact forty-two percent of the mothers who did not stay, would like to have had the opportunity. The satisfaction with the overnight stay was high (67%), and 54% of the mothers thought the opportunity to stay should be available to all parents. In spite of this some parents from all levels of satisfaction described problems of unclear expectations, and inappropriate timing of teaching. Involvement of the parents in planning this experience could clarify expectations and facilitate appropriate teaching.

Although the fathers' views on involvement in planning were not determined, their involvement in teaching was examined. In the view of the mothers, 60% of the fathers were very involved with the teaching. All the fathers who were actually interviewed, judged themselves either somewhat (33%) or very (67%) involved with the teaching. This is a reflection of their interest and availability

for involvement in the planning phase as well. Surprisingly, only 30% of the mothers said they had been very involved, and 38% were not involved in planning their discharge teaching.

In answer to the first research question the parents visited frequently, and had positive relationships with the nurses, but did not perceive themselves as being very involved in the planning process. Parents should be given opportunities for involvement in planning their discharge teaching and the success of such involvement should be evaluated periodically.

#### Perceptions of Need

The second research question was: Were the parents' needs correctly assessed? At the time of delivery many mothers had a deficit in formal infant-care education. Seventy-six percent of the mothers had not taken a baby-care class, and 40% of these would like to have had such a class. This shows a parental recognition of need and a possible deficiency in some areas of community prenatal education. From the comments of the multiparas, it is apparent that having previous children does not produce a complete dependent-care agency for parents of high-risk infants. The factors of maternal age, marital status, parity, attending prenatal classes and involvement in discharge planning were not highly correlated with parental need for teaching. Those fathers who were interviewed had need scores that were highly positively correlated with those of the mothers. Since there are no obvious factors to indicate need, all parents should be carefully assessed for dependent-care deficits and

need for discharge education.

As Table 1 indicates, not all areas of discharge teaching were implemented for all mothers. In some cases, the teaching was performed when the mothers thought it was not needed, (they perceived no dependent-care deficit). Teaching about areas where no dependent-care deficit exists implies a less than optimal use of the nurses' and parents' time.

In other cases, according to the mothers, the teaching was omitted although the mothers perceived a deficit in dependent-care information. Failure to assess and meet this deficit could have more serious consequences than the duplication of teaching. It is possible that the deficit was recognized and that teaching was actually conducted, but factors such as high stress levels interfered with the educational process.

Problems of duplication and omission could be addressed by increased parental involvement in planning plus improved assessment of need. One method for facilitating the assessment process is the use of a parental checklist of discharge teaching categories plus open-ended questions for additional needs. A second alternative is a nurse-parent interview to identify needs and preferred method of learning.

In conclusion, the answer to the second research question is that parents' needs were not correctly assessed in all cases. This could be addressed by greater involvement of parents in the planning phase plus improved assessment of dependent-care agency deficits.

### Perceptions of Satisfaction With Teaching

Sixty-six percent of the mothers had been hospitalized on the maternity unit of the study hospital, and 55% were very satisfied with the teaching they received. In this unit, infant-care teaching is usually omitted for mothers of NICU infants, with the understanding that it will be conducted at an appropriate time by NICU nurses. Indeed this was the case as 58% of these subjects stated that the maternity unit teaching had not included any baby care. Two mothers recommended the baby-care programs on closed-circuit television; however, another warned that normal baby-care education could be too stressful for parents of sick infants. Mothers at all levels of satisfaction expressed a need for more education about premature birth, the infant's condition, breastfeeding, plus additional emotional support while adjusting to the NICU.

The third research question was: Were the parents satisfied with the NICU discharge teaching? Maternal satisfaction with NICU discharge teaching did not show statistically significant correlations with age, parity, marital status, delivery type, gestational age of the infant, involvement in discharge planning, overnight stay satisfaction, presence of a helpful nurse, number of days in NICU, CCN, or at home.

Eighty-four percent of the fathers and 86% of the mothers were very satisfied with the overall NICU discharge teaching. Fourteen percent of the mothers and 12% of the fathers were neutral, and only 1 father was viewed as not satisfied. A statistically significant

positive correlation was found between overall satisfaction and the mean satisfaction of individual teaching items.

There were a few problems with lack of consistency in teaching; however, this may be decreased by encouraging flexibility while emphasizing the basic principles of a procedure. In answer to the third research question, the parents were generally very satisfied with the NICU discharge teaching.

