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CREATING MOTHERING FOR PRETERM INFANTS:
A GROUNDED THEORY OF VETERAN PARENT SUPPORT
INITIATED IN A NEONATAL INTENSIVE CARE SETTING
presented by

LEE ANNE WALSH ROMAN

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of the requirements for

Ph.D. degree in Family Ecology

A handwritten signature in cursive script that reads "Linda Nelson".

Major professor

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CREATING MOTHERING FOR PRETERM INFANTS:
A GROUNDED THEORY OF VETERAN PARENT SUPPORT
INITIATED IN A NEONATAL INTENSIVE CARE SETTING

By

Lee Anne Walsh Roman

A DISSERTATION

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ABSTRACT

CREATING MOTHERING FOR PRETERM INFANTS: A GROUNDED THEORY OF VETERAN PARENT SUPPORT INITIATED IN A NEONATAL INTENSIVE CARE SETTING

By

Lee Anne Walsh Roman

Lack of research about the processes and outcomes of veteran parent-to-parent support that is initiated in the Neonatal Intensive Care Unit (NICU) has restricted the development of this clinical intervention and has threatened the continued subsidization of such programs by health care organizations. This study was undertaken to conceptualize the processes of NICU veteran parent support so that relationships between process and outcomes of the intervention could be tested in the future. Additionally, the research will provide information to professionals who provide service to families with NICU-involved children.

This study was a component of a comprehensive demonstration and research evaluation program entitled: NICU/Perinatal Positive Parenting, a program for families with high risk infants in the Neonatal Intensive Care Unit.

Grounded theory methodology was used to identify and describe the processes of parent-to-parent support. Ethnographic interviews, observations and document inspection were the primary methods of data collection. Data were collected from NICU parents and their veteran support parent over a two year period of time from 1985 to 1987. An emerging conceptual model of parent-to-parent support was the study outcome that could be used to generate future research questions and propositions.

The findings of the study suggest that the central process which explains and clarifies the interaction between parents is a process called **being with/creating mothering**. This process can be defined as a physical and/or psychological proximity between an experienced NICU parent and an NICU parent, a space that is non-judgmental and caring, that enables the new mother to see, hear and create for herself a new mothering style that is sensitive to both the needs of her vulnerable infant and herself. Preliminary processes of parent support and conditional variables that affect the process were identified and integrated into a conceptual model from which propositions and research questions were developed.

To those parents who welcomed me into their private lives for the purpose of helping parents and professionals better understand the NICU experience--

I salute you---for your courage, your honesty, your patience, your persistence, and your caring for each other and families who are like yours.

To my own family: husband, Jim, and sons, Tim and Brian, who supported me throughout all aspects of this work--

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CHAPTER ONE

INTRODUCTION

Professional staff in the Neonatal Intensive Care Unit (NICU) have been concerned with the needs of parents of the critically ill and/or preterm infant. They have sought strategies to help families cope with this experience in ways that may enhance positive parenting relationships (Boukydis, 1982; Eager and Exoo, 1980; Field, 1980; Garrand, 1978). One intervention that health care providers have found useful is the development of supportive relationships between experienced NICU parents, whose infants have been discharged from the unit, and those parents who are currently involved in NICU care (Eager and Exoo, 1980). Although the particular forms of such supportive interventions vary, the purpose is similar. The purpose is to give the parent whose infant is in the NICU access to someone who understands the parent's experience and has practical knowledge of the NICU as well as parenting a sick and/or preterm infant. This endeavor can be labeled veteran parent support or experienced parent support. Such activity

can be described as support from another parent whose infant has been hospitalized in an NICU. While parent could refer to either mother or father, traditionally the support relationship is maintained by mothers.

Background of the Problem

The birth of a preterm infant and the subsequent hospitalization in an NICU is a significant stressor event for the family system (Blake, Stewart and Turcan, 1975; Caplan, 1960; Kaplan and Mason, 1960; Newman, 1980; Paludetto and Faggiano-Perfetto, 1981). Families who experience the birth of a preterm infant are faced with the simultaneous tasks of adapting to an intensive care unit environment, coping with the feelings of anxiety and grief that accompany a preterm birth, and forming a beginning parenting relationship with an infant who has developmental capabilities which limit participation in social interaction. Although survival rates for low birthweight infants have improved and the incidence of subsequent major handicaps is decreasing since the advent of NICU care, there is support for the belief that the preterm infant is a more difficult child to parent in the first year of life (Brazelton, 1981; Goldberg and DeVitto, 1983). Additionally, many of these children will also have what health care professionals label as mild developmental problems related to their prematurity. There is conflicting research evidence about whether NICU parents are more at risk than non-NICU parents for parental dysfunction (Hunter and Kilstrom, 1978;

Klein and Stern, 1971; Leventhal, 1981). However, there is enough concern for professionals to attempt to provide clinical support for these families as they begin the difficult task of parenting their preterm infants.

Recent studies, to be reviewed in detail later, suggest that higher levels of maternal social support facilitate mother-infant interaction. However, no attempt to document parent or family outcomes for those parents who participate in a one-to-one veteran parent support relationship has been found. Limited evidence does exist to sustain the notion that positive maternal behaviors increased for mothers who participated in a parent support group that was co-led by a veteran parent during the infant's NICU hospitalization (Minde, Shosenburg, and Marton, 1980; Minde, Shosenburg, Thompson and Marton, 1983).

Regardless of such a limited knowledge base about the process or outcomes of veteran parent support, health care providers and/or parents have widely initiated veteran parent support programs (Mangurten, Slade and Fitzsimmons, 1979; Shosenburg, 1980). Most of these programs have been operationalized with part-time professional input and supported with community funds, such as local March of Dimes organizations. However, lack of research to document the process or outcomes of this intervention has jeopardized the continuation of funding by external organizations or the securing of internal funding within the hospital system (Streeter, personal communication, March, 1987). In a

hospital system where such a program was discontinued, a majority of parents surveyed indicated that they would have liked an opportunity to meet with an experienced parent (Robertson, 1983). Health care providers who choose to provide veteran parent support services as a means of strengthening families need access to an expanded knowledge base about the processes of the support relationship in order to be able to begin to measure the outcomes of such an intervention. Additionally, providers need to understand the conditions that might optimize such an intervention and identify any aspects that inadvertently may create difficulties for families.

Statement of Purpose

Since 1981, the Institute for Family and Child Study at Michigan State University has been involved in research demonstration efforts to study parent-to-parent support. A primary prevention program that focused on first-time mothers and their full term, healthy infants, Perinatal Positive Parenting, was developed and evaluated. The results of this evaluation indicated that program families had significantly better maternal involvement and child-nurturing environments that control families at 15 months (Boger, Richter, Kurnetz and Haas, 1986). In 1985, the research institute secured funding to further develop the Perinatal Positive Parenting model for families whose infants are hospitalized in a Neonatal Intensive Care Unit and evaluate the processes and outcomes of such a program

(Boger, Roman and Haas, 1987). This study represents the qualitative analysis of support processes that complements the quantitative program evaluation. The purpose of this study was to: a) gain insight into the complex phenomena of veteran parent support from the viewpoint of the participants, b) conceptualize the processes of support in order to be able to identify and test relationships between process and outcomes of the intervention, and c) enhance the understanding of health professionals who serve families with NICU-involved children.

Statement of Research Questions

1. What is involved in veteran support parent relationships initiated in an NICU setting?
 - A. What happens when a veteran support parent has contact with a parent whose infant is or has been hospitalized in a NICU setting?
 - B. How do veteran support parents, NICU parents and other observers describe the relationship?
2. What is the central complex process that explains and clarifies the interaction between individuals under study?
 - A. What are the supporting processes?
 - B. What are the conditions under which it occurs?
3. What propositions or research questions can be generated from the emerging theory for future research?

