THE NEEDS OF PARENTS OF INFANTS IN THE NSCU

by

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To Kevin and Dad, I love you.

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Finally, it is my hope that this project will be useful to nurses in the future; inspiring them in their service to families in Neonatal Special Care Units. May this be a thought to carry them forward: "We might do well to remember that we are in charge of the child's care, but the parents are in charge of the child's life" (M. deChesnay, 1986).

Elizabeth Turner
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CHAPTER I

Introduction

Parents anticipate the birth of over 30,000 infants per year in Oregon. Of these births, approximately 3750 will be premature. The birth of a premature or ill infant is a crisis event for parents. Parents of infants in neonatal special/intensive care units (NSCU) have specific needs that must be met if they are to cope successfully with the crisis of the birth of an ill or premature infant. Nurses are faced with assisting parents in this crisis. As caregivers and family advocates, nurses employ a variety of interventions designed to meet the needs of parents in NSCU settings. Yet little research has been done to determine whether these interventions are actually satisfying and useful to parents.

The intent of this study was to determine the extent to which parents of infants in NSCUs agreed with statements reported in the literature describing their needs, and to assess whether or not the interventions commonly employed to meet these needs are perceived by them to be satisfying and

useful. Demographic characteristics that might influence parental perceptions were studied. Nurses were asked to respond to the same statements as parents. This comparison of nurses' and parents' responses allows nurses to assess whether their agreement with statements pertaining to parental needs and the satisfaction with and usefulness of interventions employed in the NSCU setting, are similar to parents' agreement on these items. The identification of areas in which agreement or a divergence of opinion exist can be used to refine interventions used in NSCUs. These data can be further used to promote the development of additional interventions for meeting the needs of parents of infants in an NSCU.

Review of the Literature

There is widespread agreement among professionals that premature birth is a crisis event in the life of a family. Caplan, Mason, & Kaplan (1965) were among the first health professionals to study crisis theory as it applied to families who experienced the birth of a premature infant. Through data collected from 86 case studies of families with premature infants, these authors identified specific features of crisis. They found that crises are predictable, self-limiting experiences brought on by developmental or situational events which disrupt family functioning. The hoped for healthy, full-term infant is replaced by a fragile newborn whose medical needs may

prohibit assumption of parenting behaviors. Common feelings among parents are grief and disappointment, anger, anxiety, and guilt. Parents must resolve these feelings and prepare to resume their parental role at the discharge of their infant. The authors believe that to the extent resolution is positive, a healthy outcome of the crisis will be achieved. If the issues are not resolved, new crises may compound the impact of the original event.

Jeffcoate, Humphrey and Lloyd (1979) compared parental stress following premature birth to the stress experienced by parents of full term, healthy newborns. Their study revealed that parents of premature infants had greater incidence of emotional disturbance, delayed mother-infant bonding, and problems related to caring for their baby, than did parents of full therm infants. Differences between mothers' and fathers' of premature infants were noted and included more delays by mothers in forming attachments to their babies. These authors concluded that lack of early contact between mother and infant affected the assumption of the maternal role, making the mothers feel inadequate. Fathers, however, had not expected to provide much care of their baby, regardless of the prematurity, and did not experience problems in developing relationships with their infants. Failure to achieve a positive maternal-infant relationship led to post-discharge problems such as failure to thrive and divorce.

Mercer, May, Ferketich and DeJoseph (1986) supported the work of Caplan et al. (1965) and Jeffcoate et al. (1979). In their review of the effects on family functioning brought on by unexpected changes in the mother's or infant's birth outcome, Mercer et al. (1986) report that family functioning is altered at the individual, dyadic and family level. Each family member's response to the stressful event has an impact on total family functioning. Dyadic relationships (such as between mothers and fathers) are affected by the event and to the extent that they were previously dysfunctional, unhealthy resolution of the crisis might occur. Total family functioning changes, and undergoes alteration until the family successfully works through the crisis. Mercer et al. (1986) listed the following factors they felt promoted successful resolution of the stressful event: reattainment of positive self esteem by obtaining mastery over the event, social support or the actual receipt of help by others from within or outside the family, and acquisition of information concerning the health status of the affected member. These authors suggest further, that if the impact of the event is not mediated by successful resolution of the crisis, family functioning will be worse than it was prior to the event.

Health professionals have recognized that parents have specific needs related to the birth of their ill or premature infant, which must be met if successful resolution

of the crisis event is to occur and negative outcomes for parents and infants avoided. These needs are considered by professionals to include a need for: communication and information, support, a parent-staff alliance, participation in infant care, and adjustment to the NSCU environment. Each of these will be considered in order, below.

Horner, Rawlins and Giles (1987) surveyed families of chronically ill children to determine what parents perceived their needs to be. Their study revealed that parents have service needs, which include the delivery of health care, provision of information and support, and assistance in learning to care for their child. Numerous review articles agree with these authors.

M. deChesnay (1986) reviewed family therapy literature regarding the needs of parents of acutely ill children. She reports that parents have needs for open communication, mutual respect and support between themselves, within their families and from hospital staff, and a need to participate in problem solving. She stressed the need to acquaint families with the environment and to create a receptive atmosphere in which they might share their concerns.

Smitherman (1979) reported that parents of hospitalized children had specific needs to understand their child's medical problem and treatment plan, and to see that their child was receiving adequate care. Steele (1987) agrees with Smitherman's reports of parental needs, using parents

of neonates as her review population. Neither authors report research supporting their conclusions.

Among the research describing parental needs for support are the works of Mintzer, Als, Tronick and Brazleton (1985). Based upon a follow up study (from birth to five years old) of children born with birth defects and their parents, these researchers found that parents needed to receive environmental support in order for them to manage the stress on the family system and to provide care to their child. Using information from their earlier work with mother-infant attachment, Klaus and Kennel (1982) identified parental needs for support and communication and information gathering. Dammers and Harpin (1982) reviewed the impact of three years of parental support groups in an NSCU and learned that parents had needs to discuss their experiences with other parents and staff members and to receive assistance in problem solving and preparing to take their infant home.

In a study involving secondary analysis of data collected from providers and recipients of health care, Thorne and Robinson (1988) identified characteristics of the alliance formed between the two groups. These researchers found that the client-staff alliance was in important factor in a person's perception of having received adequate health care. They learned that relationships established by health care providers and families moved through three predictable

stages. The stages identified by this study were naive trusting (when families believe staff understand their unique situation and specific needs), disenchantment (when families feel dissatisfaction, frustration and fear associated with staff assumption of the care giving role and unclear communication between the two groups) and guarded alliance (when there is a re-establishment of the relationship between family and staff based on the development of a shared understanding of each other's roles and expectations). They further suggest that if nurses understand the dynamics between themselves and families, strategies can be devised to minimize disenchantment and promote a consistently positive alliance with family members. These authors have not applied their work to the NSCU setting.

Thornton, Berry and DalSanto (1984) discuss the parent-staff alliance in their review of the role nurses play in supporting families of infants in the NSCU. Based upon their work with families in this setting, these authors stress the role nurses play in familiarizing families with the NSCU and establishing rapport, which then allows parents to gain control of the experience and begin to parent their infant. Welcoming attitudes by the staff, teaching parents and keeping them informed, are means of establishing and maintaining this alliance. Zeanah and Jones (1982) agree with Thornton et al. (1984), in their article discussing

maintenance of the parent-staff alliance. They add that conflicts arise between nurses and parents when breakdown in their alliance occurs.

The need for parents to become active participants in their infant's care is supported by Gill (1987). Citing the rights of families as described in the United Nations Declaration of the Rights of the Child (in which maintenance of family integrity is stressed), Gill states that parents should take care of their sick children, separation should be minimized, and nurses must promote parental care giving. Jeffcoate et al. (1979) identify lack of control and participation in care as factors promoting ineffective maternal-infant attachment. Minde, Ford, Celhoffer and Boukydis (1975) found that nurses were instrumental in encouraging parental the assumption of the care giver role by teaching parents and modeling behaviors. The value of parental participation is reported in the literature and is included in this section under the discussion of interventions commonly used in the NSCU setting.

The effects of the NSCU environment on parents is discussed by McGovern (1984). This health care practitioner believes that the environment becomes a barrier to the development of parenting behaviors because of the negative effects on parents of equipment, lack of privacy, and inexperience with the NSCU setting. Gowan (1979), as an intensive care practitioner, holds the same opinion as

McGovern. Based upon these authors' concerns, it is possible to predict that parents of infants in the NSCU need to be as comfortable as possible with the NSCU environment in order to function as parents within it and have their other needs met.

These reports of the needs of parents do not attempt to distinguish between needs held specifically by mothers or fathers. Based on Jeffcoate et als.' (1979) description of maternal attachment outcome, it was necessary to include in this study the identification of needs specifically held by mothers and/or fathers.

Specific interventions to meet the needs of parents have been reported. Perrault, Collinge and Outerbridge (1979) describe the usefulness of honest and optimistic communication with parents. Both Siegel (1982) and Perrault et al. (1979) describe the usefulness of parent support groups and auxiliary advocacy roles (social workers, family care coordinators, and psychologists). A variety of organizations have been created to meet social support needs (such as Parents Supporting Parents and Compassionate Friends). Research by Rawlins and Horner (1988) identified information gathering and sharing as benefits to parents from involvement in support groups. These two strategies seemed to allow parents to focus on needs beyond basic care and therapy. The researchers found that parents who did not participate in support groups consistently required basic

information (which would have been available to them in support groups). These parents' need for basic information prevented them from dealing with advanced concerns (such as the growth and development of their child).

Some researchers report on benefits of specific interventions, such as providing photographs of the infant (Huckabay, 1987; Minton, 1983), massage programs (Field, Scafidi and Schanberg, 1987), video recordings (Haslam, Morris, & Mertin, 1985), and unrestricted family visitation (Klaus & Kennell, 1982; Paludetto, Faggiano-Perfetto, Aspera, DeCurtis & Margara-Paludetto, 1981; Zeskind & Iacino, 1984). Of these, however, only Huckabay (1987) and Field et al. (1987) actually studied the effects of interventions. Huckabay (1987) investigated maternal-infant attachment by conducting an experiment in which mothers were given photographs of their premature infants. Using control and experimental groups, Huckaby found that mothers who received pictures of their babies scored higher than those to whom photographs were not give on the Bonding Observation Checklist and the Physical Examination Observation Checklist. The benefits to premature infants of massage therapy were studied by Field et al. (1987) in an experiment involving administration of an infant massage stimulation program to premature infants randomly assigned to experimental and control groups. This study concluded that infant massage therapy resulted in improved weight gain

and responsiveness in treatment babies. McGovern (1984) suggests turning down lights and monitor bleeps to minimize the effect of the stressful NSCU environment on visiting family members, however, this author does not report research documenting the benefits of such actions.