#### Perceptions of Importance to Infant Care

The fourth research question was: Did the parents perceive the NICU discharge teaching as being important to their care of the infant? These parents may be considered infant-care experts, as they are actually involved in the day-to-day home care of the infants. If the discharge teaching has been successful in assisting these parents, it should be viewed as important to the home care of the infants.

When judged by the group of parents that received the teaching, there was generally a close agreement on importance of individual items. Over ninety percent of the groups recalling teaching on tube feeding, breastfeeding, normal/abnormal temperatures, CPR, growth and development, medications, and apnea monitoring judged these areas as very important. The teaching of bathing, pumping/storing breastmilk, bottlefeeding, making formula, thermometer use, bulb syringe, car seats, poison control, comfort measures, infant stimulation and play were rated very important by 75% to 89% of the mothers. The only area rated as not important by over 10% of the

recall group was education on formula supplementation for nursing mothers.

There were only slight variations when the entire parent group was examined. When all parents were asked to judge importance, over 90% of the mothers thought teaching about tube feeding, normal/abnormal temperatures, CPR, and medications was very important. Over 75% of the entire group viewed teaching about bathing, breastfeeding, pumping/storing breastmilk, bottlefeeding, thermometer use, poison control, growth and development as very important. Formula supplementation for nursing mothers, making formula for bottlefeeding mothers, bulb syringe use, car seats, infant stimulation and play were rated as very important by between 62% to 74% of the mothers. For the entire group of parents, the teaching items ranking lowest in importance were formula supplements for nursing mothers and making formula for bottlefeeding mothers.

The teaching about Neonatal Progress Clinic, pediatric care, and eye examinations was rated very important by 90% or more of the groups recalling the teaching. Of the actual referrals, mothers judged the Public Health Nurse's call very important in 43% of the cases, and her visit as very important in 29% of the cases. Home visits by the Visiting Nurses were rated very important by 87% of the mothers. Only a small group of mothers had received the services of the SIDS/Apnea Group, OT/PT, or Respite Care. All mothers rated the OT/PT referral as very important, whereas 67% rated the SIDS/Apnea Group as very important. Respite Care had not been able to offer any assistance to the mother who had been

referred.

In answer to the fourth research question, the parents viewed all the discharge teaching as important to their care of the infant.

#### Adequacy of Discharge Teaching

The last research question was: Did the NICU discharge teaching include the essential areas needed for care of the infant following discharge? As the tables and comments indicate, there are some areas of teaching that need modification and other areas of teaching that should be added.

The nursing mothers had many problems and needed early teaching by maternity nurses plus special assistance from NICU nurses. In the immediate postpartum phase, the nurse is needed as a patient advocate for the nursing mother to make certain that she understands her options regarding antilactation agents. Additional teaching on the use of breast pumps and syntocinon is needed during the period when the infant is unable to tolerate nursing.

The actual process of breastfeeding premature infants and infants with feeding difficulties requires extensive teaching, support and appropriate privacy. Perhaps the services of a lactation consultant or the support of nurses who are especially interested in assisting nursing mothers would solve the major problems. A referral to maternal support groups such as La Leche League would help with post-discharge problems.

The parents' ability to read a thermometer should be carefully assessed, and the type of thermometer available in the home should



be discussed. Instructions plus the use of a pamphlet on normal/abnormal temperatures and appropriate actions would be helpful for parents.

CPR teaching was conducted for most of the parents, and this training had been instrumental in saving the lives of two infants following discharge. The few parents who were neutral on satisfaction with the CPR teaching, complained of problems in arranging a convenient time for the teaching. Parental suggestions for improving the CPR teaching included more time for questions, more practice, making the practice more realistic by increasing the stress, using more lifelike models and incorporating props such as a working telephone. The suggestions of requiring CPR training for all parents and offering yearly refresher courses, are interesting ones, worthy of consideration by nurses.

NICU nurses should give special car-seat instructions and demonstrations for the parents of small, weak or disabled infants. For infants requiring an apnea monitor, additional teaching on the use of the device with a car seat should be included.

Instruction on growth and development needs additional emphasis, as the satisfaction level was relatively low and a large percentage of those who were not taught, thought they needed the information. This was a major problem for several families following discharge, and could be addressed by written material, material mailed to the home at appropriate intervals, videos or group classes. Infant stimulation and play could also be taught through group classes as well as role modeling by nurses.