Conceptual Background

Symbolic interaction theory and a family ecological perspective were used as the researcher's frame of reference for approaching the research problem. Symbolic interaction is a theory of the inner or experiential aspects of human behavior, that is, how people act in relation to their beliefs (Chenitz and Swanson, 1986). Symbolic interaction theory guided the researcher to study behavior on two levels: the behavioral/interactional level and the symbolic level, with the full range and variation of behavior sought (Denzin, 1970). The researcher who uses symbolic theory attempts to understand behavior as the participants understood it, learn about their world, learn about their interpretation, and then translate the meaning derived to the language of the research discipline (Chenitz and Swanson, 1986). Grounded theory is a process of research that was developed from symbolic interaction theory. This grounded theory approach guided the researcher in viewing the participants of parent support, the NICU parent and the experienced parent, as those most knowledgeable about interpreting the processes of parent support, both in behavior and in descriptions of the processes.

A family ecological perspective was useful in drawing attention to the processes of support and the participants of parent support in their life context. Experienced parents and NICU parents were viewed as members of two distinct family systems. These two family systems are

embedded in environments that provide both resources and demands , which can enhance or limit the potential for the growth and development of family members (Paolucci, Hall and Axinn, 1977). The NICU family system, at the time of the initiation of the support relationship, is coping with the NICU as a highly stressful, new environment. The program that facilitates the establishment of the support relationship and the support parents are important components of the environment for the NICU family.

The transactions that occur between family members and the environment are a critical component of a family ecological perspective. Transactions between family and environment can be defined as the mutual, simultaneous influences that occur between the individual family member and the family system and the family system and the environment (Melson, 1980). Stress can arise from a transaction between the family and environment if the family perceived environmental input as damaging, threatening or challenging (Scott, Oberst, and Dropkin, 1980). If environmental demands increase and resources are not available or mobilized, the family may not be able to sustain adequate family functioning and allow for the full development of all family members while maintaining a functional unit (Whall, 1982).

The family ecological perspective guided the researcher to broaden the scope of the investigation from a view of only the veteran support parent and the NICU parent to a

more holistic view of the parents' family systems embedded in complex environments. The processes of support will be conceptualized broadly as any transaction between the NICU parent and the veteran parent perceived either as helpful or as an additional resource or demand.

Assumptions

The following assumptions were made by the researcher prior to the initiation of the research process:

1. The ability of the family system to maintain its functioning is challenged by the birth of an infant who is critically ill and requires NICU care.
2. Whether the family is able to perform its functions effectively, including its child nurturing function, depends on the resources the family brings to the situation and the availability of external resources that may augment the family's resources.
3. The health and development of the preterm infant and other family members are viewed as outcomes of the transaction between the individual family member, the family unit and the environment in which the family is embedded.
4. Veteran support parents, NICU parents and professional health care providers will be able to articulate or describe in writing their perceptions of the processes of veteran parent support.

Definitions

In using grounded theory methodology the traditional approach of deciding on operational definitions of important concepts in advance of collecting data is not used (Wilson, 1985). Instead, concept specification is used where concepts are identified as data are collected and analyzed (Glaser and Strauss, 1967). However, in order to clarify how selected terms are used in this research, the following terms will be defined:

Family: Those persons whom the veteran mother or the supported mother identify in response to the question "Whom would you identify as family members?"

Neonatal Intensive Care Unit (NICU): a hospital-based, specialized nursery, usually designated a level III (referral) facility, equipped and staffed to admit for care those infants who are critically ill due to prematurity, congenital or neonatal illness.

Preterm infant: A preterm infant is generally considered to be an infant who was born less than or equal to 37 weeks gestation. For the purposes of this study, a preterm infant is described as an infant with no diagnosed congenital anomalies, born less than or equal to 37 weeks gestational age, weighing less than 2500 grams and hospitalized in an NICU for a minimum of one week.

Support: Any behavior or action that a parent whose infant is or has been hospitalized in a NICU perceives as being helpful in coping with parenting a preterm infant.

Veteran support parent: A parent who has coped with the experience of having his/her own child hospitalized in an NICU, whose child has been discharged from the NICU for over a year's period of time, who has participated in a group preparation program and assumes a supportive role with parents whose infant is currently in the NICU or discharged from the unit for less than eighteen months. Such a parent may also be referred to as an experienced parent.

New NICU parent: A parent whose infant is either currently hospitalized in the NICU or whose infant has been discharged less than 18 months after a minimum of one week stay.

Significance of the Study

At this point in time, no published research on the clinical intervention of dyadic parent-to-parent support in the NICU setting has been found. Although there are many such support programs being carried out across the country, continued funding for these programs is currently jeopardized because of the lack of evaluation research. This research will call attention to the delivery of this non-traditional health care service and increase the professional's understanding of the mechanisms of this intervention. This will enable the professional care provider to optimize the intervention and try to prevent unintended negative consequences for the families involved in such a program.

Because the grounded theory methodology is particularly suited to a careful study of all the personal and environmental characteristics which shape the central process of support, this study will contribute to an ecological understanding of families and health crises. The methodology will be useful to clarify future research directions in the study of social support interventions and families at risk for health and developmental problems.

CHAPTER TWO

PRELIMINARY LITERATURE REVIEW

Consistent with the methodology of grounded theory, this preliminary literature review described a few selected research studies that support the selection of the research problem and the proposed research strategies. Literature was again reviewed as concepts were identified and developed in the process of data analysis.

Since the researcher has been unable to locate research evidence that documents the process or outcomes of experienced parent-to-new parent support initiated in a NICU setting, this review will briefly cover what is known about the participants in this relationship. This will include what is known about parents with an infant currently hospitalized in the NICU, and parents whose infant has been discharged from an NICU who form the pool of volunteers for the support role. Written documents that relate to NICU support parent processes will also be used to begin the study. Additionally, a review of literature that describes experienced, lay support for other health crises will be

described. Only those studies that focus on the support person who has coped with a physical and/or psychological problem in the past and who now volunteers to support a person with a similar problem will be reviewed.

Prior to undertaking the review, it is important to note that most of what is written about NICU parents is primarily related to parents of preterm infants. Studies of parents whose infants have congenital anomalies or acute neonatal disease will not be included in this review. The former has a distinct body of literature in which parental adaptation to the child's handicap and the early NICU experience are interwoven and difficult to distinguish. The latter group, those infants with neonatal disease, has not been carefully studied, since many children with neonatal illness are also born prematurely.

The Period of Birth and NICU Hospitalization

Maternal Reaction To Premature Birth: Classic Studies

The majority of the early research that described parents of preterm infants was focused on the mother's responses to the birth of the premature. Caplan, Mason, and Kaplan (1965) and Kaplan and Mason (1960) conducted the classic studies that described the emotional problems of mothers who deliver prematurely. Data consisted of records representing 86 cases of preterm births. No sampling procedures were used. Data were collected by observation and interview. Families were visited by the researchers within seven to ten days after birth during a routine public

health nursing home visit. The interviews were conducted by a variety of interviewers. The families were visited approximately 11 times during the three months following the infant's discharge from the preterm nursery.

Caplan (1960) analyzed 10 cases and had an independent judge rate the parental outcome as "healthy" or "unhealthy". Healthy was defined as characterized by unambiguous, positive evidence that the dyadic relationships among family members were at least as "healthy" as prior to the preterm birth. "Unhealthy" was defined as characterized by evidence that one dyadic relationship in the family appeared to be worse after the birth. Healthy outcomes were evidenced by the parents actively gathering information about the baby and prematurity, showing awareness of negative feelings and expressing those feelings with others, and seeking help from within the family or the community. In the unhealthy outcomes, the parents were not able to assess the reality of the situation, could not express feelings, and were reluctant to seek or accept help even from each other.