Thornton, Berry and DalSanto (1984) suggest that primary nursing, in which one nurse cares for an infant throughout his/her stay, should become a standard in NSCUs. According to Thornton et al. (1984) sensitive communication techniques (such as listening and conveyance of a caring attitude), familiarization of the parents with the environment and the medical needs of their infant, promotion of frequent visitation by family members and promotion of the assumption of the caregiver role by parents are among the essential tasks of nurses in the NSCU. Shared understandings between parents and professionals concerning their respective roles and outcome goals for the infant are crucial elements in the formation of the parent staff-alliance.

The value to parents of common interventions such as provision of mementos, use of tape recorded music and family members' voices, scheduled telephone calls, dressing infants, and anecdotal information regarding infant behavior, as well as less common interventions like videotaping, has not been established by research.

The needs described in the literature have been combined with existing interventions in Figure 1, the domains of parental need. Each domain includes specific parental needs and the strategies currently employed to meet these needs. Statements of needs and interventions naturally overlap.

Insert Figure 1 about here

Although no reported studies have examined the effectiveness of overall strategies for meeting parents needs, Turecki (1982) conducted a research study on the needs of parents with dying neonates, and Freitas-Nichols(1986) examined the needs of parents whose children were transferred from critical to basic care units. In both studies communication and information were emphasized as key element of effective strategies used in meeting parental needs.

Satariano, Briggs, and O'Neal (1987) created the Parent Satisfaction Questionnaire for use in NSCU settings, as a means of obtaining feedback from parents regarding their experiences in NSCUs. This questionnaire is a survey instrument covering a broad range of topics about which statements of satisfaction are elicited from parents following discharge of their infant. Parents' responses are used in developing

I. Communication and Information

A. Parents need--to have consistent information given to them, to know what is happening to their infant, to be informed of progress and set-backs (in a timely manner), to be informed in an honest and realistic yet hopeful manner, to be listened to and have their concerns dealt with, and to have privacy when discussing infant concerns.

B. Interventions--patient/family care conferences, daily/regular telephone calls, telephone calls following status changes and diagnostic procedures, primary nursing, family care coordinators, parents rooms, and appropriate referrals (social service, psychologists, etc.).

II. Parent/Staff Alliance

A. Parents need--to have confidence and trust in their infant's caregivers, to be involved in decision
making, to have their concerns and preferences respected, to have conflicts resolved, and to know that their opinions are valuable.

B. Interventions- role modeling of conflict resolution techniques, primary nursing, family care coordinators, encouragement of: visiting, making decisions, participation in care, talking about their infant's progress and related concerns, access to charts and staff explanations of documentation, individual treatment plans, and attitudes from the staff which are friendly, courteous and non-judgmental.

III. Support

A. Parents needs--involvement of their significant others, to feel their authority is respected by the staff, to be included in decision making, to be assisted in dealing with the socio-economic problems arising from premature birth, and to feel welcome and included in their child's care.

B. Interventions--primary nursing, family care coordinator, parent support groups, after discharge follow-up programs, involvement of siblings, other family members and friends,

social service referrals, and open visitation policies.

IV. Participation in Care

A. Parents needs--to learn to care for their infants, to be allowed to do as much as possible for their infant as early as possible, and the nursing staff to teach and support them; not replace them.

B. Interventions--open visitations, provision of mementos (locks of shaved hair, name tags, pictures, decorations, notations in calendars and baby books), feeding, clothing, bathing and other infant care activities, rooming-in before discharge, provision of breast milk, promotion of attachment (infant stimulation regimen, massage programs), tape recordings of: music, the uterine souffle sound and family members' voices, and participation in special care procedures (physical therapy, gavage feedings, etc.).

V. Environment

A. Parents need--to feel comfortable in an environment over which they have little control, to understand as much as is possible and relevant to their situation about bedside technology and the duties of personnel, and the removal of unnecessary restrictions.

B. Interventions--privacy, decreasing stimuli provided by lights and sounds, cleanliness, minimizing crowding, pre-birth tours of the NSCU, and familiarization with apparatus, personnel patterns and supportive roles.

Figure 1. Domains of need and related interventions.

strategies for improving parental satisfaction with the NSCU experience.

Siegel (1982) described the development of a parent support program designed to assist parents in meeting their needs. A team of health professionals meets regularly with parents to discuss parent and staff concerns. This team is led by a family care coordinator (a position created specifically for the program), who functions as a parent-staff liaison and parent support person.

The relationships between parent demographic characteristics and perceived needs has yet to be clarified. Though it is documented in the literature that the existence of personal support systems assist parents in managing the stress of premature birth (Perrault, et al., 1979; Siegel, 1982), specific characteristics of these support systems are not defined. Parent characteristics (such as age, race, income, and education), may exert an influence on parents' perceived needs. The author has identified situational factors common in the lives of parents she has worked with in the NSCU setting. One of these is the that NSCUs are commmonly located in large cities and many of the infants cared for in them have been transported from outlying areas. Parents sometimes have to travel long distances in order to see their

newborns. Other factors include adequacy of insurance coverage, stability of living situation, number of children in the home, and availability of friends or relatives in the immediate vicinity to provide help (such as take siblings when parents must go to the hospital unexpectedly). Combined, all of these characteristics make up the parental background, and their influence on parental perceptions of need must be determined.

In summary, the literature reveals that the birth of an ill or premature infant is a crisis event for parents and families. It acknowledges the existence of specific needs of parents and families which include the need for communication and information, support, the development of a parent-staff alliance, parent participation in care, and adjustment to the NSCU environment. Further research is needed in the NSCU setting to substantiate these descriptions of parental needs. Various interventions have been developed to meet parent's needs.

Conceptual Framework

Based on the notion of premature birth as a crisis event, previously described in the review of the literature, resolution of the event may be achieved by parents and families through helping them to cope with the situation. Coping is the multifaceted process by

which the experience of crisis is dealt with and resolution of the stress of the event is attained with relief of guilt, anger, and disappointment. Coping has been conceptualized by Folkman and Lazarus (1980) as behavior based upon the essential need to survive and retain one's sense of equilibrium. These authors place coping behaviors into two categories: emotion focused (to decrease the stress of the event) and problem focused (to manage the problem itself). Successful resolution of crisis requires emotional adjustments to the event and involvement in the problem solving necessary for managing the situation and its consequences.

Siegel (1982) identified five emotional tasks parents must accomplish when faced with the crisis of having an infant in an NSCU. These tasks are: anticipatory grieving and withdrawal from the relationship established with the infant during pregnancy, acknowledgement of feelings of guilt and failure, adaptation to the intensive care environment, resumption of the previously disrupted relationship with the infant, and preparation for taking the infant home.

Family dynamics adds to our understanding of stress and coping responses to the crisis of premature birth by highlighting the importance of pre-existing

parent/ family relationships. Such factors as prior family functioning, social support, satisfaction with interfamilial relationships, self-esteem, and conflict resolution styles have been shown to be related to the way parents cope with what they encounter in the NSCU (deChesnay, 1986; Mercer et al., 1986).

In addition to providing care to the newborn, nurses serve families by helping them face the crisis event and by facilitating successful coping. The interventions cited in the review of the literature are used by nurses to promote parental movement through the emotional tasks described by Seigel (1982). By aiding parents in the mobilization of family strengths and in the development of the skills needed to care for their infant, nurses act to help families re-establish their equilibrium. Assisting parents to develop a new relationship with their infant and preparing them for assumption of the parental role necessitates an understanding of parental needs by nurses. It is vital that nurses understand parent's perceptions of their own needs. There must be a common base of understanding between the two groups if nurses are to facilitate the development of a positive growth producing relationship between parents and newborn. The development of new nursing strategies to assist parents in coping and in achieving attachment to their

infant are the long-range goals of the work reported here.

Research Questions

Research questions are based on the assumption that parents have needs associated with the crisis of having an infant in an NSCU and that nurses are key respondents to these needs. Therefore, nurses and parents should have similar perceptions of parental needs.

Perceptions mean those attitudes or responses held by respondents as evidenced by the extent of their agreement on questionnaire items. The term satisfaction referred to contentment or gratification with a specific intervention. Usefulness was used to indicate actual helpfulness of an intervention. The term "parents" indicated both mothers and fathers. Where only one party is referred to, a specific reference to their identity was made (i.e. mothers).

The research questions are:

1. What do parents whose infant is in an NSCU perceive their needs to be?
2. What do nurses perceive to be the needs of parents whose infant is in an NSCU?
3. Are there differences between mothers' and fathers' responses to statements regarding perceived needs of parents whose infant is in an NSCU?

4. Are there differences in the perceptions of parents and nurses concerning the needs of parents whose infant is in an NSCU?

5. How satisfied are parents with the interventions used to meet parental needs? How useful do parents feel these interventions are?

6. How satisfied do nurses believe parents are with interventions used in an NSCU? How useful do nurses believe parents find these interventions?

7. Are there differences between parents' and nurses' perceptions of parental satisfaction with interventions used in an NSCU? Are there differences between parents' and nurses' perceptions of the usefulness of these interventions?

8. How often do parents report that nurses meet parental needs in an NSCU?

9. How often do nurses report that nurses meet parental needs in an NSCU?

10. Do nurses and parents report similar frequencies with which nurses meet parental needs in an NSCU?

11. Are there demographic variables that correlate with specific needs and with satisfaction with interventions?

12. Do parental perceptions of needs and satisfaction with interventions change over time?

CHAPTER II

Methods

Research Design

The design of this project was that of a non-experimental, longitudinal, descriptive-corelational study. In answering Research Questions One through 10 and 12, those questions pertaining to parental needs and perceived satisfaction with and usefulness of interventions commonly used in the NSCU, a longitudinal, descriptive format was employed. A two-part questionnaire was developed to measure parent and nurse agreement with statements of parental needs and perceived satisfaction with and usefulness of interventions. An open-ended question was included in each section to facilitate collection of information not included in the questionnaire.

The questionnaire was administered twice to parents, following the admission and discharge of their infant from the NSCU. This allowed for the assessment of change over time in parent perception of their needs and satisfaction with and usefulness of interventions. Nurses working in an NSCU were used as a comparison group so that the presence of differences of opinion

between the groups, on questionnaire items, could be ascertained. Nurses completed the questionnaire once.