The area of infant comfort should have more emphasis as it was a major problem for many families following discharge. More teaching, role modeling, and pamphlets could help to prevent this as a major post-discharge family problem.

Although all of the mothers receiving teaching on medication administration needed the teaching, three-fourths of those who did not receive the teaching thought they needed it also. Mothers wanted more teaching, or written explanations of their infant's specific medications, side effects and signs of overdose. The concerns of two families about their initial inability to understand the measurements for the medication, support a need for more thorough evaluation of teaching. Another area of safety, that of poison control, produced a somewhat lower overall satisfaction, but was thought to be very important by 80% of the mothers. Poison control teaching could be included with education on medication administration for all infants.

There was a deficit in understanding of the purpose and services of Neonatal Progress Clinic. Possible reasons for this are the nurses' lack of knowledge plus uncertainty on which infants will be returning for follow-up care. Inservice programs for nurses plus the use of a discharge pamphlet on Progress Clinic are possible solutions. The rationale for eye examinations caused some parental confusion that could be clarified with a pamphlet or additional teaching.

The only mother who was not satisfied with apnea monitor teaching, stated that the teaching was done too rapidly and without

time for parental questions. Although this problem occurred only once, the critical nature of the material justifies careful planning and thorough evaluation of satisfaction.

#### Post-Discharge Problems and Sources of Help

Eighty-two percent of the parents had experienced problems following discharge of the infant from NICU. These problems involved the infants' health, feeding and G.I. tract, crying and colic, stress and the lack of a predictable schedule, real/false apnea alarms, lack of sleep, sibling adjustment and follow-up care.

The mothers experiencing problems suggested anticipatory teaching about basic baby care such as calming a crying/colicky baby; promoting sleep; solving feeding, spitting-up, and stool problems; types of formula; cleaning bottles; starting solids; taking the baby out; caring for the nails and ears; and promoting normal growth and development. In the area of infant-health, mothers want information on immunizations, safe home remedies, giving medications, guidelines on when and whom to call for serious problems, and additional help with infants suffering from congenital/genetic problems.

There is a documented need for anticipatory teaching about sibling preparation, sibling management, and methods to help the family adjust to the unpredictable schedule of a newly discharged NICU infant. For mothers returning to work, anticipatory guidance on planning would be particularly helpful.

With the exception of a few mothers who said they needed no help (8%), the mothers had located a source of post-discharge

infant-care information. Thirty-four percent cited their pediatrician, 18% used family members, 16% called NICU, 14% consulted a community-based nurse, 6% used a baby-care book, and 4% asked friends.

In answer to the final research question, the discharge teaching includes most but not all of the essential areas needed for care of the infant following discharge. The mothers in this study had many of the same needs for anticipatory guidance as mothers of normal infants, and would benefit from additional teaching on basic baby-care, family adjustment and problem solving.

It is recognized that busy NICU nurses need to prioritize their teaching and may not have sufficient time for all aspects of anticipatory education. In that event, alternative methods could be used to assist parents. For example, all infants will have pediatric care following discharge, and the pediatrician or pediatric nurse is a good source of information on basic problems. Visiting Nurses and Public Health Nurses visit many of these families after discharge, and they should be able to assist with the major basic infant-care questions. Pamphlets could be given; however, they may have to be redesigned to use more graphic illustrations and fewer elaborate explanations. Videos on basic-baby care could be viewed as discharge time approaches. A post-discharge source of basic information, such as Bronson Hospital's Health Answers could also be suggested.

### Limitations of the Study

Some components of the parent population, such as single parents, adolescent parents and those with racial or cultural variations are not well represented by this sample. Furthermore, information on the fathers' actual perceptions is represented by less than one-third of the fathers, with the mothers giving their perceptions of the others. The fathers were interviewed jointly with the mothers, and it is possible that their answers were influenced by the mothers' views. Although the interview method had many advantages, it may have inhibited some parents from verbalizing dissatisfaction.

The gratitude expressed by the parents for survival of their infants, along with the high esteem for the staff, may have influenced their opinions positively toward all NICU nursing care. In fact the high level of satisfaction may not be as much an evaluation of the teaching, as a reflection of the positive nurse-parent relationship.