Kaplan and Mason (1960) also conducted a study of maternal reactions to preterm birth by interviewing 60 families during the period following the preterm birth and continuing until the baby had been home for two months. By examining the clinical material from these interviews, the researchers described mothers of preterm infants as agonizing over the survival and long-term health of the baby, and feeling guilty and experiencing loss of self-

esteem from an inability to bear a normal, healthy child. Four psychological tasks of the mother whose infant is born prematurely were identified. These include: a) preparation for the possible loss of the child while hoping the baby survives, b) acknowledgement of maternal failure to give birth to a normal full term infant, c) resumption of the interrupted process of relating to the baby, and d) coming to understand the special needs and growth patterns of the preterm infant as different from the normal full term infant.

These early studies of the effects of prematurity on the mother were limited by many factors. The sample selection, small number of the sample population, and the lack of sample characteristics, such as socio-economic levels and cultural backgrounds, limited generalizability of the studies. This was especially important when labeling "good" and "bad" processes and outcomes. Also, the infant's behavior as a potent influence on the mother-infant relationship was not assessed. Longitudinal follow-up of the mother, infant and other family members was not accomplished. It is also important to consider that these studies were conducted during a period of hospital care when parents were not allowed to touch or care for their infants. However, these early studies were able to draw attention to the experience of the mother of the preterm infant and provided useful descriptive information for future research and clinical practice.

Parental Reactions to Preterm Birth: The NICU

Since the advent of neonatal intensive care units, much attention has been focused on the effects of mothers having decreased access to the infant which limited the physical and emotional intimacy of the early caretaking experiences. Early research endeavors were primarily focused on the timing and the extent of the first contacts (Klaus and Kennel, 1972; Leifer, Leiderman, Barnett and Williams, 1972). Results of these and other more recent studies indicate that early contact may enhance parents' initial experiences and may facilitate early parent-infant relationships. However, early contact studies have not consistently indicated comprehensive, long term effects on the infant that can be attributed directly to the early contact experience (Goldberg and DeVitto, 1983; Leiderman, 1982). Although the benefits of early contact may be short term, access to contact with the infant could be viewed as helpful for NICU parents. The lack of such access, caused by the infant being transferred to a regional intensive care unit and the mother remaining at the hospital of delivery, could be viewed as an additional stressor. The review of this body of literature is beyond the scope of this chapter, yet it is important to note the need for longitudinal research that addresses a more comprehensive view of maternal contact over time and the effects on all family members.

Since the advent of parental visiting in the NICU, studies have continued to support the notion that most parents are under severe emotional distress at the birth of the preterm infant and subsequent hospitalization in the NICU (Klaus and Kennel, 1972). One study was designed specifically to evaluate parental reactions to the demands of prolonged visiting of sick and preterm infants in the NICU (Harper, Concepcion, and Sokal, 1976). Ninety-one families whose infants had been hospitalized for two or more weeks were mailed questionnaires; there was a 64% response rate. Three families returned the questionnaires unanswered and noted that the questionnaire stimulated unpleasant memories for the family. Correlations of rising levels of anxiety were associated with increased infant morbidity, and increased infant contact. Mothers had a slightly higher mean score on anxiety than fathers, however this difference was not significant. In retrospective questioning, only 10% of the parents reported they would have visited less.

Paludetto and Faggiano-Perfetto (1981) also studied the reactions of 60 parents who were allowed unrestricted access to the NICU and were encouraged to touch, change and feed their infants. The increased contact with their preterm infants also appeared to increase the distress of those families who participated in the study. Yet, at the same time, extra contact stimulated paternal interest the child. The authors indicated that if unrestricted access to infants does increase the parent's distress, the NICU staff is then

challenged to provide the resources to cope with the stress. This study and the Harper et al. (1976) study raise concern about whether access to the critically ill infant is a resource for parents, or a resource for the baby at the parent's expense. Visiting in the NICU appears to be a stressful demand for new parents.

The notion that parental reactions to the birth of the preterm infant include a grief response to the loss of the fantasized, normal infant is consistent with a study designed to assess grief feelings and behaviors. Benfield (1976) studied 101 mother-father pairs whose critically ill infants were transported from the hospital of birth to a regional neonatal intensive care nursery. Parents were 97% white and predominantly middle class. This was the firstborn child for a little less than one-half the study group. Forty-one infants were classified as low birth weight; gestational age was not reported. The authors designed a questionnaire that included descriptions of 13 feelings or behaviors related to the grieving process. Most parents in the study reported grief reactions similar to those parents whose infants do not survive the newborn period. The level of anticipatory grief did not appear to be associated with the severity of infant illness.

Data were collected by parents filling out questionnaires on the day of the infant's discharge. The day of infant discharge is a potent stressor event in itself and the timing of questionnaire administration may have

affected the parents' responses. Benfield's findings are similar to the early descriptive studies of Kaplan and Mason (1960) for middle class families.

In a small qualitative study (N = 10) among a demographically homogeneous group of parents, individual variations between parental perceptions of their low birthweight infants, individual coping styles and adaptation to the stress of preterm birth were described (Newman, 1980). Two major approaches to family coping were identified. One approach was "coping through commitment" identified as an intense involvement in care of the infant. The other style was described as "coping through distance", identified by a slower acquaintance process, expression of anxiety and reliance on professional care. This study was useful for bringing to attention the variability of family coping styles and the description of two different patterns of coping. However, it is not known how the particular styles of coping relate to parent and child outcomes and how the parent's current environmental demands and access to resources affect the coping style.

Another qualitative study of the NICU environment and parents was undertaken by Bogdan, Brown and Foster (1982). This study drew attention to the complexity and intensity of the NICU environment for parents of infants. Using participant observation methodology, researchers described parents and professionals and the nature of their transactions in the NICU setting. The researchers

identified the family's lack of prior experience or knowledge in dealing with such a system as a major factor that contributed to the difficulty parents have in coping with the demands of the setting. The researchers discovered that the parents' communication system is radically different from that of the NICU health provider. The NICU care providers appeared to have developed their own system to describe and selectively supply information to parents about their child's health status and recovery potential. This mode of communication was reinforced by the health care providers' inability to predict accurately the child's outcomes from current knowledge and research. This study depicted the NICU as a demanding environment for parents with obscure patterns of them transacting successfully with the system.

Another finding of this study is the way NICU staff categorized parents and thus responded to their needs. The researchers discovered that the NICU staff were likely to categorize the infant's parents as good, not so good, and troublemakers. Parents were identified as good parents if they understand. Characteristics of understanding included: ask appropriate questions; understand the baby's condition and potential outcomes, which are usually ambiguous; are grateful for the care that is available to their baby; and understand and abide by unit policies. Another characteristic of good parents is that they care about the baby. They demonstrate this caring by visiting regularly,

responding in appropriate ways to good news and bad, and appearing to bond to the baby. Good parents also show potential for giving the baby proper care after they leave the hospital. The staff report that they like to talk to such parents, and parents are liberal with their praise for the staff and let them know how they have been treated by the staff. Additionally, the staff believed that social class, race and age are related to being a good parent (Bogdan et al., 1982).

Parents described as "not so good", had the opposite characteristics of good parents. They did not have the ability or refused to show that they understood the condition of their baby. Parents did not visit, call, or show interest in the babies. Many were poor, young, and culturally different from the staff. Troublemakers were those parents who made unreasonable demands on the staff. They were not satisfied with the treatment that their child received and, rather than being grateful, were overly critical. The staff believed they might be planning to sue them.

This study was useful in understanding how the NICU can be a demanding environment for families when staff expectations for parent behavior were somewhat rigid. Those parents identified as "not so good parents" also appeared to have many other environmental demands and thus may have had difficulty coping with the additional demands of the NICU setting.

This study was also useful because former NICU parents are frequently chosen to be support parents because the staff perceives them as "good" parents. Volunteer parents may share those characteristics of parents that Bogdan et al. described as "good" (high resource) parents. To what degree these "good" parents by staff assessment are those parents that would be most helpful to other parents experiencing the NICU is an important area for future study.