Question 11, which concerned the existence of demographic variables that might correlate with parental perception of needs and satisfaction with and usefulness of interventions, required a descriptive-corelational design. Background information forms were given to parents and the data collected were used in assessing the presence of significant relationships between demographic variables and questionnaire items.

Subjects

The target populations for this study included mothers and fathers (or mothers' partners) of infants in an NSCU and nurses working in that same NSCU. The accessible population included those persons involved in the NSCU of a large, metropolitan, tertiary care facility. The NSCU used in the study typically serves families from a wide range of socio-economic backgrounds.

The criteria for inclusion in this study were:

1. Parents whose infant(s) are an NSCU:
   a. Mothers and fathers.
   b. Persons who considered themselves parents and would be assuming a parental role during the infant's convalescence and at discharge, called partner.

c. Parents of ill and/or premature infants who are patients in an NSCU and are not moribund (to avoid focusing on death and dying issues). If the infant is preterm it should be between 26-36 weeks gestational age by Ballard examination and not less than 26 weeks (in order to avoid the ethical issues surrounding resuscitation of the very premature).

2. Female nurses who were functioning in staff nurse positions and who had one or more years experience working with infants in an NSCU were included in this study. Only female nurses were used to avoid adding the variable of gender to nurse responses to questionnaire items. A random selection of female nurses working in this unit was made.

Data Collection Methods

The two-part questionnaire was developed to measure parent and nurse agreement with statements about parental needs as well as satisfaction with and usefulness of commonly employed interventions. In addition, parent and nurse background information forms (Appendices A, B, respectively) were developed for the study. The questionnaire also included a comments section to facilitate the collection of new information on parents' needs (Appendix C).

The parent background information form included demographic and socioeconomic data thought to represent

the most salient extraneous variables likely to affect parents' perceived needs and satisfaction. Based upon the author's experience with families in the NSCU, common situational factors (such as number of visits per week, distance travelled to the hospital, and amount of the bill parents expected to pay) were included on this form. Parents were asked to rate their stress level (1 as low, 10 as high) prior to the birth and at the time of completion of the form. An abbreviated background information form was given to the nurse respondents in order to document eligibility and obtain information about possible previous experience as parents of infants in an NSCU.

The questionnaire created for this study was a modification of Turecki's (1982) tool, developed by Turecki on the basis of a structured interview guide developed in 1976 by Molter. The recommendations of Dillman (1978) were used in developing Turecki's tool for this study. The questions included in the tool were developed from the statements of parental needs and intervention strategies contained within the five domains of parent needs (communication and information, parent and staff alliance, support, participation in care and environment) derived from the literature. It was divided into two sections, the first pertaining to needs and the second to satisfaction with and

usefulness of interventions. The information contained in Figure One served as a table of specifications in the development of the questionnaire.

A six-point Likert scale was used with possible responses of strongly disagree, disagree, slightly disagree, slightly agree, agree, strongly agree (one through six, respectively). In the section describing interventions, respondents were asked to circle the staff members' title who most often performed an intervention for them (registered nurse, doctor, social worker, other). Open-ended questions were included to facilitate provision of additional information. A section requesting responses from participants about the usefulness of additional interventions was also included.

Questionnaire content validity was established through interviews with four experts in the field of neonatal nursing and three sets of parents of children hospitalized in an NSCU. The experts and parents interviewed were asked to review the instrument and make comments about its content. Their comments were utilized in revising the questionnaire.

Procedures

Tool development was the first step in this study followed by the acceptance of the study by the Human Subjects Review Board of the hospital where the study

was conducted. Next, subjects were recruited. A letter explaining the study was provided to each potential participant (Appendices D and E). The explanation of the study was uniform and included a discussion of subject anonymity. Informed consent to participate was obtained (Appendix F and G) from those persons agreeing to participate.

The researcher was the data collector. Data were collected in parent rooms located in the NSCU at Time One and by mail at Time Two. Data were collected from nurses only once. Nurses were asked to answer the questionnaire from the standpoint of what they felt a parent would need and would find satisfying and useful.

During the initial interview with parents the background information form and the questionnaire were filled out. Post-discharge data collection involved only completing the questionnaire. Parents filled out the first questionnaire two to three weeks after admission of their infant. They completed the questionnaire a second time, two to three weeks following discharge of their baby from the NSCU.

Protection of Human Subjects

Confidentiality of study participants was maintained by the researcher. Only the researcher knew who was participating in the study. Neither nurses or

parents were informed of the identities of the participants in the study. There were no direct risks to participants in the study.

Description of the Sample

Six sets of parents of infants in the NSCU agreed to participate in the study. They each completed a background information form, a questionnaire when their infant was admitted, and the same questionnaire when their infant was discharged from the NSCU. Only four couples completed the questionnaire the second time. Six mothers and four fathers filled out the questionnaire and background information form initially; two couples dropped out for unknown reasons. They were encouraged by telephone and in letters accompanying their questionnaires to complete the study. However, none of those who did not complete the questionnaire the second time made contact with the researcher regarding their decision to withdraw. The resulting sample included six mothers at Time One, four mothers at Time Two, and four fathers at Times One and Two.

The parental sample was composed of married couples, primarily Caucasian (one father was a Native American). Their ages ranged from 21 to 39 with a mean age of 27. Almost half (44%) reported church involvement. The mean educational level was 14 years.

The sample included one homemaker, five were non-professional, and three were professional workers. Fifty-six percent owned their own homes, and the remainder rented living quarters. Family income ranged from $15,000 to $24,999. All stated they had health insurance with 63% expecting to pay some of the costs of the hospitalization.

For five of the couples completing the background information form, this was their first child. This was the first child for the four couples who completed the study. No parent described previous experience in an NSCU; 44% of this group reported receiving pre-birth tours of the NSCU. The frequency of parental visits to their infant ranged from 16 to 56 times a month, the mean being 35. One couple lived more than 50 miles from the NSCU, and the majority lived between 5 to 19 miles away. All had their own means of transportation. Fifty percent of the respondents called the NSCU twice a day, with a range in reported weekly calls from 3 to 112 times.

Seventy-eight percent of the respondents did not expect their infant to be ill at birth. Eighty-nine percent did not attend parent support meetings. Seventy-seven percent of these respondents had relatives living in Oregon. Respondents reported receiving assistance from their parents (86%), friends

(57%), and others (33%). Their greatest concern was their infant's medical condition (89%). Another concern was prior family problems. Stress before birth had a mean score of 4, after birth 7.

Twenty nurses were asked to participate in the study and 15 agreed to do so. The age range for nurses was from 26 to 41 years, with a mean age of 33. Nine (63%) of the nurses were parents, one reporting the loss of a child in infancy. One nurse had previous experience as a parent of an ill or premature infant in an NSCU.

CHAPTER III

Results

Overview of Data Analysis Procedures

In measuring agreement with questionnaire items pertaining to parental needs and satisfaction with and usefulness of interventions, parents' and nurses' scores were examined for each item. Questionnaire items were combined into scales in order to evaluate data pertaining to differences between groups and correlations between background variables. The reader is referred to Appendix C for the description of questionnaire items. Quantitative analysis of results was conducted on questionnaire items and scales by examining respondent's answers by group (mothers, fathers, parents, and nurses). Where parents are referred to specifically, their scores were obtained by combining the results of mothers and fathers responses to questionnaire items. Agreement meant respondents scored five ("agree") or six ("strongly agree") on statements.

Three sets of scales were constructed by combining items in the questionnaire most representative of the five needs concepts. The sets were made up of questionnaire items pertaining to parental needs (items

1-35), satisfaction with interventions (items 37-73), and usefulness of interventions (items 37-81). This resulted in the development of fifteen scales. Table 1 presents the scales created for data analysis with their corresponding alpha coefficients. All but two of the scales received alphas greater than 0.60. The needs scales of communication and environment achieved alphas of only 0.39 and 0.43, respectively.

Insert Table 1 about here

Appendix H presents the complete list of questionnaire items included in each scale.

Answers to Research Questions

Study Questions One, What do parents whose infant is in an NSCU, perceive their needs to be?, and Two, What do nurses perceive to be the needs of parents whose infant is in an NSCU?, were analyzed by examining the frequency with which nurses and parents agreed with all questionnaire statements describing parental needs. Scores of five and six ("agree" and "strongly agree") represented agreement with statements. Parents and nurses tended to agree with the needs statements. Parents agreed on 26 of the 35 items in this category for both Times One and Two.

Table 1

Scales Created from Questionnaire Items* Under the Concepts of Domains of Parent Needs

Domains of Parental Needs	Parental Needs	Satisfaction with Interventions	Usefulness of Interventions
1. Communication	6 items alpha = 0.39	8 items alpha = 0.78	9 items alpha = 0.69
2. Alliance	5 items alpha = 0.75	5 items alpha = 0.77	5 items alpha = 0.72
3. Support	2 items alpha = 0.65	11 items alpha = 0.65	11 items alpha = 0.63
4. Parent Participation	8 items alpha = 0.75	22 items alpha = 0.85	22 items alpha = 0.76
5. Environment	4 items alpha = 0.43	3 items alpha = 0.61	3 items alpha = 0.63

* Appendix C contains all items included in the questionnaire.

Agreement was obtained on 28 of the 35 items for nurses (the only time nurses were tested). Appendix I lists the percent of agreement between groups on each statement in this category.

There were six statements with 20% or more difference in agreement at Times One or Two or between parents and nurses, (items 6, 13, 14, 19, 28 and 33). ANOVAs were conducted on these items by comparing the mean scores for parents at Time One and at Time two, and for nurses. Significant differences were found between parents and nurses on item six, encouraging parents to cry, ($F=3.88$, $df=29$, $p=<.05$) and between parents at Time One and Time Two on item 28, requesting certain nurses as caregivers, ($F=4.96$, $df=32$, $p=<.05$). Parents indicated support for the need to be encouraged to express emotion, whereas nurses felt they did not need this encouragement. Parents wanted to request specific nurses as care givers more at Time One than at Time Two. Parent agreement on this item closely resembled that of nurses at Time Two (percent agreement was 38% for parents and 41% for nurses). Table 2 presents the results of ANOVAs on these statements.