### Recommendations for Future Studies

Future studies should determine the reasons for the parents' lack of involvement in discharge planning and explore ways to increase this involvement. Subsequent studies should also determine the needs of special groups such as single parents, adolescent parents, and those parents with racial and cultural variations. The unique needs of fathers should be studied, along with the fathers' views of the ideal ways to teach the male parent. Perhaps fathers

would benefit from modifications such as teaching sessions separate from those of the mother. Their learning may also be facilitated by male role models demonstrating infant-care and parenting.

It would be useful to study the special needs of siblings during the long, stressful period of hospitalization and the initial post-discharge period. The effect of family structure, family stress, and the existence of support systems should also be explored.

To obtain candid comments from those parents who might have been inhibited by the personal interview, a confidential questionnaire could be mailed following the interview. Future studies should examine the demographic background of those eligible parents electing not to participate, in order to determine whether they are adequately represented by the study sample. Perhaps those parents have unique needs that contributed to their refusal to participate.

The effects of timing, teaching method, and stress on satisfaction should be considered in future studies. The relationship between the high satisfaction with discharge teaching and the close nurse-parent relationship needs further exploration. Studies to separate these two factors would be useful in order to determine whether satisfaction is truly a measure of the success of discharge teaching, or a covariant with the nurse-parent relationship.

### Nursing Implications

Orem's self-care deficit theory of nursing was found to be a useful conceptual framework for examining parental perceptions of NICU discharge teaching. Using this theory the nurse would assess for deficits in the parental dependent-care agency and involve the parents in setting goals and planning the educational process to correct the deficits.

Mothers' suggestions for improvement of Maternity Unit teaching are to give more emotional support, show appropriate slide/tapes on the infant, discuss the infant's problems and where appropriate, assist with preparation for breastfeeding. It is important to get mothers to NICU as rapidly as is feasible considering their health problems. When possible the maternity nurse should accompany the mother for the first NICU visit. It would be helpful for maternity nurses to assess these mothers for understanding of the infant's problems and for their specific expectations and teaching needs. Thus the dependent-care agency assessment could be started by the maternity nurses and shared with the NICU nurses as a basis for a common care plan to meet family needs.

The mothers in this study were found to have little formal infant-care teaching at the time of their delivery. Even the multiparas expressed a need for teaching due to the special requirements of the high-risk infant. An accurate assessment of parental knowledge would prevent unnecessary teaching, but assure education for those with a deficit. Surprisingly the mothers in this study were not so involved in discharge planning as expected.

This low involvement may be reflected in both the group who recalled but did not need the teaching, as well as in the group that needed, but did not receive information.

The frequent parental visits, plus the special nurse-parent relationship constitute an excellent basis for family involvement in assessment, goal-setting, planning, teaching and evaluation. An increase in involvement could be facilitated by offering more opportunities, encouraging involvement and seeking feedback from the parents on current educational needs, requests and satisfaction.

An assessment of the dependent-care agency could be facilitated by a simple check-list of baby-care information and tasks. The parents could check unfamiliar items or areas needing review. An alternative method is a brief nurse-parent interview to determine the level of understanding and mutually identify areas of need. Using either of these techniques, goals, methods and timing for the teaching could be jointly determined. This could assure the nurses that the mothers who needed the information were being identified and save busy nurses and parents from using valuable time on unnecessary information.

Since there are many effective teaching strategies, such as role modeling, demonstrations, booklets, audiovisual materials, and group or individual teaching, the parents could be given a choice and encouraged to select their preferences. This may require purchase or development of new materials, as well as education of nurses on the use of new teaching tools and methods.

The mothers generally thought that all areas were important to



care of the infant at home, thus no areas of teaching currently listed on the Discharge Referral/Parent Education Sheet need to be eliminated. There are some areas that need modification and other areas that could be added. Parental distress caused by a lack of consistency in teaching might be solved by an emphasis on rationale instead of method.

Nursing mothers need additional help with breastfeeding, pumping and storing their milk and anticipatory guidance on getting the weak infant to nurse. Some teaching areas of lower satisfaction, such as modified growth and development, eye examinations, and Progress Clinic services will require additional elaboration or written information for nearly all parents. Having videos, books or a series of pamphlets on the altered growth and development of the premature or sick infant would be helpful. Information could be sent periodically to the home, along with suggested sources of community support and assistance for problems.