In summary, the results of classic and recent studies advanced the belief that most parents are extremely stressed by the birth and subsequent hospitalization of their infant in the NICU. Early research studies, while methodological weaknesses were apparent, contributed useful descriptive information in order to understand further the mother's reaction to such a stressor. However, little is known about the resources mothers use to deal with the increased demands of a preterm birth. Research is also lacking on family system responses to the infant's hospitalization and the interaction between family members, especially the father and siblings, at this time. Although Benfield's (1976) study attempted to document grief feelings and behaviors of parents, it lacked preciseness in identifying a grief trajectory and its interaction with parenting behaviors over time. Although early and extended contact has not been demonstrated to have significant long term effects, it does appear to be related to additional demands on the parents, with no reports as to the resources that could be helpful to

parents. One such resource that may be of help is some kind of assistance in dealing with the NICU and the staff as a unique environment. Qualitative research reinforced the concept that parental coping with the preterm infant and the NICU experience differs across families. Further research is necessary to study the resources and demands of the NICU parents and their transactions with the NICU environment.

The Period After the NICU Hospitalization

Early retrospective studies indicated that prematurely born infants were more vulnerable to child abuse and neglect, failure to thrive and other parenting dysfunctions than full-term infants (Elmer and Gregg, 1967, Klein and Stern, 1971). Current prospective studies failed to confirm these earlier study results (Leventhal, 1981). Yet, for all the research concern about the child outcomes of dramatic parenting dysfunctions, few investigators have attempted to study the parents of preterm infants. Excluding the few studies of parents during the initial crisis of the preterm birth, most studies have focused on predicting and explaining the varying developmental outcomes of preterm infants (Parmalee, 1981; Sigman, Cohen, Beckwith and Parmalee, 1981). However, these studies support the idea that parenting a preterm infant is difficult work, especially in the first year of life (Brown and Bakeman, 1980; Goldberg, 1979). Because of the infant's neurological immaturity, preterm infants are difficult to arouse for social interaction, irritable and difficult to soothe

(Als,1976). The infant's lack of social responsiveness to parent's caretaking makes the infant's demands more frustrating for parents. Although a review of this literature is beyond the scope of this chapter, the preterm infant's behavior is now acknowledged to be a potent contributor to the nature of the parenting relationship.

Maternal-Preterm Infant Interaction: Infancy

Minde, Marton, Manning and Hines (1980a) observed 32 mothers of very low birth-weight infants during visits to the nursery and during infant feedings at home. Interaction patterns of the mothers were categorized as high, low or middle level of interaction. One quarter of the mothers were in either the high or low category; one half were in the middle category. Certain psychological variables within the mother's background were significantly related to maternal activity patterns. Low interacting mothers reported poorer relationships with their own mothers and with the father of the infant; high interacting mothers reported more satisfying interpersonal relationships. Mothers maintained their position in the three groups on evaluations done at three months post discharge. In analyzing the infant's contributions, mothers who were in the high interaction category co-occurred with infant's abilities to send social signals.

Minde, Shosenburg, and Marton (1980b) studied those mothers of preterm infants who participated in hospital based parent support group meetings while their infant was

in the NICU. Sixty infants weighing under 1501 grams were assigned to experimental or control groups. Approximately 75% of the mothers were married, most were in a low socioeconomic class and almost 50% had experienced past obstetric difficulties. Following the infant's birth, experimental mothers attended approximately seven to twelve weekly sessions which were co-led by a nurse coordinator and an experienced NICU mother. Observations of specific mother and infant behaviors were made in the NICU and at monthly home visits for the first three months post discharge. Interviews were conducted during the hospitalization period, at the time of discharge, and at home after discharge.

Mothers in the experimental group visited their infants significantly more often in the hospital than control parents ($P < .05$). There were significant differences in all areas tapped by the interview especially comfort in caring for their infant and satisfaction with health care ($P < .05$). No differences in infant maternal behaviors were disclosed between the two groups during the first two weeks. At three, four and five weeks experimental mothers were significantly more active in interaction than comparison mothers. At three months, experimental mothers talked to, looked at and touched their infants for longer periods of time than control mothers.

In order to document any long term benefits of mothers' participation in a support group during the NICU hospitalization period, Minde, Shosenburg, Thompson, and

Marton (1983) attempted to contact these same parents when their child reached one year of age. Fifteen experimental and sixteen control families participated in this evaluation.

The behavior of each mother and infant pair was observed during an infant feeding and play situation in the home. Treatment mothers spent less time feeding their infants and talking to other persons than did the control mothers. They also provided more physical contact during the infant feedings. The infants' behaviors that differentiated the experimental from the control group were feeding themselves more, playing more, and wanting to share some of their food with their mother. Observations were also made of mother-infant play sessions and a post-reunion play episode following a brief separation. During the initial play sessions, the treatment infants looked at and touched their mothers more often and also showed more fussing than the controls. During both episodes, treatment mothers looked at their infants less but vocalized to them more often. After the reunion, both groups of mothers increased verbalizations with their infants, but the treatment mothers provided their infant with more physical support following separation.

The researchers interpreted these results as indication that treatment mothers encouraged more autonomy and sociability with their infants. They offered additional evidence from analysis of occupational, educational, and

psychological changes that took place during the mother's first year. The researchers interpreted the data to indicate that treatment mothers showed a significant improvement in their relationship with significant others and an increase in personal autonomy.

This study is of interest because of the provision of a supportive intervention that included other NICU mothers. The addition of a support group of NICU mothers during the period of hospitalization may help mothers cope with the intense parenting demands of the first year. One concern about the group of mothers, however, is the participation rate of those mothers assigned to the two groups. The characteristics of those mothers who refused to participate in the treatment groups and differences between these mothers and participating mothers were not reported. Perhaps those mothers who are willing to participate in support group activities have more resources available that enable them to do so.

A substudy examined the influence of medical complications on preterm infants and mothers' caretaking (Minde, Whitelaw, Brown and Fitzharding, 1984). This was a part of a larger study on the effects of specific medical complications of prematurity on outcomes. Sixteen matched mother-infant pairs of sick and well infants were observed during feeding time at the two months post discharge home visit. The sick infants' behaviors were similar to those of the well infants. The mothers of the sick infants touched

and smiled at their infants significantly less than did the mothers of the well infants. The mothers of seriously ill preterm infants showed persistently low interaction with their infants. In order to explore the cause in more detail, the total group of sick infants was divided into those who were seriously ill (rated as 2 or 3 on the Minde morbidity index) and these were subdivided into those who were hospitalized for more than 36 days or for less than 17 days. Mothers with seriously ill infants who had short illnesses increased their vocalization, touching and looking, while mothers of seriously ill infants with long lasting complications showed no significant change over time.

The contribution of past experiences to a mother's behavior with a preterm infant was also studied in this research (Minde et al., 1984). Data from interviews with the mothers were examined. Questions related to the mother's present pregnancy, the social conditions of the family, and past psychological events of her life were analyzed. Mothers whose infants had long illnesses, independent of their personal background, showed a uniformly low rate of interaction with their infants. A long term illness in a preterm infant had a more powerful effect on the mother's degree of interaction than other important psychological variables in the mother's background. This contradicted the findings of Beckwith and Cohen (1978), Field and Sostek (1979) and Goldberg, (1979) all of whom

found mothers of "sick" preterm infants to overcompensate in interactions when the infants had recovered. The severity of illness was not specified in these previous studies. Perhaps infants in these studies were not as seriously ill as the Minde population. Thus, it seems important to assess NICU parents for the length of hospitalization and the severity of illness.