Insert Table 2 about here

Table 2

Analysis of Variance Between Parents and Nurses on Those Statements of Parental Needs with >20% Difference in Agreement At Time 1 and/or Time 2

Item		X and SD by Item			F Tests
		Parents Time 1	Parents Time 2	Nurses	
6	x	4.67	4.00	5.40	
	SD	2.14	1.00	0.63	3.88* (df=29)
13	x	4.36	4.75	4.93	
	SD	1.00	0.89	1.22	0.87 (df=30)
14	x	4.55	5.00	4.93	
	SD	0.76	0.92	1.22	0.55 (df=30)
19	x	4.95	5.25	4.47	
	SD	1.12	0.71	1.51	1.13 (df=30)
28	x	4.60	4.43	3.20	
	SD	1.26	0.84	1.32	4.96* (df=30)
32	x	5.00	4.55	3.47	
	SD	1.05	1.00	1.23	6.68** (df=30)
33	x	4.33	4.88	4.29	
	SD	1.03	1.36	0.91	0.83 (df=28)

* F Test = $p < 0.05$
** F Test = $p < 0.01$

T-tests were used in answering research Questions Three, Are there differences between mothers' and fathers' responses to statements regarding perceived needs of parents whose infant is in an NSCU?, and Four, Are there differences in the perceptions of parents and nurses concerning the needs of parents whose infant is in an NSCU?. No statistically significant differences of opinion were found on these statements between fathers and mothers. Appendix J presents the results of t-tests for these groups. A significant difference was found between parents at time two and nurses on the environment scale ($t=-3.99$, $df=21$, $p=<0.05$). Parents indicated more agreement than did nurses on statements describing the need for privacy, feeling welcome, and providing opportunities for personalizing their infant's bedside. Appendix K presents the results of t-tests between parents and nurses on scales of needs.

Frequency of agreement as to satisfaction with interventions designed to meet parental needs and the perceived usefulness of these strategies was examined for Questions Five, How satisfied are parents with the interventions used to meet parental needs? How useful do parents feel these interventions are?, and Six, How satisfied do nurses believe parents are with interventions employed in an NSCU? How useful do nurses believe parents find these interventions?.

Parents indicated more overall satisfaction with interventions than did nurses. At Time Two there was marked increase in agreement among parents regarding satisfaction with interventions. This indicates the support parents feel for most of the strategies used in the NSCU.

Parents' agreement at Time Two, on satisfaction with interventions, increased to 100% on statements pertaining to telephone calls (items 39 and 40), the same nurse caring for the baby (item 47), assistance with medication administration (item 54), nursing procedures (item 55), physical therapy (item 56), provision of mementos such as locks of hair (item 57), donated gifts (items 62), donated clothing (item 63), education regarding appropriate toys (item 70) and infant massage techniques (item 74). A decrease in agreement at Time Two was noted on item 44, visitation of friends, and may reflect a greater interest by parents in those interventions directed towards the acquisition of care giving skills.

Nurse support of interventions was more varied than that of parents and indicated a divergence of opinion among nurses regarding the perception of parent satisfaction with interventions. Agreement with items ranged from 34% to 100%. Appendix L lists the

frequencies of agreement for each group on statements pertaining to satisfaction.

Usefulness of interventions was strongly reported by parents. Agreement was high, with 80% agreement or above found at Time One among parents on 29 of the 45 statements in this category. At Time Two, 35 of the 45 items received scores of 100% agreement by parents. Nurse agreement with the usefulness of items ranged from 45% to 100%. Nurses reported less than 50% agreement with the following items (for which parents had high agreement): visitation of friends (item 44), parent participation in gavage feedings (item 51), assistance with nursing procedures (item 55), and donated gifts (item 62). Appendix M lists the frequencies of agreement on the 45 items pertaining to usefulness for each group.

To answer research Question Seven, Are there differences between parents' and nurses' perceptions of parental satisfaction with interventions used in an NSCU? Are there differences between parents' and nurses' perceptions of the usefulness of these interventions?, t-tests were conducted on scales measuring satisfaction with and usefulness of interventions. Between parents at Time One and nurses, significant differences were reported on the satisfaction with interventions scales of alliance ($t=-2.27$,

df=20, p=<0.05) and support (t=-2.90, df=15, p=<0.05), and the usefulness of interventions scale of alliance (t=-2.43, df=21, p=<0.05). Parents showed more support than did nurses for parent inclusion in activities representative of the parent and staff alliance (conferences, assistance with reading charts and open visitation policies). Significant differences were found between parents at Time Two and nurses on all scales pertaining to satisfaction with and usefulness of interventions. Parents found the interventions more satisfying and useful, particularly post-discharge, than nurses thought they would. Table 3 presents the results of t-tests at Time Two.

Insert Table 3 about here

Appendices N and O present the results of t-tests on all scales measuring satisfaction and usefulness.

There were 37 questions (items 37-81) addressing nurse involvement as interveners (research Questions Eight, How often do parents report that nurses meet parental needs in an NSCU?, Nine, How often do nurses report that nurses meet parental needs in an NSCU?, and Ten, Do nurses and parents report similar frequencies of nurses meeting parental needs in an NSCU?). Nurses were reported by both groups to be more involved in

Table 3

Results of T-tests Measuring Differences Between Parents at Time 2 and Nurses on Scales Measuring Satisfaction with and Usefulness of Interventions Designed to Meet Parental Needs

Scales	df	t
Satisfaction:		
Communication	19	-2.24*
Alliance	19	-3.85*
Support	16	-3.25*
Participation	17	-2.82*
Environment	19	-2.33*
Usefulness:		
Communication	16	-2.82*
Alliance	18	-3.31*
Support	15	-2.24*
Participation	16	-4.26*
Environment	18	-3.59*

* p=<0.05

performing interventions than any other person. Greater than 80% report of nurse involvement was found for parents on 28 of the 45 items at Time One and 31 of the 45 items at Time Two. Nurses showed agreement with 37 of the 45 items. No respondent reported nurse involvement on item 80 (insurance and finance counseling). Appendix P lists the frequencies of report of nurse involvement as interveners.

Correlations between parent and nurse background information variables and the scales measuring needs and satisfaction with interventions were examined in answering Question 11 (Are there demographic variables that show high correlations with specific needs and satisfaction with interventions?). Significant correlations were found between the number of living children (this was the first infant for 89% of the parents) and the needs scales of communication ($r=0.73$), support ($r=0.71$), and participation ($r=0.69$). The number of living children correlated highly ($r=0.79$) with the intervention scale of communication.

Parents visited an average of 35 times a month. The frequency of visitation was correlated with the intervention scales of support ($r=0.71$), participation ($r=0.69$), and environment ($r=0.66$). Parental report of perceived stress level "now" (mean rating was 7)

correlated with the needs scales of participation ($r=0.68$) and the intervention scales of support ($r=0.83$) and participation ($r=0.74$). There were no significant correlations found between nurse background variables and scales.

Paired T-tests were conducted on needs and satisfaction scales for mothers and fathers at Times One and Two to answer Question 12, Do parental perceptions of needs and satisfaction with interventions change over time?. The only evidence of a significant difference over time was found for mothers on the environment scale ($t=-2.50$, $df=8$, $p=<0.05$). Mothers' agreement with items pertaining to privacy, feeling welcome when they visit, and decorating their infant's bedside increased over time. No significant differences were found for fathers over time. Appendix Q lists the results of these t-tests.

Answers to Questionnaire Items 36 and 82

Respondents' answers to questionnaire items 36, Are there other needs that have not been covered by these questions?, and 82, Are there other things that could have been done for you that would have been helpful?, were also examined. In response to question 36, parents stated that there was a need for day care for siblings, for consistency of information from staff, for understandable explanations regarding an

infant's condition, for consistent medical caregivers and for meetings with social workers to discuss non-medical issues. In response to Question 82, parents mentioned the need for more involvement in preparation for discharge, increased involvement in making care giving decisions coupled with more discussions with physicians, and more space for activities related to infant care. Appendix R lists the comments as parents wrote them.

Nurses answered Question 36 by mentioning the need for educational offerings for parents, alterations in unit based staffing expectations, help with emotional support and ethical issues, for ongoing training of staff in crisis intervention, and for parents to feel some control over what is happening. Possible interventions (question 82) included providing more scheduled time for nurses to interact with parents, more private time for parents with their infant, and the use of pictures and flowers at the bedside. Appendix S presents nurses' statements to these questions.

CHAPTER IV

Discussion

Examination of the Results

The domains of parent need conceptualized in this tool coincide with parents' own perceptions of their needs. Parents agreed with statements on the tool about parental needs. Their answers also indicated they felt the interventions were both very satisfying and very useful. Parents' perceptions of their needs did not change dramatically over time, though after their infant's discharge they perceived the interventions to be even more satisfactory and useful than they had realized before discharge. Parents placed high value on involvement in decision making and in participation. Changes in parents' perceptions over time, where significant, may have been related to increased familiarity with the NSCU environment and staff. Post-discharge, parent's evidenced greater satisfaction with participatory activities than for matters such as choice of nurse care giver.

Nurses scored similar to parents on the scales of needs, satisfaction, and usefulness. There was general agreement between parents and nurses that parents' wishes and preferences should be followed and that they

should have a say in who cares for their infant, and in allowing parents to help care for their infant. On the items pertaining to increased involvement of parents in nursing activities, nurses had less agreement than did parents.

Marked increase in satisfaction with interventions was seen at Time Two for parents. Parent participation in gavage feeding was an intervention supported by parents but not by nurses. This activity is considered to have an element of risk and thus requires specialized skill by the caregiver. It is not commonly taught to parents unless an infant is to be discharged on gavage feedings. It was not possible to assess the possibility that nurses' answers on parent involvement in gavage feedings might reflect personal values about the appropriateness of parent participation in such an activity. Parents indicated an interest in being taught more skills; however they did not support the idea of a formal parent class. Nurses did support the idea of such a class. Nurses did not support assistance for parents in reading charts or parental involvement in making nursing care plans. This may come from a belief that parents should not be involved in such activities or may result from constraints of time. The topic bears further investigation. It is

notable overall that parents found the interventions more satisfying and useful than did nurses.

As expected, parent and nurse report of nurses' involvement as interveners were similar. Both nurses and parents identified the nurse as the staff person most often involved in performing interventions. Those items on which low involvement of nurses was reported included activities not routinely practiced in the NSCU (video taping, grandparent and sibling support groups, and insurance and finance counselling).

The most significant relationships pertaining to parental background were seen in the frequency of visits with support, participation and the environment. Considering the fact that in this sample most of the parents visited often, it would be expected that they became familiar with the NSCU environment and staff. This may have promoted feelings of increased support by the parents from the staff. Parents reported feeling moderate stress. Their agreement with the scales pertaining to the usefulness of interventions, indicated a belief that such activities would assist them in coping with the stress of having an infant in an NSCU. Learning to care for one's infant may supercede the effects the environment has on the parents as well as contributing to an overall sense of ease with the surroundings. As a parent becomes more

involved and less an observer he/she may become increasingly more comfortable in the NSCU milieu.