Many areas of basic baby care could be added or expanded to handle the problems experienced by most parents of newborn infants. It is recognized that busy NICU nurses may have to find alternative sources of information for parents, if time for teaching is not available. The areas of basic baby care could be taught through specially-designed pamphlets and videotapes. Many areas of baby care could be taught by the Visiting Nurse, the Public Health Nurse and by nurses in the pediatric office following discharge. The selection of methods should be based on the parents' reading level, life style and preference.

The emotional support of the family should be reinforced and supplemented. The NICU staff could encourage the development of an active parent-support group or compile a list of parent-volunteers to supply advice and encouragement. Booklets and articles for grandparents and other members of the extended family could describe their important role and suggest ways to assist the parents both during and after hospitalization. Articles and support groups are available for parents of infants with special congenital or genetic problems, but the effectiveness of these should be assessed.

Siblings are obviously affected by the hospitalization, and its accompanying demands on parents' time and energy. At the very least, these children's needs should be included in planning for family care. Nurses should encourage parents to bring a family member or friend to entertain the siblings when their short interest-span has been exhausted. It is obviously beyond the scope of nursing practice to babysit with the siblings, but nursing care could include education of parents about appropriate expectations, as well as anticipatory teaching on sibling problems.

Eighty-two percent of the mothers had experienced problems following discharge. More anticipatory teaching on potential home problems, particularly in the area of family adjustment to the new infant would be a useful addition to the dependent-care agency. Parents need methods and resources to handle the infant's crying, feeding problems, minor health problems, sibling adjustment and an unpredictable schedule. Making certain the parents have a reliable and accessible source of post-discharge baby-care information could

help with resolution of problems.

Those parents for whom referrals were made, should receive a list of services to be expected, and the appropriate person to contact if problems are encountered. NICU nurses also need feedback on the effectiveness of their referrals. This could be done through a simple follow-up questionnaire to determine parental satisfaction and suggestions for modification of services.

### Summary

Orem's self-care deficit theory of nursing was used to examine the perceptions of 50 mothers and 15 fathers of infants' discharged from NICU. Approximately one-third of the mothers had attended prenatal classes, but 76% had never taken a baby-care class. Even the experienced multiparas commented on their educational deficits regarding the needs of the premature or sick infant.

The parents were involved as most visited the infant daily and 74% formed a special nurse-parent relationship. These factors should provide an excellent basis for involvement of parents in planning and mutual goal-setting; however, only 30% of the mothers perceived themselves as very involved in discharge planning.

There were problems with assessment of need, as teaching was conducted in some cases although the mother did not perceive a need for the information. Other mothers had not received teaching but thought they needed the education. No specific background factors were found to be highly correlated with the need for teaching. Thus involvement in planning and a thorough assessment of need should be

conducted for all parents.

Parents expressed a high degree of satisfaction with most of the teaching, even when it was not perceived as needed. It was recognized that the high satisfaction may be a covariant of the strong nurse-parent relationship. Thus satisfaction should not be used as a single measure of the success of NICU discharge teaching.

Although the degree of importance varied, the parents agreed that the teaching items of the discharge instrument were important to their care of the infant. A few areas should be elaborated and anticipatory teaching should be included on basic baby care and family adjustment. If time does not permit the expansion of NICU teaching, alternative sources of information could be suggested. Eighty-two percent of the families had experienced post-discharge problems, and all parents had located a post-discharge source of infant-care information.

Families needed additional information on referrals and their services and these should be evaluated for effectiveness following discharge. The parents of infants with specific health needs will benefit from supplemental information and referrals.

It is recommended that professional personnel who function with parents in NICU discharge planning, increase parental involvement in the planning phase. This may be implemented by ensuring them of a variety of opportunities for involvement. Such involvement should facilitate assessment of dependent-care deficits and improve the efficiency with which the dependent-care agency is developed prior to discharge.

NICU nurses can and do assist in the parents' development of an adequate dependent-care agency that facilitates the transition of parents to full infant-care providers following their infants' discharge from NICU.