Maternal-Infant Interaction: Beyond Infancy

There have been only a few studies of mothers and NICU-involved children that have extended beyond infancy. Blake, Stewart and Turcan (1975) conducted a descriptive follow-up study of 160 infants whose birth weights were under 1500 grams. These infants were followed in a hospital-based clinic after discharge. Data were collected by clinical observations and infant health assessments. The researchers indicated that, in spite of attempts to minimize maternal separation and the distressing aspects of the NICU experience, an emotional crisis was observed in mothers. This crisis did not resolve itself until after the infant was discharged. The authors identified three phases of post NICU-discharge adaptation. An initial honeymoon phase was followed by a phase of parent exhaustion. A phase where problems disappear occurred at the same time that the infant was showing increased responsiveness. Although the duration and the degree of crisis showed variation across families, two variables were identified that appeared to be associated with outcomes. Mothers who received support and sympathy

from the baby's father appeared to have least difficulty. A rigid maternal personality and circumstances surrounding the birth which predisposed the mother to feelings of guilt and failure seemed to prolong the crisis. Although follow-up evaluation indicated that the parents formed satisfactory relationships with their children, the mothers tended to be anxious and overprotective, and the children mildly overdependent, shy and anxious.

The description of outcomes in mothers and children in the Blake et al.(1975) study is similar to that reported in the literature that describes parents whose infants were expected to die. A classic study of vulnerable infants and their parents contains information about parents of preterm infants (Green and Solnit, 1964). A recent case study also describes potential parenting difficulties (Naylor, 1982).

Parental mourning is described in the literature as premature mourning for the acutely ill young child, and mourning the loss of the hoped for normal, healthy infant when a defective infant is born. Green and Solnit (1964), in a classic study, described what they called a "vulnerable child syndrome." This syndrome describes children whose parents expect them to die prematurely and who may subsequently show a disturbance in psycho-social development. Cases of 50 school age children were examined in this descriptive study. Seventeen of the children experienced a critical illness under the age of twelve months, ten during the neonatal period. A group of clinical

features of the syndrome were identified in the study children. These included a) difficulty in separation, b) infantilization, c) bodily overconcern, and d) school underachievement. Separation difficulties included: infrequent use of babysitters, sleep problems for baby and mother, and difficulties with school separation. Parents were often characterized as overprotective, overindulgent, and oversolicitous, and often unable to set disciplinary limits. This parenting style then became reflected in the child's behavior, as overdependent, disobedient, irritable, argumentative, and uncooperative. Mothers were depicted as being overly concerned about such things as minor respiratory problems, bowel movements, and skin color. The child was frequently seen for apparent hypochondriacal complaints, such as stomach pain, and headaches. School difficulties appeared to be related to separation anxiety, and inability to concentrate freely on the learning exercises.

The authors did acknowledge that all children who recovered from a critical illness did not develop this syndrome and identified numerous predisposing factors. Of concern in this review are the following factors: a) the child is the first child born to older parents after they had resigned themselves to being childless, because of fertility problems, frequent miscarriages or stillbirths; b) the child was preterm; c) the mother was told during the pregnancy that the baby might not survive because of the

pregnancy complications; and d) the child has an acquired handicap or congenital illness.

The authors interpreted the reactions to be pathological after-effects of a persistent, disguised mourning reaction that was evoked by the child's critical illness. The researchers believed that parents appeared to experience a modified grief reaction when they were informed that the child might die. This grief reaction was prematurely aborted and incomplete when the child then survived.

In addition to the small study size and methodological weaknesses, these data must also be placed in historical perspective. The study was accomplished prior to the regionalization of intensive care units, where the increase in technology and knowledge has increased the survival of infants who most likely would have died in the past. This study was also conducted at a time when hospital policies prevented the parents' contact with the preterm infant until discharge.

A more recent case study (Naylor, 1982) of premature mourning and failure to mourn described the conflict between mothers and their intellectually normal children who were critically ill. Two cases of mother infant dyads were analyzed. Similar to Green and Solnit's findings, Naylor found that during the dependency of the child's first year, repression of mourning continued. However, this repression appeared to give way, stimulated by the toddler's

assertiveness during the separation-individuation phase. In both cases, mothers' defenses against angry, hateful feelings broke down when the child was perceived as aggressing against the mother. The children perceived themselves to be hated and reacted with behavior that only exacerbated their mothers' anger. The author acknowledged that anger can be a powerful component in overprotection, however, there was no behavior in either parent suggestive of overprotection. Acting out of anger is in contrast to the finding of Green and Solnit. The author acknowledged the limitations of case study methodology, but hoped that the research would stimulate more research interest in the topic.

Boyle (1977) conducted an investigation that compared a group of 55 families who had children born at birth weights over 2500 grams with 75 families who had children born under 1501 grams and hospitalized in the NICU. Most of the families were of average income and intact. The purpose of the research was to document whether the preterm children were a continuing burden to their parents. This would be evaluated by interviewing parents about the child's functioning and extra difficulty in caretaking. Seven areas of functioning were chosen for evaluation: development, health, play, toilet training, feeding, sleeping and discipline. Parents of the preterm infants gave less favorable evaluation of their children in the areas of development and play. These differences were accounted for

by a subgroup of children with neurological and intellectual deficits. Boyle, on the basis of no significant differences in caretaking problems, concluded that there is no continuing impact on the family of the preterm infant. Although this research purports to be a study of the impact of a preterm infant on the parents, caretaking was the only outcome measured. Another concern is the reported incidence of the divorce and separation of study families. Approximately 13% of the families were separated or divorced by the time of the interviews which occurred 3-5 years after the infant's birth. No comparison figures are given for such rates with the NICU population or the population as a whole.

White and Dawson (1981) designed a study of families who were categorized as high, medium, or low risk based on the health status of their newborn infants. The study variables were family solidarity, parent concerns, parental depression, infant status, parents' perception of the behavior of their infants, and life events in the family. Risk was conceptualized as possibility for physiological disequilibrium and/or developmental delay. There were 53 families with low risk infants, 33 families with moderate risk infants and 13 families of high risk infants. Sixteen families were originally in the high risk group, but three families did not return the questionnaires. Data were collected from both mothers and fathers using the Brookline Early Education Project Inventory to determine risk status.

The investigator developed a parental reaction questionnaire and a family solidarity scale which were used in the study. In addition, the Beck Depression Inventory, the Social Readjustment Scale, and the Broussard Neonatal Perception Inventory were used. A package of questionnaires for both mothers and fathers was mailed to the families when the infants were three months of age and six months of age.

The infants' scores on the Risk Inventory were negatively correlated with the mother's age and education. There were no significant differences among the three groups or between mothers and fathers on the Life Events scale. The majority of parents in all groups reported perceiving their infants' behavior as better than that of the hypothetical average infant. No parental concern items discriminated among groups. However a trend emerged in response to a rating of the degree of concern parents experienced relative to home activities. Parents in the low and moderate risk groups expressed more concerns.

When the three risk groups were compared for incidence of depression, the highest percentage occurred at three months among mothers of the low risk group. However the difference between the number of mothers in the low moderate and high risk groups were not significant. At six months, the low risk group did show a significant decrease in the numbers of mothers who scored in the depressed range. Additionally, there was a significant difference between

high risk and low and moderate risk groups on the number of mothers who returned the depression questionnaire. Five of the thirteen mothers in the high risk group did not return the depression questionnaire or the life events scale at six months, even though they did return the other mailed materials.

The construct of family solidarity, defined as a closeness of family members to each other, was operationalized using four categories: togetherness, communication, team performance, and ritual. A scale was designed to measure instrumental and expressive dimensions of each of the above categories. Chronbach's alpha for communication and ritual were stronger (communication 0.69 and ritual 0.69, togetherness 0.45, and team performance 0.54). Analysis of the data indicated that those families with infants in the high risk group reported less parental going out, more eating together, less closeness in the marital relationship, greater dissatisfaction with the sexual relationship and low frequency of sexual intercourse. Mothers of the high risk infants had more responsibility for infant care, and perceived that they received less help in comparison to the other groups. The amount of communication between husband and wife did not change in any of the three risk groups, but the high risk group did indicate less agreement than the other groups.