The comments made by parents on the open ended questions were similar to those domains of parent needs identified by this study and included in the questionnaire. Parents' comments stressed the need for clear communication and knowing what was going on with their infant. This reinforces the importance of ongoing sharing of information between parents and staff regarding the infant's status. Day care for siblings was requested by parents. For those parents with other children, providing day care might assist them in meeting their needs by allowing them to attend support groups or spend more time at their infant's bedside. Parents changed from mild to strong support for sibling support groups, possibly reflecting the need mentioned above. Parents reported an interest in obtaining more information regarding insurance, finance counseling and social security. This indicates the need for hospital staff to address the non-health related concerns of parents while their infant is in the NSCU.

Nurses' responses to open ended items on the questionnaire indicated the presence of constraints to nurse involvement with parents imposed by unit staffing practices and not related to infants or their parents.

Nurse to patient rations that do not allow nurses to spend time with parents interferes with the nurses' ability to assist parents. Infant care is prioritized as the first concern of nurses, with provision of care to parents and families allowable as time permits. The need for communication and education were constant themes in nurses' comments. Providing parents with information regarding common responses by parents to the crisis of having an infant in the NSCU was suggested by the nurses as another useful intervention. Other suggestions included more involvement by nurses in parents conferences, providing more privacy to parents and allowing nurses more time to teach and support parents.

The tool created for this study maya prove useful to nurses in designing care plans for the NSCU setting. The items included in the questionnaire as statements of needs and interventions may serve as a reference list in the development of nursing strategies to meet parents' needs. Those items with substantial parent agreement but only moderate or low nurse agreement bear close scrutiny. Questioning the divergence of opinion between parents and nurses may assist nurses to better help parents cope with the NSCU experience. Clearly, communication, support, alliance and participation are

important. The impact of the environment remains less well defined.

Limitations

Because of the small sample size and homogeneous character of the subjects it would not be justified to generalize the results of this study to all NSCU settings. Few differences between parents were seen in their background characteristics. The questionnaire was global and did not detect fine differences among respondents or on specific topics. The tool would require revision in structure and content prior to reuse for research or as an assessment tool.

Implications for Nursing Practice

Because of the limitations of this study it is difficult to make generalizations from the data to current nursing practice. If this study was repeated using a large sample and the results obtained identical, nurses should consider the benefits to parents of wider participation in infant care and pre-discharge assumption of the care giver role. That parents were less concerned with nurse-parent relationships and more concerned with interventions at the bedside indicates the need for nurses to focus on participatory activities with parents.

At discharge, the initial crisis caused by the infant's birth and prematurity or illness may be

resolved, through parental receipt of support and the development of the parent-staff alliance. Discharge may present another crisis, in which parents find themselves wholly responsible for their infant's care. To off-set the impact of discharge, parents need to assume the role of care giver while the infant is hospitalized and the supportive staff available. Failure to provide the information and support necessary to meet parents' initial needs may result in poor adaptation by parents to the environment and ineffective establishment of the parent-infant relationship. Taking the infant home under these circumstances becomes a new situational crisis. It is vital that the need for information gathering and support identified by Rawlins and Horner (1988) be met for all parents so that the crisis of discharge might be avoided or minimized.

That parents found routine practices such as telephone calls, primary nursing (the same nurse caring for their baby), the provision of mementos including photographs, and open visitation satisfying and useful, supports the inclusion of these interventions in nursing care plans. The development of infant massage therapies is advisable, based on the documented effect cited in the literature and parental support for its usefulness determined by this study. Such routine

nursing procedures as gavage feeding may be appropriate for parent involvement. A retrospective study of the incidence of morbidity associated with gavage feedings may serve to convince nurses that it is safe for parents to regularly conduct such feedings.

This study verified the need for consistent communication with parents. Because of the high report of nurse involvement in NSCU activities, it is important for nurses to recognize their role as coordinators of not only infant care but parent understanding and information sharing. Nurses must make every effort to see that parents are informed of their infant's status, particularly when medical practitioners have been changed. Recognition that this has an impact on parental feelings of support, and the development of the parent-staff relationship is essential. Inclusion of parents in care giving activities may assist nurses in working out conflicts between themselves and parents (an unavoidable occurrence in stressful hospital environments).

The possible existence of a nurse value structure affecting nurses willingness to involve parents in infant care, points to the possibility that there are parent characteristics that nurses respond to favorably or unfavorably. A positive perception of parents may facilitate nurse involvement of parents in

participatory activities. If this is true, it is essential that nurses become aware of their preferences and prejudices and develop strategies for promoting parent involvement despite their personal feelings.

An additional concern is for those parents who are unable to make frequent visits to the NSCU. Nurses must keep these parents well informed in order for them to feel supported and involved. When these parents visit their infant, they should be involved in care giving activities. The focus on participation may serve to reduce parental lack of familiarity with the environment and increase the parent-staff alliance.

Because parents want information and education but are seemingly unwilling to attend special parent classes or support group meetings, nurses must assume the role of educator. While education is a primary function of the nursing profession, the need for information in the NSCU is particularly emphasized by the unique circumstances having an infant in the NSCU presents. The need to meet the basic needs of parents allows parents to focus on the advanced concerns Rawlins and Horner (1988) identified. The opportunity to teach parents about their infant is present in all nurse-parent interactions.

Recommendations for Further Research and Conclusions

Studies are needed to identify of the effects staffing patterns have on nurses meeting parental needs. Attitudinal or environmental barriers were not included in the questionnaire used in this study but were alluded to.

In-depth study of parents' needs and expectations may reveal the need for involving parents more in decision making and care giving. The appropriateness of parent participation in staff assignments and specific tasks bears further investigation. The reasons given for their lack of participation in certain activities needs to be explored. For example, would the provision of child care increase parent utilization of support groups or attendance at parent classes?

Adequacy of parental preparation for discharge needs further clarification. The thoroughness of discharge teaching may be a major factor in parental perception of satisfaction with the NSCU experience. Those interventions most valuable in supporting parental assumption of care in the home were not identified by this study though participation was found to be an important need of parents.

Differences in parent and nurse perception of parental needs may prohibit successful resolution of

crisis if needs go unmet by staff members. The barriers confronting nurses, alluded to by nurses' comments referring to staffing practices, must be identified.

On a general level, this study showed support by parents for the descriptions of parental needs found in the professional literature. The study offers needed data on parents' satisfaction with some intervention strategies. Though significant limitations exist, the parents consistently supported the fact that they experienced common needs. It is clear that nursing personnel need to support parents in becoming involved in infant care. This study also reinforces the need for communication with parents and continued use of the interventions commonly employed in the NSCU.

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APPENDIX A

Parents' Background Information Form

Dear Parents:

You are being asked to participate in a study to help nurses learn more about the needs of parents with infants in a Neonatal Special Care Unit (NSCU). I am interested in learning if parents think the things the staff, particularly nurses, does for them are helpful. Suggestions from parents about other ways to meet their needs are encouraged.

In order to get this information, you are being asked to fill out this questionnaire. Because many personal factors influence parental needs, background information is needed from the parents who are helping with this study. All of the information collected will be confidential. The first time you fill out the questionnaire the background information form needs to be completed; after this only the questionnaire is necessary.

Your participation will help to develop nursing's knowledge about what parents need and find helpful when their infant is in an NSCU. Your input is valuable and appreciated.

Thank You!

Elizabeth Turner

1.	Are you the infant's:	Mother_____ Father_____ Mother's partner_____
2.	Age:	_____
3.	Race:	Asian__Black__ Caucasian__ Hispanic__Native American__ Other_____
4.	How long have you been married or together?	_____months _____years
5.	Do you belong to a church?	yes_____ no_____
6.	Do you attend church regularly?	yes_____ no_____
7.	Education: Please circle the highest grade completed.	8 9 10 11 12 college _____years
8.	Occupation:	_____
9.	Which of the following best describes your income for 1988?	less than $5,000_____ 5,000-9,999_____ 10000-14999_____ 15000-24999_____ more than 25000_____
10.	Do you have health insurance?	yes_____ no_____

11. How much do you expect the total cost to be?

12. How much do you expect to have to pay of your infant's bill?
    none_____
    some_____
    all_____

13. Do you own your own home?
    yes_____ no_____

14. Do you rent your home or apartment? yes_____ no_____

15. Will you have to move before your baby comes home? yes_____ no_____

16. Do you have relatives who live in:
    Portland_____
    Oregon_____
    out of state_____

17. Please list those persons living with you in your home:
    _____
    _____
    _____
    _____
    _____

18. Is this baby your:
    first_____
    second_____
    third or more_____

19. Have you ever had in infant in an NSCU before? yes_____ no_____

20. Did you have any prior experience in an NSCU before? yes_____ no_____
    Describe

21. How often do you visit?
    _____times a day
    _____times a week
    _____times a month

22. How far away do you live?
    less than 5 miles_____
    5-19 miles_____
    20-50 miles_____
    more than 50 miles_____

23. What transportation do you use?

car_____
do you drive_____
bus_____
friends_____
relatives_____

24. How often do you call?

_____times a day
_____times a week

25. Did you expect this baby to be premature or ill?

yes_____ no_____

26. Did you have a tour of the NSCU before your baby was born?

yes_____ no_____

27. How long has your baby been in the NSCU?

_____days

28. Are you now or have you previously attended parent support meetings? If yes, how often?

yes_____ no_____

29. Who is helping you at home while your baby is in the hospital?

your other children_____
your siblings_____
your parents_____
your partner's parents_____
friends_____
others_____

30. What concerns you the most at this time?
your infant's medical condition?_____
how you will pay for the costs of hospitalization?_____
family problems before the birth of this infant?_____
family problems that have occurred since the birth of this infant?_____
Other:

31. If 1 is low and 10 is high, how would you rate <u>your</u> stress level:

before the birth_____
now_____

APPENDIX B

Nurses' Background Information Form

Dear Nurses:

You are being asked to participate in a study to help nurses learn more about the needs of parents with infants in a Neonatal Special Care Unit (NSCU). Nurses are being asked to fill out the questionnaire parents are given in order to compare parent and nurse response to the items pertaining to parental needs and parents satisfaction with interventions employed in an NSCU.

To clarify any previous experience you may have had as a parent of an infant in an NSCU you are asked to fill out the background information form below. All information is confidential.

Your participation will help to develop nursings' knowledge about what parents need and find helpful when their infant is in an NSCU. Your input is valuable and appreciated.