## APPENDICES

## Appendix A

### Parental Perceptions of NICU Discharge Teaching

RESEARCH INTERVIEW INSTRUMENT  
PARENTAL PERCEPTIONS OF NICU DISCHARGE TEACHING

Background data from chart, nursing staff, parents:

1 Code # \_\_\_\_\_ 2 Birth Date \_\_\_\_\_ 3 Del(1Vag, 2Csex) 4.Gest Age \_\_\_\_\_ 5 Apgars \_\_\_\_/\_\_\_\_

6 NICU Admission: \_\_\_\_\_ 7 # Days in NICU: \_\_\_\_\_ 8 Discharge Date: \_\_\_\_\_ 9 Age at Disch: \_\_\_\_\_ days

10 Transferred to Convalescent Nursery: 1.yes (date: \_\_\_\_\_) Discharge Date: \_\_\_\_\_ 2.no \_\_\_\_\_

11 Significant Neonatal Problems: 1.yes \_\_\_\_\_ 2.no \_\_\_\_\_

12 Significant Problems Remaining at Discharge: 1.yes \_\_\_\_\_ 2.no \_\_\_\_\_

Mother:

13 Grava \_\_\_\_\_ 14 Para \_\_\_\_\_ 15 Living Children \_\_\_\_\_ 16 Ages \_\_\_\_\_ 17 Any hospitalized in NICU? yes no

18 Age at this Delivery: \_\_\_\_\_ 19 Marital Status: 1.S 2.M 3.S/D 4.W

20 Prenatal/Intrapartal/Postpartal Problems Affecting Teaching/Planning: 1.yes \_\_\_\_\_  
2.no \_\_\_\_\_

21 Is the Family Home Separate from the Extended Family? 1. yes 2. no

22 Will the Parents be the Major Infant Care Givers After Discharge? 1.yes 2.no

23 Other Significant Information: \_\_\_\_\_

24 Interview 24.1 Mother Father Interview 24.2 Infant's Age \_\_\_\_\_ days Infant Home \_\_\_\_\_ Days

25 Have you ever attended prenatal classes? 1.yes 2.no

25.1 (If no) Reason: 1. Inadequate time 2. Not needed 3. Other \_\_\_\_\_

26 Have you ever attended a baby care class? 1.yes 2. no

27 If no, would you like to have attended a baby care class? yes no

28 How often were you able to visit your baby in NICU? daily 3x/week weekly less than w.

29 What time of day did you usually visit your baby?

6-9am 9-12noon 1-3pm 3-6pm 6-9pm 9-12midnight 12-6am variable times

30 Were you a patient on the BMH maternity unit? 1.yes 2.no

31 (If yes), How satisfied were you with the teaching you received on the maternity unit?  
0=NOT SATISFIED, 1=NEUTRAL, 2=VERY SATISFIED

32 Did you stay overnight with your baby in NICU? 1.yes 2.no

32.1 (if yes) # of times? \_\_\_\_\_ How satisfied were you with this experience? 0 1 2

32.2 (if no) Would you like to have stayed overnight in NICU? yes no

33 Was there a nurse who was especially helpful to you in NICU? 1.yes (Name: \_\_\_\_\_) 2.no

34 How involved were you in planning your discharge teaching?

0=NOT INVOLVED, 1=SOMEWHAT INVOLVED, 2=VERY INVOLVED

35 In general how satisfied are you with the NICU discharge teaching?

0=NOT SATISFIED, 1=NEUTRAL, 2= VERY SATISFIED

Comments: \_\_\_\_\_

V. Passero, R.N.



DISCHARGE	TEACHING	CHARTED		TEACHING		NEEDED		TIMES	SATIS-	IMPORTANCE	COMMENT
CONTENT	AREAS			RECALLED				PRACT	FACTION		
36	Bathing your baby:	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
Feeding Your Baby:											
37	Tube Feeding:	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
Breastfed Babies:											
38	How to Breastfeed	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
39	Amt & Freq	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
40	Pumping & Storing	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
41	Formula Supplements	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
Bottlefed Babies:											
38	How to Bottlefeed	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
39	Making Formula	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
Temperature:											
42	Use of Thermometer	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
43	Normal/Abnormal Range	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
Bulb syringe:											
44	How/When to Use	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
CPR & Safety:											
45	CPR Slide-Tape	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
46	CPR Demonstration	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
Information on:											
47	Car Seats	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
48	Poison Control	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
Comfort Measures:											
49	Swing, Rocking, Bundling, etc.	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
50	Infant Stimulation/Play	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
51	Normal Growth/Development of Infants	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
Medications Needed at Home: 1. yes 2. no											
52	Type & Reason	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
53	When & How to Give	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
54	Reactions/Side Effects	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
55	Contacting Pharmacist	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
Information on Follow-Up Care: 1. yes 2. no											
56	Neonatal Progress Clinic	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
57	Pediatric Care	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
58	Eye Examination	Yes	No	Yes	No	Yes	No	NA	0 1 2	0 1 2	
59	Special Home Needs: 1. yes 2. no										
	Apnea Monitor	Yes	No	Yes	No	Yes	No		0 1 2	0 1 2	
	Others										
V. Passero, R.N.											