The investigators have added to the very limited knowledge base of families with at risk infants, yet the

study raises many questions. The risk status of the infants was determined during a two week post birth period. There were no data to indicate what the health status of the infant was at three months and six months when the parents responded to the questionnaire. Thus, the risk status seems to relate to the infant's initial health status. Attrition of subjects, especially those parents with high risk infants, may indicate that the mailed questionnaire was either too difficult, time-consuming, or perhaps just too threatening to parents who have already been labeled in the popular press at risk for parenting problems. Survey methodology is probably not the ideal research methodology to use with stressed families, such as those with high risk infants. Perhaps it takes a well functioning family to participate in a mailed questionnaire survey.

One other group of parent studies has been selected to be included in this review, because these studies provide some information on the effects of resources and demands on parenting functions. Hunter and Kilstrom (1978) assessed 255 families whose infants were discharged from the NICU. Although the purpose of the study was to document the incidence of child abuse and neglect, some information about families was obtained in the study. Data were obtained by family interviews, medical chart audit, newborn intensive care unit visiting records, outpatient clinic records, contact with local health providers and state records. Eight of the 255 families were reported for neglect, and two

families for abuse. Of the eight families reported for neglect, five were cited for failure to provide needed medical care for acute or chronic illness and two for inadequate nutrition.

In a subsequent analysis of their data, the researchers examined the data from those parents who had parental histories of abuse and neglect in their own childhood. Out of 49 families, nine were reported for abuse and neglect. Forty families were then identified as non-repeating families and were studied as a subset. In addition to sharing with maltreating families an abusing background, they were also similar in respect to young marriages, early pregnancies in the marriage and financial difficulties. However they were different from abusing families in the following ways: less ambivalence about the pregnancy, more open in talking about early experiences and concerned about the parenting role, healthier infants and shorter stays in the NICU, more frequent NICU visits by the mothers, fathers and other extended family members. The social resources of the non-repeating families also differed from the maltreating parents. From interview data, at the time of the birth, the non-repeating families were more likely to discuss concerns with important friends, extended family, church or other social groups and use community agencies.

Pascoe (1984) in a related study located 30 of the 41 families who were identified at risk in the original project using the Hunter-Kilstrom scale. A group of 39 non-risk

families were matched to form a comparison group. The 69 children from rural working class families were 2 1/2 to 3 years old at the time of the study. The relationships among mother's life change scores, social support and the preschool home environment of their children were analyzed three years after discharge from the NICU. The number of reported life changes that occurred to mothers since the births of the children were not related to the amount of home stimulation provided the children; however, mothers who reported more social support provided a more stimulating home environment unrelated to number of life changes.

Self Help Literature:

Experienced Support

The researcher was unable to find studies of NICU parents who volunteered for support roles, or participated in one-to-one parent support. Therefore, studies in the self-help literature were reviewed in order to better understand how experienced parents may help other parents. Studies from the self-help literature are included since the NICU support program purposively structured the volunteers' experiences to include peer support relationships between the volunteers. The helper therapy literature described effects of participation in the helping role. Studies are included that described either the characteristics of the program participants or effects of participation. Additionally, the studies must have described a volunteer

helper functioning in a program that supports persons who share similar physical or psychological health problems.

Trainor (1980) designed a study of ostomy patients which described the volunteers' benefits that come from helping another person. Ostomy patients are those persons who have had a surgical opening made on the abdominal wall in order to treat colon disease. The purpose of the research was to examine whether persons who function in a visiting role demonstrate a greater level of acceptance of their own ostomy than persons enrolled in the same group, United Ostomy Association(UOA), who do not participate in the visiting role. The relationship between a person's acceptance and other study variables was also examined. These variables included: age, gender, type of ostomy, length of time since ostomy surgery, education, period of time in the visitor role and the average number of persons visited each year.

Acceptance of ostomy was operationalized as the subject's score on the Acceptance of Disability Scale Modified(ADM). The population was composed of UOA members who attended monthly group meetings and volunteered to fill out the ADM. There were 318 respondents, of which 54% were visitors and 46% nonvisitors. This study group was comprised of predominately persons over 50 years of age, with 44% female and 55% male. More than half the respondents had their ostomy surgery less than four years prior to the study.

Chi Square analysis of visitor and nonvisitor members indicated that the visitors had a higher level of education ($p < .05$) and had experienced their surgery a greater length of time in the past ($p < .001$) than nonvisitors. Visitors showed a significantly greater level of acceptance of their ostomy than nonvisitors. A significant relationship ($r = .27$, $p < .006$) was demonstrated between the person's ADM score and the length of time in the visitor role. Using multiple regression analysis the factors age, gender, type of ostomy, and length of time since first surgery did not contribute significantly to the linear equation. The length of time a person had the ostomy was a significant predictor of serving in the visitor role; age, gender, type of ostomy were not. The longer the person served in the visitor role, the more likely increased acceptance of the ostomy was reflected on the ADM.

Abrahams (1976) conducted a small descriptive study identifying differences in veteran widows' helping styles. An analysis of varying inputs and rewards of the helping process was used for four different caregiving styles. The study was conducted through a widow service line, a telephone mode of service delivery, staffed by volunteer widows. The service received approximately 150 calls per month.

Descriptive characteristics of the volunteers were reported. A majority of the volunteers had full time jobs and families. Most of the volunteers had no more than a

high school education and were between 40-50 years old. Criteria for participation included the woman being sufficiently over her own grief, sensitive to others, perceptive and committed to the program.

Four distinct helping styles were identified. These included: a) informative-supportive, non-self revealing; b) emotive-supportive, non-self revealing; c) emotive-supportive, some self revealing; d) integrative-friendship, self revealing. In order to further clarify the four helping styles, Abraham described the style and the helper's inputs and satisfactions for each style.

Volunteers in the informative-supportive style were busy active people who were not looking for friends among the other widows. They were usually involved in many volunteer activities and other social organizations. They wanted to feel needed in helping others. The rewards they received were from an enjoyment of problem solving with new widows. These widows did not perceive helping as a means of their own growth. Their helping style was characterized by a focus on information and activities.

Emotive-supportive, non-self revealing volunteers were characterized as warm, outgoing people whose personalities attract others. These volunteers felt they were helped by others and wanted to repay the debt to other widowed persons. They seemed to approach life from a spiritual perspective as a process of giving and receiving. They were not looking for emotional involvement with others and their

main reward was their own growth and development. Their style of helping focused more towards feelings than activities, but they had no need to unload their own feelings.

Type three, emotive-support, self-revealing volunteers had not participated in formal helping activities before joining the program. Most of them were helped by another widow at the time of bereavement. They had found that their usual sources of support, family and friends, were unable to help them. Participating in the program helped them expand social contacts and made them feel valued by persons outside the family. They still needed to talk about feelings and this was incorporated into their helping style. The rewards for these helpers were the mutual sharing that occurred, an increased understanding of their own development, increased self confidence and a more positive image from feeling appreciated. In sharing their experiences with new widows they worked through their own feelings.

Type four, integrative friendship, widows were usually not involved in other helping roles, and were more isolated from kin. They were recruited into the program by friends motivated to join by loneliness. They sought the helping role to fill up time and take their minds off their own troubles. The rewards for these persons were extensive in terms of their own development toward reintegration and adjustment. Feeling needed and appreciated by others increased their self confidence.

The experienced helper role was operationalized differently for each level of volunteer, depending on the volunteer's own needs and current resources. Volunteers entered the program at any level, and often changed their helping style as they gained experience in the role. This study, although not directly identifying specific support processes, implied that volunteer widows provide information, emotional support and sometimes friendship to new widows. This was a small descriptive study of experienced helpers, which the investigator viewed as an initial step in beginning to understand the characteristics of the provider and the processes of support.