Thank You!

Elizabeth Turner

1. How long have you worked in the NSCU? 1 year_____ more than one year_____

2. Age: _____

3. Are you a parent? yes_____ no_____

4. Has a child of yours ever been a patient in an NSCU? yes_____ no_____

7. Has a child of yours ever died in infancy? yes_____ no_____

APPENDIX C

Questionnaire

The following are statements about the possible needs of parents of infants in an NSCU. To the right of each statement is a series of numbers, 1-6. The numbers match statements about whether or not you agree with the sentence. Please circle the number that matches the amount of agreement or disagreement you feel about the statement. The numbers mean: 1=strongly disagree, 2=disagree, 3=slightly disagree, 4=slightly agree, 5=agree, 6=strongly agree.

1.	Parents need consistent information from staff members.	1 2 3 4 5 6
2.	Parents need to know about their infant's progress.	1 2 3 4 5 6
3.	Parents need to know about set-backs in their baby's condition.	1 2 3 4 5 6
4.	Parents should be told about changes in their baby's conditon when they occur.	1 2 3 4 5 6
5.	Parents need to be given information in a realistic and honest way.	1 2 3 4 5 6
6.	Parents do not need to be encouraged to cry and express emotion.	1 2 3 4 5 6
7.	Parent's concerns should be answered by the staff.	1 2 3 4 5 6
8.	Parents need privacy when they visit.	1 2 3 4 5 6
9.	Parents need to be listened to.	1 2 3 4 5 6
10.	Parents need to help take care of their baby while he/she is in the NSCU.	1 2 3 4 5 6
11.	Parents need their support persons to be involved.	1 2 3 4 5 6
12.	Parental authority needs to be respected by those caring for their baby.	1 2 3 4 5 6
13.	Parents should help make decisions about their baby's medical care.	1 2 3 4 5 6
14.	Parents should help make decisions about their baby's nursing care.	1 2 3 4 5 6
15.	Parents need to know that the staff takes a special interest in their baby.	1 2 3 4 5 6
16.	Parents need help dealing with the costs of the hospitalization.	1 2 3 4 5 6

1=strongly disagree, 2=disagree, 3=slightly disagree,
4=slightly agree, 5=agree, 6=strongly agree

17.	Parents need help dealing with the stress of the hospitalization.	1	2	3	4	5	6
18.	Parents need to feel welcome when they visit.	1	2	3	4	5	6
19.	Parents need to help take care of their baby no matter how sick he/she is.	1	2	3	4	5	6
20.	Parents need the nursing staff to support their care giving efforts.	1	2	3	4	5	6
21.	Parents need the nursing staff to teach them how to take care of their baby.	1	2	3	4	5	6
22.	Parents need the staff to allow them time alone with their baby at the bedside.	1	2	3	4	5	6
23.	Parents need to bring toys in for their baby.	1	2	3	4	5	6
24.	Parents need to decorate their baby's bedside.	1	2	3	4	5	6
25.	Parents need to feel that the staff likes their baby.	1	2	3	4	5	6
26.	Parents need to know how the NSCU is run.	1	2	3	4	5	6
27.	Parents need to know which nurse will be caring for their infant each shift.	1	2	3	4	5	6
28.	Parents need to be able to request certain nurses for their baby.	1	2	3	4	5	6
29.	Parents need to be comfortable in the NSCU.	1	2	3	4	5	6
30.	Parents need to have confidence in their baby's care givers.	1	2	3	4	5	6
31.	Parents need to trust their infant's care givers.	1	2	3	4	5	6
32.	Parents need to have a say in who takes care of their baby.	1	2	3	4	5	6
33.	Parents need to have staff members follow their wishes/preferences.	1	2	3	4	5	6
34.	If parents have disagreements with staff members, they need help in working them out.	1	2	3	4	5	6
35.	Parents need to know their opinions are valuable.	1	2	3	4	5	6

1=strongly disagree, 2=disagree, 3=slightly disagree,
4=slightly agree, 5=agree, 6=strongly agree

3

36. Are there other needs that have not been covered by these questions? yes_____ no_____.

If yes, please describe these needs below:

1=strongly disagree, 2=disagree, 3=slightly disagree,
4=slightly agree, 5=agree, 6=strongly agree

The following are interventions the staff does to help meet the needs of parents in an NSCU. As with the previous questions, you are asked to circle the number that matches how satisfied you were with the intervention. Also, the staff persons most often meeting this need for you needs to be mentioned (nurse (RN), doctor(MD), social worker(SW), other. If you choose other, please identify that person. There is a second row of numbers for each statement. Please circle the number that matches how useful you felt the intervention was.

37.	Conferences with staff members	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
38.	Regular telephone calls	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
39.	Telephone calls following conditions changes	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
40.	Telephone calls following diagnostic procedures	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
41.	One nurse overseeing the care of your baby	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
42.	Parent rooms	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
43.	Open visiting hours	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
44.	Allowing friends to visit	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
45.	Allowing the baby's brothers and sisters to visit	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
46.	A nurse whose job is to help families.	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
47.	The same nurses caring for their baby.	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6

Allowing parents to do the following for their baby:

48.	take the temperature	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
49.	diaper	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6

1=strongly disagree, 2=disagree, 3=slightly disagree,
4=slightly agree, 5=agree, 6=strongly agree

5

50.	bottle feed	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
51.	gavage feed	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
52.	hold	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
53.	bathe	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
54.	give medications	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
55.	help with nursing procedures	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
56.	help with physical therapy	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
	Providing parents with mementos:	
57.	locks of hair	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
58.	pictures	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
59.	foot-prints	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
60.	decorations	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
61.	name cards	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
62.	donated gifts	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
63.	donated clothing	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
64.	calendars noting infant progress	1 2 3 4 5 6 RN MD SW Other Usefulness: 1 2 3 4 5 6
65.	calendars filled out by nurses	1 2 3 4 5 6 RN MD SW Other

1=strongly disagree, 2=disagree, 3=slightly disagree,
4=slightly agree, 5=agree, 6=strongly agree

Usefulness: 1 2 3 4 5 6

66. photographs — 1 2 3 4 5 6 RN MD SW Other
Usefulness: 1 2 3 4 5 6

Rooming-in:

67. whenever possible — 1 2 3 4 5 6 RN MD SW Other
Usefulness: 1 2 3 4 5 6

68. before discharge — 1 2 3 4 5 6 RN MD SW Other
Usefulness: 1 2 3 4 5 6

Taught activities to help develop the parent/infant relationship:

69. infant stimulation techniques — 1 2 3 4 5 6 RN MD SW Other
Usefulness: 1 2 3 4 5 6

70. appropriate toys — 1 2 3 4 5 6 RN MD SW Other
Usefulness: 1 2 3 4 5 6

71. tape recordings — 1 2 3 4 5 6 RN MD SW Other
Usefulness: 1 2 3 4 5 6

Other:

72. Assistance in reading notes on the chart — 1 2 3 4 5 6 RN MD SW Other
Usefulness: 1 2 3 4 5 6

73. Involvement in making care plans — 1 2 3 4 5 6 RN MD SW Other
Usefulness: 1 2 3 4 5 6

How useful do you think each of the following interventions might be and which staff person would most likely be the one performing them?

74. infant massage techniques — 1 2 3 4 5 6 RN MD SW Other

75. video recordings — 1 2 3 4 5 6 RN MD SW Other

76. Infant stimulation programs — 1 2 3 4 5 6 RN MD SW Other

77. Special parent classes — 1 2 3 4 5 6 RN MD SW Other

78. Grandparent support groups — 1 2 3 4 5 6 RN MD SW Other

79. Sibling support groups — 1 2 3 4 5 6 RN MD SW Other

80. Insurance/finance counseling — 1 2 3 4 5 6 RN MD SW Other

1=strongly disagree, 2=disagree, 3=slightly disagree,
4=slightly agree, 5=agree, 6=strongly agree

7

81. Parent manuals 1 2 3 4 5 6 RN MD SW Other

82. Are there other things that could have been done for you that would have been helpful? yes_____ no_____
What are these?

1=strongly disagree, 2=disagree, 3=slightly disagree,
4=slightly agree, 5=agree, 6=strongly agree

APPENDIX D

Parents' Information Letter

Date:

Dear _____:

I am a registered nurse and a graduate student in the family nursing department at the Oregon Health Sciences University in Portland. I am conducting an investigation into the needs of parents of infants in a neonatal special care unit (NSCU). I am also investigating parental satisfaction with the interventions staff, particularly nurses, use to help meet parental needs.

Nurses working in NSCUs will be asked to participate in the study so that comparisons may be made between parent and nurse responses to questions regarding parental needs and satisfaction with interventions.

Many personal factors influence parental needs. Because of this, background information is needed from study participants. All of the information collected will be confidential. Participant's identities will be known only to the researcher.

There are no direct risks to participants in the study. Benefits include helping to develop strategies for meeting the needs of future parents whose infants are in the NSCU. Also, the development of nursing's knowledge about what parents need and find helpful will be valuable. Benefits to your participation are that you may be able to help improve the quality of care to families in an NSCU.

This study has been reviewed and approved by the review board at _____Hospital. Those persons agreeing to participate in the study will be asked to fill out an informed consent form. After this is completed, participants will be asked to fill out a background information form and a two part questionnaire. Parents are asked to fill out the questionnaire two separate times coinciding with stages of their infant's care an the NSCU. The amount of time reqiured for filling out the forms is estimated to be one hour the first time and thrity minutes the second time.

Your participation in this study is voluntary. You may withdraw from the study at any time without consequence to you or your infant. If you have any questions please do not hesitate to call the researcher, Elizabeth Turner at (503) 224-6241.

Sincerely,

Elizabeth Turner

APPENDIX E

Nurses' Information Letter

Date:

Dear _____:

I am a registered nurse and a graduate student in the family nursing department at the Oregon Health Sciences University in Portland. I am conducting an investigation into the needs of parents of infants in a neonatal special care unit (NSCU). I am also investigating parental satisfaction with the interventions staff, particularly nurses, use to help meet parental needs.

Parents of infants in an NSCU are being asked to fill out a background information form and a questionnaire. The questionnaire contains two parts, the first describing parental needs and the second listing interventions, on two separate occasions coinciding with their infants care in an NSCU.

Nurses are being asked to fill out the questionnaire parents are given in order to compare parent and nurse response to the items pertaining to parental needs and parent satisfaction with interventions employed in an NSCU.