DISCHARGE TEACHING	TEACHING CHARTED RECALLED	NEEDED	TIMES PRACT	SATIS FACTION	IMPORTANCE	COMMENTS
60 Special Referral Information: 1. yes 2. no VNA, School Program, OT/PT, SIDS/Apnea Program _____	Yes No	Yes No	Yes No	0 1 2	0 1 2	
61 Program-"Going Home" _____	Yes No	Yes No		0 1 2	0 1 2	
62 How involved was the baby's father with the NICU teaching? 0= NOT 1=SOMEWHAT 2=VERY						
63 How satisfied is the baby's father with the NICU teaching? 0 1 2						
64 Has the Public Health Nurse called you? 1.yes 2.no Visited you? 1. yes 2. no						
65 How important was the Public Health Nurse's call? 0 1 2 Visit? 0 1 2						
66 What major problems have you experienced in caring for your baby since discharge?						
67 What NICU teaching might have prevented or helped with these problems?						
68 What other baby care information would have been helpful?						
69 Who or what has been your major source of baby care information since discharge? _____						
Comments: _____						

## Code:

TEACHING RECALLED? YES NO

TEACHING NEEDED? YES NO

SATISFACTION WITH THE METHOD OF TEACHING? (0=NOT SATISFIED 1=NEUTRAL, 2=VERY SATISFIED)

IMPORTANCE TO CARE OF YOUR INFANT? (0=NOT IMPORTANT,1=SOMEWHAT,2=VERY IMPORTANT)

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RESEARCHINST/w/6/26/87

## Appendix B

### Discharge Referral/Parent Education Sheet

## 91

**DISCHARGE TEACHING:**

- [illegible]

Discharge Weight: \_\_\_\_\_ Length: \_\_\_\_\_ Head Circumference: \_\_\_\_\_

Nurses's Signature

NS-462-419 REVISED

## Appendix C

### Consent Form

## CONSENT FORM

Name of Study:

Parental Perceptions of NICU Discharge Teaching

Purpose of Study:

The purpose of the study is to determine parental perceptions of recall, need, satisfaction and judgement of importance of the current NICU discharge teaching.

Procedures:

Parental perceptions of NICU discharge teaching will be determined through an interview with parents in the family home or place of their choice, within 20 weeks after discharge. The interview will last about 30 minutes and will be conducted by Virginia Passero, the nurse researcher. The interviewer will not perform the discharge teaching, but will help parents obtain referrals for additional teaching should the need arise.

Study Participants:

Participants must be parents of an infant, hospitalized in the Bronson Neonatal Intensive Care Unit for at least five days and discharged from the Bronson NICU or Convalescent Nursery. Parents must be 18 years of age or older, maintain their own place of residence, provide the major part of the infant's home care, and have no other infants discharged from a neonatal intensive care unit.

Risks and Benefits:

There are no anticipated risks for parents, infants or families as the study will not alter normal nursery routines. There is a

time factor of approximately 30 minutes to answer questions on infant care teaching. Participation will benefit future parents by helping nurses to evaluate their discharge planning and make changes needed to increase its effectiveness. The opportunity to discuss problems or concerns, and to obtain referrals if needed is an additional benefit to the family.

Confidentiality:

Parental opinions will be confidential, and only the nurse interviewer will have access to parent names and opinions. Consent forms will be kept in a locked box separate from complete questionnaires and data. Summaries of interview results will be used, but individuals will not be identified. The research study may be published to assist nurses with evaluation and improvement of parent discharge teaching.

The Nurse Researcher:

The study is being conducted by Virginia Passero, R.N., graduate nursing student at Wayne State University and Western Michigan University, in partial fulfillment of the requirements for the Master of Science in Nursing and the Doctor of Philosophy degree. If there are questions about the study, please contact the researcher at 383-7643.

## CONSENT FORM

## Parental Perceptions of NICU Discharge Teaching

Parental Acknowledgement:

"I understand that the purpose of this research study is to determine parental perceptions of NICU discharge teaching. If I agree to participate, I will be asked about my recall, need, satisfaction, judgement of importance and comments regarding the infant care teaching I received prior to my baby's discharge. This interview will take place in my home or a place of my choice following my baby's discharge and will last approximately 30 minutes."