A study of bereaved parents was conducted by Videka-Sherman(1982). Members and non-members of a self help group, Compassionate Friends, were compared for trends in changes in depression and personal growth, and levels of involvement in the program. Compassionate Friends(C.F.) is a group therapeutic intervention for bereaved parents. The intervention includes primarily a monthly meeting that consists of a speaker and an open discussion for parents.

Two constructs were used to measure effects of participation. Levels of depression were used as an indicator of progression through the grief process. Personal changes were defined as an alteration in one's sense of self in which individuals see themselves as moving towards their ego ideals, as a result of mastery of the crisis of loss. The research question was: Is increased

involvement in compassionate friends associated with patterns of change in levels of depression, or in assessment of personal change after the death of a child? Parents from eighteen chapters of C.F., whose child had died less than eighteen months previously, were recruited to participate in the study. Two hundred and forty two questionnaires were mailed to potential participants. Two and one-half percent of the letters were undeliverable, and 28% of those persons who received the questionnaire agreed to participate. Approximately one year after the first survey was completed, a repeat questionnaire was mailed:

Level of involvement was operationalized as the number of meetings attended, whether the parents considered themselves members of the group, and formal roles taken in the group. For analysis purposes, level of involvement was then categorized in low, high, and moderate levels. An open ended question was used to assess aspects of personal change. These responses were coded as positive, both positive and negative, no change, only negative change, and no answer at all.

The study respondents were 70% women, mean age 41.2, a range of 21-67 years, and 88% married. The women were middle and upper middle class, and 41% were homemakers. Out of the employed women, 39% held professional or managerial positions. Univariate analysis indicated significant change in parents' growth scores. Involvement in compassionate friends did not change depression. Multivariate analysis,

testing change across membership levels, indicated psychological adjustment to be linearly related to levels of involvement at $p < .05$ level.

This study added to what is known about the characteristics of persons who participate in a self help group. Most participants were women, married and middle to upper middle class. Although participating in a group support program such as this is different from the individual volunteer support role, both share the important aspect of mutual support. The results of this study indicated that although the grief response was not lessened, personal growth may be enhanced by contact with peers who have experienced similar crises.

Bond (1979) published a descriptive article of visitors in Mended Hearts, a program for recovering heart patients. Visitors rated Mended Hearts program more highly than nonvisitor members on relevance, enjoyment and helpfulness. Forty-six per cent of the visitors reported talking to other group members at least weekly, only nine percent of nonvisitors reported such contact. Field observations and interviews strengthened the belief that visitors derived satisfaction from their role. One visitor described the "sense of communion" felt with the hundreds of heart patients he has talked with over the years as a visitor. Another described the "energizing" effect of visitation, even following a hard day of work. Retiree visitors often indicated that it gives them something to do with their

time. The status and importance of their role in the hospital environment was also perceived as a benefit. Non-visiting members of the Mended Hearts group perceived minimal benefits of group membership and maintained a peripheral involvement in the organization.

A Canadian study was conducted to determine how participants of self-help groups perceived the benefits of their participation and their level of involvement in the program(Levy,1979). The investigators distinguished between three kinds of groups for this survey study. They included a) loss-transition groups (L-T), b) one-step removed from the problem (OSR), and c) those for stress, coping and support (SC&S). The respondents were derived from 18 self-help groups who were willing to have a representative distribute the questionnaire. One-hundred and nine questionnaires were returned out of 175 distributed. A final group of 87 persons remained after excluding those with limited contact with the group or a type of group that did not fit with the investigator's categorization.

Of interest in this study is the analysis of the perceived benefits of participation and level of involvement. Elements of self-help group support were identified from the literature. Three global measures of overall benefit, behavior change and attitude change were also measured. On a seven point Likert-type scale where 1 = least, 7 = most benefit, the mean overall benefit score was 6.3. Members of the OSR group provided the highest ratings

of benefit on 7 of the 12 measures. The L-T group had the lowest ratings on the 12 measures. This sample supported eight benefits selected from the literature. These eight elements include benefits from helping others, help from others, coping strategies, sense of community, coping with public attitudes, factual information, spirit of hope, and self confidence. Eighty-eight percent of the sample responded positively to the nine elements of support.

An analysis of the characteristics of members' involvement indicated the mean length of group membership was 39 months, with a range from 3 to 237 months. At least 83% had monthly attendance at a group meeting, while 53% had weekly or biweekly contact. More than one-third of the members of each type of group in this study maintained either daily contact or numerous weekly extra group contacts with co-members. The investigators acknowledged that the groups were biased in favor of those members who volunteered to complete the questionnaire and were active group members.

As part of this study, a descriptive field study of several kinds of self help groups was conducted. A survey of 80 members of 9 self-help groups that were either behavioral control group (Alcoholics Anonymous, Parents Anonymous) or stress coping groups (Parents without Partners, Make Today Count) was undertaken in order to describe the characteristics of participants and their views of self help groups. The survey questions were developed from reading the literature and a period of nonparticipant

observation of several groups. Of interest in this study is the description of demographic characteristics and responses to items that dealt with how participants were helped by their group. The mean age of respondents was 40 years, ranging from 16-67 years. There were fewer married persons in the stress coping group, although this difference disappeared if Parents without Partners, whose membership requires single status, was excluded.

The researchers were careful to point out the problem of bias. The members of such groups are voluntary and are self-defined sufferers of the problem. Since no records are kept by the group, it is not known what proportion of the total population of individuals with a particular problem are represented by current membership. The respondents are from four cities in the midwest and south. A return rate of 67% for both kinds of groups was reported.

When group members were asked how they had been helped by their group, 41% percent of the group members indicated that the group had provided social involvement or fellowship. Twenty one percent of the behavior control group members indicated that the group had helped them in reaching goals. Helping to understand and accept their own problem (11%) and facilitating personal growth (8%) were also identified as benefits to group participation. When participants were asked to further describe why their group was effective, the following findings were named: supportive accepting environment (83%), greater

understanding of themselves and own problems (33%), and learning that it was possible to reach goals (10%-in behavior control group only). When asked to respond to open-ended questions on benefits, one-half of the respondents described specific benefits. Forty percent of the respondents identified encouragement, and 23% said acceptance and social contact were benefits.

One additional study about parent-to-parent support and a descriptive article about an NICU support program were also included in this review, although they do not fit in the previous categories. The NICU parent-to-parent demonstration program that was used as the setting for this study was developed as part of a second generation research endeavor of the Perinatal Positive Parenting program model. An initial three year demonstration program for parents with full term, healthy infants was carried out at the William Beaumont Hospital in Royal Oak, Michigan, in 1981. A follow up, in-home evaluation of differences between control and treatment mothers on parent-infant transaction measures and the quality of the environment was conducted (Boger, Richter, Kurnetz, and Haas, 1986). The results of this evaluation indicated that program families had significantly better ($p < .01$) maternal involvement and child-nurturing environments than control families at 15 months. Using in-home time sampling observations, program mothers initiated interactions more often than did their control counterparts. The impact of the program on younger treatment mothers in

the follow-up research sample (<23 years at delivery) was significantly greater than on older mothers sampled.

Although it is not a research study, a descriptive article of an NICU parent-to-parent support program was included because it contained transcripts of NICU volunteer support parents discussing their role. Livermore (1980) described volunteer parents who participated in one particular support program, and who did not receive any preparation for the role. The volunteer parents met as a group every six weeks to exchange experiences and give each other support. The meetings also served the function of providing new information and meeting with the NICU staff. The central purpose of the NICU program was person-to-person exchange.