There are no direct risks to participants in the study. Benefits include helping to develop strategies for meeting the needs of future parents whose infants are in an NSCU. Also, the development of nursings' knowledge about what parents need and find helpful will be valuable. Benefits to your participation are that you may be able to help improve the quality of care to families in an NSCU.

This study has been reviewed and approved by the review board at _____Hospital. Those persons agreeing to participate in the sutdy will be asked to fill out an informed consent form. After this is completed, participating nurses will be asked to fill out the two part questionnaire one time only. The amount of time required for completing the questionnaire is estimated to be forty minutes.

Your participation in this study is volunatry. You may withdraw from the study at any time. Your identity will be known only to the researcher, Elizabeth Turner.

If you have any questions please do not hesitate to call the researcher at (503) 224-6241.

Sincerely,

Elizabeth Turner

APPENDIX F

Parents' Informed Consent

Parent's Informed Consent Form

I,_____, agree to serve as a subject in the investigation named, The needs of parents of infants in an NSCU, by Elizabeth Turner, RN, under the supervision of Marie Scott Brown, RN, PhD. The purpose of this investigation is to determi
ne whether parents and nurses have similiar or different ideas concerning the needs of parents whose infants are in an NSCU. Evaluation of interventions commonly used in an NSCU is included in the study. Comparisions will be made between parent and nurse responses to questions about parental needs and satisfaction with interventions employed in an NSCU.

I understand that I will be asked to fill out a background information form and a two part questionnaire. The questionnaire is to be filled out two times. I understand that this information is confidential and that my identity will be known only to the researcher, Elizabeth Turner.

I understand that the benefit to my participation in this study is to help improve the quality of care to families of infants in an NSCU by providing information that will be useful to nurses regarding parental needs and the effectiveness of interventions. There is no personal gain for myself or my infant.

I understand that there are no direct risks to my participation in this study.

I understand that I may withdraw from the study at any time without affecting my relationship with or the care my infant is receiving at _____Hospital.

Elizabeth Turner, RN, has offered to answer any questions I might have about my participation in this study. I can contact her at (503) 224-6241.

I have read the above statements and agree to participate in the study as described.

Date:_____ Signature_____

Time:_____

Witness_____

APPENDIX G

Nurses' Informed Consent

Nurses Informed Consent Form

I, _____, agree to serve as a subject in the investigation named, The needs of parents of infants in an NSCU, by Elizabeth Turner, RN, under the supervision of Marie Scott Brown, RN, PhD. The purpose of this investigation is to determine whether parents and nurses have similiar or different ideas concerning the needs of parents whose infants are in an NSCU. Evaluation of interventions commonly used in an NSCU is included in the study. Comparisions will be made between parent and nurse responses to questions about parental needs and satisfcation with interventions employed in as NSCU.

I understand that I will be asked to fill out a two part questionnaire, with one part containing questions about the needs of parents of infants in an NSCU. The second part of the questionnaire contains questions pertaining to parent satisfaction with interventions used in the NSCU for meeting parent needs.

I understand that participation in this study is voluntary and that I may withdraw at any time. My identity will be known only to the researcher, Elizabeth Turner. I understand that partcipation in this study is confidential and that I was chosen through a process of random selection.

There are no direct risks to me by participating in this study. Benefits may include the development of nursing strategies to meet the needs of parents of infants in an NSCU.

Elizabeth Turner, RN, has offered to answer any questions I might have about my participation in this study. I can contact her at (503) 224-6241.

I have read the above sta'ements and agree to participate in the study as described.

Date:_____ Signature_____
Time:_____

Witness_____

APPENDIX H

Questionnaire Items Included in the

Scales Used for Data Analysis

Scales	Parental Needs	Satisfaction with Interventions	Usefulness of Intervention
Pertinent Questionnaire Items	1-35	37-73	37-81
	1. Communication/ Information 1, 2, 3, 4, 5, 9 alpha = 0.39	37, 38, 39, 40, 41, 42, 46, 47 alpha = 0.78	37, 38, 39, 40, 41, 42, 46, 47, 72 alpha = 0.69
	2. Alliance 13, 14, 15, 33, 35 alpha = 0.75	37*, 41*, 43*, 72*, 73 alpha = 0.77	37, 41, 43, 72, 73 alpha = 0.72
	3. Support 11, 16 alpha = 0.65	41*, 43*, 44, 45, 46*, 47*, 64, 65, 66*, 67, 68 alpha = 0.65	41, 43, 44, 45, 46, 47, 64, 65, 66, 67, 68 alpha = 0.63
	4. Participation 10, 13*, 14*, 19, 21, 23, 24, 32 alpha = 0.75	48, 49, 50, 51, 52 53, 54, 55, 56, 57, 58, 59, 60*, 61*, 62, 63, 66*, 67*, 68*, 69, 70, 71, alpha = 0.85 alpha = 0.89	48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 66, 67, 68, 69, 70, 71 alpha = 0.76

Scales	Parental Needs	Satisfaction with Interventions	Usefulness of Intervention
Pertinent Questionnaire Items	1-35	37-81	37-73
	5. Environment 8, 18, 22, 24* alpha = 0.43	42*, 60*, 61* alpha = 0.61	42, 60, 61 alpha = 0.63

* Indicates those items repeated in needs and satisfaction scales* deleted from usefulness scales as these scales necessarily repeated items from satisfaction categories.

** Appendix C contains all items included in the questionnaire.

APPENDIX I

Agreement with Statements of Parental Needs

(% Scores with "Agree," "Strongly Agree")

Questionnaire Item *	Parents		Nurses
	Time 1	Time 2	
1	100	100	100
2	100	100	100
3	100	88	100
4	100	87	100
5	100	100	100
6	55	51	93
7	90	87	100
8	70	100	86
9	100	100	100
10	90	100	100
11	89	100	100
12	90	75	80
13	30**	50**	77
14	50	63	87
15	100	100	100
16	70	88	100
17	80	88	100
18	100	100	100
19	70	88	53
20	80	100	100
21	90	100	100
22	80	100	100
23	90	88	87
24	90	88	73
25	100	88	100
26	80	63	71
27	90	76	78
28	70	38	41
29	90	88	100
30	100	100	100
31	100	100	100
32	70	63	60
33	33***	76	86
34	80	100	100
35	90	100	100

* Appendix C contains all items included in the questionnaire.

** 50% slightly agree.

*** 44% slightly agree.

APPENDIX J

Results of T-tests at Times 1 and 2 Between Mothers and Fathers on Scales Representing Parental Needs

Scale	M	SD	t
Communication			
Time 1:			
Mothers	29.00	0.63	
Fathers	29.75	0.50	-1.98
Time 2:			
Mothers	28.75	1.50	
Fathers	29.00	1.41	-0.24
Alliance			
Time 1:			
Mothers	24.92	2.84	
Fathers	23.75	4.65	0.50
Time 2:			
Mothers	25.75	3.10	
Fathers	26.00	4.10	-0.10
Support			
Time 1:			
Mothers	10.17	1.33	
Fathers	10.75	1.90	-0.58
Time 2:			
Mothers	11.00	1.41	
Fathers	11.25	1.00	-0.29
Participation			
Time 1:			
Mothers	41.00	2.97	
Fathers	39.25	5.50	0.66
Time 2:			
Mothers	43.00	3.27	
Fathers	40.60	4.65	0.85
Environment			
Time 1:			
Mothers	20.83	1.94	
Fathers	22.25	2.07	-1.10
Time 2:			
Mothers	23.50	1.00	
Fathers	22.75	1.00	1.08

(p=<0.05)

APPENDIX K

Results of T-tests at Times 1 and 2 Between Parents and Nurses on Scales Representing Parental Needs

Scale	M	SD	t
Communication			
Time 1:			
Parents	29.30	0.68	
Nurses	28.80	1.32	-1.10
Time 2:			
Parents	28.88	1.36	
Nurses	28.80	1.32	-0.13
Alliance			
Time 1:			
Parents	24.45	3.47	
Nurses	25.42	3.05	0.74
Time 2:			
Parents	25.58	3.36	
Nurses	25.42	3.05	-0.33
Support			
Time 1:			
Parents	10.40	1.51	
Nurses	11.13	0.83	1.57
Time 2:			
Parents	11.13	1.13	
Nurses	11.13	0.83	0.02
Participation			
Time 1:			
Parents	40.30	3.97	
Nurses	39.11	5.55	-0.61
Time 2:			
Parents	41.80	3.93	
Nurses	39.07	5.55	-1.23
Environment			
Time 1:			
Parents	21.40	2.01	
Nurses	20.80	1.47	-0.86
Time 2:			
Parents	23.13	0.99	
Nurses	20.80	1.47	-3.99*

(p=<0.05)

APPENDIX L

Agreement with Statements of Satisfaction with Interventions

(% Scores of "Agree," "Strongly Agree")

Questionnaire Item *	Parents		Nurses
	Time 1	Time 2	
37	88	100	64
38	88	100	86
39	88	88	86
40	50	76	59
41	76	88	57
42	100	100	86
43	100	100	69
44	90	75	46
45	80	100	46
46	86	100	92
47	76	100	78
48	100	100	92
49	100	100	93
50	100	100	100
51	40	60	38
52	100	100	100
53	88	100	100
54	63	100	77
55	76	100	42
56	75	100	85
57	71	100	100
58	100	100	100
59	86	100	100
60	100	100	85
61	90	100	85
62	67	85	63
63	67	100	72
64	100	100	84
65	85	100	75
66	100	100	100
67	76	67	62
68	100	100	100
69	100	100	77
70	66	100	67
71	100	100	77
72	90	85	54
73	80	100	54

* Appendix C contains all items included in the questionnaire.

APPENDIX M

Agreement with Statements Regarding Usefulness of Interventions (% Scores of "Agree," "Strongly Agree")

Questionnaire Item *	Parents		Nurses
	Time 1	Time 2	
37	89	100	72
38	90	76	100
39	100	88	100
40	63	100	60
41	89	100	67
42	100	100	100
43	100	100	84
44	90	72	45
45	80	100	75
46	87	100	100
47	100	100	77
48	100	100	92
49	100	100	92
50	100	100	100
51	67	75	50
52	100	100	100
53	100	100	100
54	63	100	75
55	76	100	45
56	87	100	92
57	71	100	92
58	100	100	100
59	88	100	100
60	100	100	76
61	100	100	92
62	50	100	45
63	67	100	64
64	100	100	67
65	100	100	80
66	100	100	100
67	75	84	83
68	100	100	100
69	100	85	84
70	58	100	84
71	100	100	61
72	90	100	54
73	80	100	69
74	60	100	43
75	60	61	34
76	75	100	86
77	77	61	93
78	33	83	21
79	55	100	39

Questionnaire Item *	Parents		Nurses
	Time 1	Time 2	
80	76	100	90
81	100	61	92

* Appendix C contains all items included in the questionnaire.