"I have been given an opportunity to ask questions regarding this research study and these questions have been answered to my satisfaction. I understand that if I have any additional questions I may contact Virginia Passero at 383-7643."

"In giving my consent, I understand that my participation in this research project is voluntary, and that I may withdraw my consent and discontinue my participation in the project at any time without affecting my future medical care or the medical care of my infant. I also understand that the investigator in charge of this study, with my welfare as a basis, may decide at any time that I should no longer participate in this study."

"I hereby authorize the investigator to release the information obtained in this study to the nursing science literature. I understand that my child, my family and I will not be identified by name."



"Because no medication or invasive procedures are involved in collection of this information, no physical or psychological injury is anticipated due to this study. In the event of unanticipated injury resulting from the research procedures, no reimbursement, compensation or free medical care is offered by Bronson Methodist Hospital, Wayne State University, Western Michigan University, or the investigator, Virginia Passero. If I have further questions or concerns regarding my participation in this study, I may direct them to the investigator in charge."

"I acknowledge that I have read and understand the above information, and that I agree to participate in this study. I have received a copy of this document for my own records."

Parent: \_\_\_\_\_ Date: \_\_\_\_\_

Witness: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix D

### Selection Criteria Memo

MEMO

To: THE SUPERVISORS AND NURSING STAFF OF NICU

From: Ginny Passero

Date:

I have obtained approval for my research study on NICU discharge teaching and need your help in selecting the subjects from among the mothers of infants currently in NICU. I would like to interview mothers who fit the following criteria:

Parent Criteria

1. Parents who are at least 18 years of age
2. Parents who are maintaining their own place of residence, separate from the extended family
3. Parents who are the main infant care providers
4. Parents with no previous children discharged from a neonatal intensive care nursery

Infant Criteria

1. Infants admitted to NICU within 24 hours after birth.
2. Infants with a minimum of five days in NICU
3. Infants discharged directly from Bronson Hospital NICU or Convalescent Nursery

As you identify parents who fit these criteria, please give them a copy of the attached letter from Suzanne Shelton, NICU Director. The letters will be on the shelf in the NICU office. When the letter has been signed, please give it to your shift supervisor, who will return it to me. Your supervisor will answer questions regarding the project, or I may be reached by phone at 383-7643.

Thank you so much for your help! I will share the results of the study with you as soon as it is completed.

criteria/w

## Appendix E

### Preconsent Letter to Parents

# BRONSON METHODIST HOSPITAL

## PERINATAL CENTER

**Director,**  
**Maternal/Fetal Medicine:**  
Silvio Aladjem, M.D.

**High Risk Obstetrical Service:**  
Silvio Aladjem, M.D.  
Robert J. Austin, M.D.  
Donald S. Schaefer, M.D.

**Neonatology Service:**  
John V. Hartline, M.D.  
Michael N. Musci, D.O.  
William A. Rimmke, M.D.  
William H. Scott, M.D.  
Samuel M. Sefton, M.D.  
Gerald D. Purdy, M.D.

**Perinatal Coordinators:**  
**Obstetrics:**  
Linda Root, R.N.  
**Neonatology:**  
Wendy Finsterwald, R.N.C.

**Maternal Referral Coordinator:**  
Linda Haley, R.N.

**Neonatal Transport Coordinator:**  
Mary Magin, R.N.C.

**Departmental Secretaries:**  
**Perinatology:**  
Peggy Kerr  
**Neonatology:**  
Debra Hartman

**Telephone:**  
**Maternal Referrals:** 616/383-7887  
**Neonatal Referrals:** 616/383-6475

232 EAST LOVELL  
KALAMAZOO, MICHIGAN 49007  
616/383-7654

**Dear Parents:**

You are eligible to be included in a study we are doing on information you need to take your baby home from N.I.C.U. We hope to learn more about this process and how we can do a better job of preparing for discharge. If you are interested in participating in this study you will be contacted by a nurse researcher, Virginia Passero, who will explain more about the details and answer specific questions.

Suzanne Shelton, R.N., M.S.N.  
Director, Neonatal Services

Your Name: \_\_\_\_\_

Your baby's name: \_\_\_\_\_

Phone #: \_\_\_\_\_

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