APPENDIX N

Results of T-tests at Times 1 and 2 Between Parents and Nurses on Scales of Satisfaction with Interventions

Scale	M	SD	t
Communication			
Time 1:			
Parents	40.66	4 48	
Nurses	39.16	5.73	-0.63
Time 2:			
Parents	44.41	4.84	
Nurses	39.16	5.73	-2.18*
Alliance			
Time 1:			
Parents	31.33	3.63	
Nurses	27.32	4.99	-2.27*
Time 2:			
Parents	34.44	1.84	
Nurses	27.32	4.99	-3.85*
Support			
Time 1:			
Parents	59.37	3.54	
Nurses	53.81	4.34	-2.90*
Time 2:			
Parents	62.38	3.07	
Nurses	53.81	4.34	-4.01*
Participation			
Time 1:			
Parents	113.21	9.89	
Nurses	114.44	9.21	-0.26
Time 2:			
Parents	126.00	6.04	
Nurses	114.44	9.21	-2.58*
Environment			
Time 1:			
Parents	17.10	0.88	
Nurses	16.15	1.70	-1.62
Time 2:			
Parents	17.625	0.74	
Nurses	16.15	1.90	-2.33*

* p=<0.05

APPENDIX O

Results of T-tests Between Parents and Nurses at Times 1 and 2 Regarding Scales Measuring Usefulness of Interventions

Scale	M	SD	t
Communication			
Time 1:			
Parents	48.76	3.70	
Nurses	46.97	4.10	-1.02
Time 2:			
Parents	51.80	2.40	
Nurses	46.96	4.10	-2.82*
Alliance			
Time 1:			
Parents	32.96	2.85	
Nurses	28.86	4.69	-2.43*
Time 2:			
Parents	35.00	1.73	
Nurses	28.86	4.69	-2.43*
Support			
Time 1:			
Parents	60.81	4.52	
Nurses	57.52	4.58	-1.52
Time 2:			
Parents	62.53	2.92	
Nurses	57.52	4.58	-2.24*
Participation			
Time 1:			
Parents	101.50	9.14	
Nurses	99.65	6.60	-0.54
Time 2:			
Parents	112.60	1.67	
Nurses	99.65	6.60	-4.26*
Environment			
Time 1:			
Parents	17.35	0.75	
Nurses	16.15	1.35	-2.52*
Time 2:			
Parents	18.00	0	
Nurses	16.15	1.35	-3.59*

* p=<0.05

Questionnaire Item	Parents		Nurses
	Time 1	Time 2	
37	78	87	100
38	100	100	93
39	100	75	85
40	75	67	84
41	100	87	91
42	100	100	100
43	100	75	87
44	100	100	100
45	100	100	100
46	80	80	91
47	83	100	100
48	100	100	92
49	100	100	92
50	100	100	100
51	100	100	92
52	78	100	92
53	100	100	92
54	100	100	92
55	88	100	100
56	86	57	83
57	60	100	92
58	75	100	92
59	67	100	92
60	86	100	100
61	78	88	100
62	50	60	82
63	33	67	73
64	100	100	100
65	100	100	100
66	100	100	100
67	80	67	91
68	100	100	91
69	100	86	85
70	100	66	77
71	60	100	85
72	100	100	92
73	100	86	100
74	100	75	92
75	25	28	45
76	76	87	77
77	67	66	71
78	25	0	39
79	25	0	37
80	0	0	0
81	50	83	84

APPENDIX Q

Results of Paired T-tests Measuring Differences Over Time for Mothers and Fathers on Needs and Interventions (Satisfaction) Scales

	Needs Scales			Satisfaction with Interventions		
	M	SD	t	M	SD	t
Communication						
Mothers:						
Time 1	29.00	0.63		49.29	8.11	
Time 2	28.75	1.50	0.37	54.16	10.29	-0.80
Fathers:						
Time 1	29.75	0.50		50.33	7.10	
Time 2	29.00	1.41	1.00	55.75	4.20	-1.28
Alliance						
Mothers:						
Time 1	24.92	2.84		30.52	4.37	
Time 2	25.75	3.10	-0.44	35.63	0.75	-2.28
Fathers:						
Time 1	23.75	4.65		33.25	2.06	
Time 2	26.00	4.10	-0.73	33.25	1.89	0.00
Support						
Mothers:						
Time 1	10.17	1.33		76.84	5.41	
Time 2	11.00	1.41	-0.95	80.97	9.59	-0.80
Fathers:						
Time 1	10.75	1.89		73.51	11.46	
Time 2	11.25	0.96	-0.47	85.50	5.00	-1.34
Participation						
Mothers:						
Time 1	41.50	2.97		133.00	7.45	
Time 2	32.00	3.27	-1.01	142.76	4.54	-1.98
Fathers:						
Time 1	39.25	5.50		125.83	19.06	
Time 2	40.60	4.65	-0.38	141.32	9.61	-1.26
Environment						
Mothers:						
Time 1	20.83	1.94		17.167	0.41	
Time 2	23.50	1.00	-2.50*	17.75	0.50	-2.03
Fathers:						
Time 1	22.25	2.06		17.00	1.41	
Time 2	22.75	0.96	-0.44	17.50	1.00	-0.58

* p=<0.05

APPENDIX R

Statements Made by Parents in Response to Questionnaire Items 36 and 82

Question 36: Are there other needs that have not been covered by these questions?

"It was extremely difficult, frustrating and stressful to have 3 doctors in charge at different times in this last month. Very hard to have trust and relationship when switching so often. Parents already stressed. Each Dr. has a different personality and provide varied info."

"What about social workers? We were never introduced to one or asked if we would like to see one. I think it would have been helpful for many questions regarding insurance, payments, discharge, possible help with social security papers and talking about concerns without having this person on a time-line like nurses and doctors were."

"The hardest thing for us during our stay was the fact that our other children could not visit and had to stay with a baby sitter. This made it hard since we live 45 miles from the hospital and either had to haul everyone over to Portland or leave them with someone near our house. If the hospital offered some kind of supervised daycare (even if they charged for it) so moms could spend time with siblings when the baby was sleeping and make the children feel like they're part of visiting too. We have such a place at the Vancouver Clinic where I go for my OB visits and it's great."

"I feel the staff needs to keep things simple for the parents to understand--take time to explain the terms and what's happening and could happen in layman terms."

"The biggest problem we have had is in finding child care for our 3 other children. Our daughter has already been here a month--with 1-2 more to go and family and friends burn out real fast. A nursery in the hospital or even a referral service would be extremely helpful."

Parents need to know exactly what is going on. Doctors and nurses need to communicate so that when a parent asks a questions they get the same answer."

Question 82: Are there other things that could have been done for you that would have been helpful?

"I have been so pleased w/his care. I don't have any complaints. They only problem I have had is trying to use the parent rooms for breast-pumping--maybe 1 room could be used for pumping mothers and maybe a schedule."

"More discussion with the doctor--even if over the phone. Most are very good about letting the parents know what's going on but we need consistency.

Longer rotations would be nice. Stay with the same doctor longer.

Letting us help make some of the caring decisions, talking the situation over with us before going ahead when possible."

APPENDIX S

Statements Made by Nurses in Response to Questionnaire Items 36 and 82

Question 36: Are there other needs that have not been covered by these questions?

"Staff need training/retraining in crisis/crisis intervention. Bottom line--parents need to feel some level of control at whatever level."

"Parents need to have formal educational opportunities--their baby's disease process, developmental needs; info later on "down the road"--school performances, etc."

"Need help to anticipate emotional changes they will feel as a result of grief reactions and the different than expected outcome of pregnancy.

Need help to locate other support people within NSCU and outside (family, support groups, etc.) who can help during and after hospitalization.

Need to know they are not alone and are not the only one this happens to.

Need to know possible outcome for the baby of treatments.

Need to know if nontreatment of the problems are an option."

"Parents need to know that while we strive to have consistent caretakers for their infant while he/she is in our unit, they will most likely still see a variety of nurses caring for their baby. I strongly disagree with the idea that parents be able to dictate who will or who will not take care of their baby. Parents need to be told and (have reinforced throughout the baby's stay) that our entire unit is comprised of caring, competent, specially trained professionals."

"I feel that a lot of these questions depend on the family and the degree of illness of the child. We should make every possible effort to keep the family bonding."

Question 82: Are there other things that could have been done for you that would have been helpful?

"I think night nurses need to be helped to stay involved with parent conferences--always conflicting with our hours. Also I think a lot of responsibility is heaped on us to deal with families, bonding, stimulation, etc. When the assignments are light this is fine but when our assignments are heavy care comes first and other things have to be neglected--we have no choice.

So unless grasp numbers can really show the time spent on parents needs these desire are extras--things I would love to be able to do one constant basis."

Authors note: "grasp numbers" are patient acuity ratings used in determining nurse to patient rations for staffing purposes.

"Access to flowers for pictures especially for dying/ deceased infants. Time to support, teach and be with parents."

"More private times for parents with infants, even (or especially) very sick infants. Our parents seem hesitant to talk 'baby talk' with their babies. Any they are rarely able to put their faces next to their babies, actually touching and sensing them. This may help improve bonding in spite of the high tech environment."

Abstract

Title: The Needs of Parents of Infants in the NSCU

In order to clarify the needs of parents of infants in a neonatal special care unit (NSCU) five domains of parental needs were conceptualized and a questionnaire based on these domains was created. Four sets of parents of infants in an NSCU participated in the study, filling out questionnaires two weeks after admittance of their infant and two weeks following discharge from the NSCU. Fifteen nurses working in a NSCU were sampled using the same questionnaire for comparison purposes. The tool asked respondents to indicate agreement with statements pertaining to parental needs and satisfaction with and usefulness of interventions employed in the NSCU to meet these needs. Respondents were asked to identify those persons most likely to meet these needs. Data was analyzed by parent groupings (mothers, fathers, parents) and nurses with comparisons made among groups. The results of this study indicate general agreement among groups with statements of parental needs. Parents placed emphasis upon involvement in decision making and infant care activities. Nurses indicated reluctance to have parents choose specific nurses to care for their infant and involvement by parents in some caretaking activities. Agreement on satisfaction with and usefulness of interventions was seen

among groups, with parents increasing their agreement on some items at time two. Nurses were identified over any other person as the individuals most likely to perform interventions. Further tool development with a larger sample is necessary before these results may be generalized to larger populations.

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