Of interest in this article were statements from the experienced parents that applied to the volunteer role. One mother stated that she clearly felt most comfortable helping another mother who shared similar characteristics to her own situation (mother over 35, has adopted children, and twin preterm infants). She also discussed how important it was to see the new mother's baby and make some positive comment. She believed that this was valuable from her own personal experiences of having someone respond positively to her babies. This mother described how she talked with mothers about the mother's own comfort and not feeling guilty about self care. Most often, she believes mothers want to talk about their feelings.

Another mother discussed how she helped mothers get involved with their infants by asking questions about their baby. She found it helpful to have another mother tell her it is okay to love the baby even though it is painful. Encouraging parents to talk with professional staff about their concern is another important role function. An important part of the support role appeared to be the follow-up of the relationship after the infant's discharge and preparing parents for some difficult times at home.

Summary

This preliminary review of the literature can be used to justify the selection of the research questions and the use of qualitative research methodology. What occurs in families of NICU-involved children during the period of hospitalization and after discharge has not been well studied. Additionally, the unique support processes that experienced helpers use have not been delineated in the self-help literature. Further review of the literature occurred during the conceptual development phase of the research.

CHAPTER THREE

METHODOLOGY

The purpose of this chapter is to present the grounded theory research methodology used to address the research questions. The study setting, the study design, the identification of research informants, data collection strategies, and data analysis are described. Issues of reliability and validity are discussed as well as limitations of the study and procedures used for the protection of human subjects.

Setting

This study was conducted in conjunction with the research demonstration project # 38-600-5984w entitled: "NICU Perinatal Positive Parenting: A parent-to-parent support program for high risk families" that was carried out at a 40 bed, Level III regional Neonatal Intensive Care Unit in a community hospital located in western Michigan (Boger, Roman and Haas, 1987). The project was funded by the Children's Trust Fund of Michigan and the community hospital. This parent-to-parent support program for high

risk families was developed and implemented conjointly by the hospital and Michigan State University, Institute for Family and Child Study.

This setting was chosen as the program demonstration site on the basis of recommendation by the State of Michigan Department of Public Health consultants. This particular nursery had a history of providing innovative NICU parent support strategies. A very small, loosely organized parent-to-parent support program, was functioning at the time of the project initiation and NICU administrators were enthusiastic about the development and evaluation of a comprehensive program. Thus, the NICU administrators philosophically valued what experienced parents could do for new parents. This setting may be atypical of most NICU's in their commitment to experienced parent involvement in the nursery.

Since study informants were chosen from the NICU/Perinatal Positive Parenting program, three major characteristics of the program are briefly described. First, there was a 25 hour volunteer preparation program, where prospective support parents were given current information on the NICU, infant treatments, and caretaking strategies unique to the preterm infant. An important goal of the preparation program was to have the volunteer parents learn from each other's experiences how different families cope with the NICU and parenting challenges of a sick and/or recovering infant, by re-examining their own NICU

experience. In doing so, the parents formed supportive relationships with each other in the group for both personal support and support in their new volunteer role. These relationships were maintained by monthly meetings of the volunteer parents with the professional program coordinator.

Second, there was access to a professional program coordinator, who works on a 20 hour/week basis, and whose job description includes matching volunteer parents with new parents and supporting the volunteer parents in the support role. Third, there was access to educational materials (videotapes, booklets) that volunteer parents can use to share information with NICU parents.

Study Design

Qualitative methodology was chosen to document and describe the major features of veteran parent support initiated in a Neonatal Intensive Care Unit (NICU) setting. Qualitative methodology was an appropriate technique to research a complex phenomenon that has not previously been studied, since theory testing cannot be done without the identification of variables relevant to the concepts. Consistent with conceptualizing veteran parent support as a transaction between parents, the research methodology supported the identification of the critical interrelationships between the veteran parent family, the NICU family, and the broader environments in which both systems exist.

The goal of qualitative methodology is to document and interpret as fully as possible the totality of whatever is being studied in particular contexts from the people's viewpoint or frame of reference (Leininger, 1985). The choice of methodology was also influenced by the nature of the neonatal intensive care experience for parents. Parent informants needed an opportunity to establish some degree of trust with the researcher before sensitive family information could be shared.

There were a variety of qualitative research designs that could have been used to explore parent support relationships. The researcher chose grounded theory methodology, a method well suited to the generation of explanatory theory that furthers the understanding of social and psychological phenomena (Chenitz and Swanson, 1986). Thus, the study was done to produce abstract concepts and propositions about the relationships between them.

Informants

Grounded theory methodology includes a purposeful method of sampling called theoretical sampling, where sampling decisions are dependent on the analysis of the incoming data and the developing theory (Glaser and Strauss, 1967). Theoretical sampling was used for discovering variation and situations that provide new properties of a process. In this kind of qualitative research, the sample can only be representative in a sense that the events or instances collected and recorded attempt to cover the entire

range of the phenomena and the results are as full of meaning as possible (Diers, 1979). Those persons identified as the sample are often referred to as informants in a qualitative study.

Informants were categorized in this study as either parent or observer informants. Parent informants were those parents whose infants had been hospitalized in the NICU and were either providing support or receiving support in the context of a NICU parent support program. Observer informants were those persons who had contact with the veteran parent and/or the NICU family and were able to describe support processes from informal observations or verbal disclosures with parents. Both parent and observer informants were also categorized as general or key informants. Key informants were selected for intensive interviews.

Parent Informants

General parent informants were initially identified as the 28 parents who volunteered in the fall of 1984 to be a part of the demonstration program, and those NICU parents who were assigned to them by the program coordinator for the purpose of support. Since informants for this study were identified primarily through the research demonstration project, NICU/ Perinatal Positive Parenting Program, a brief summary of volunteer parent and new NICU parent recruitment procedures is included.

Veteran parents. Veteran support parents were recruited for the program in the following manner. All parents who had experienced hospitalization of their infants in the selected NICU since its inception, seven years prior to program initiation, were mailed information about the role of the NICU support parent volunteer and the preparation required for participating in the role. They were invited to talk with the nurse program coordinator if they were interested in becoming a support parent. Thus, no pre-screening of volunteer parent candidates prior to the preparation program was done.

Following the volunteer preparation program, no parent candidate was advised to withdraw from the volunteer program because of staff concerns about readiness to implement the role. All support parents had had an infant hospitalized in the NICU at the project hospital and the child was over one year of age at the time of participation in the support role. At least one parent in the family had participated in approximately 25 hours of group discussion sessions with other volunteer parents preparing for the role. At least one parent was currently supporting an NICU family or had terminated such a relationship within the last six months as part of the Perinatal Positive Parenting program. All 28 volunteer support parents were willing to be involved in the research, they signed consent forms, and were identified as general informants.

NICU parents. The first 35 NICU parents whose infants were admitted to the NICU during the period of the study, and whose infants met specific study criteria were asked by the program nurse coordinator if they would like to participate in the support program. These study criteria included: an infant whose birthweight was under 2500 grams, gestational age at birth is 37 weeks, 6 days or under, and has no diagnosed congenital anomalies; born at the project hospital or transferred from an outlying hospital into the NICU, and hospitalized for a minimum of one week; mother and one significant other share emotional and/or material resources; and are participating in the Perinatal Positive Parenting Program with a support parent. Most of the mothers chose to meet with the support parent, with the exceptions being experienced mothers who had other children at home or mothers whose infants were not critically ill in the unit. This group of NICU parents were then matched with the corps of trained parent volunteers and are identified as NICU parent informants. All of these mothers, with the exception of one young mother, were willing to sign consent forms for the evaluation research. However, program and study attrition with younger, low socio-economic mothers was more pronounced. Key parent informants were a subgroup of NICU and veteran parents who were purposively selected for intensive interviewing.

Observer Informants

Observer informants were identified as those persons who have contact with the support parent and/or the NICU family and are able to describe the processes of parent-to-parent support from informal observations or verbal disclosures of the parents. General observer informants were classified as either health professionals who work in the NICU and/or in community health setting, or nonprofessional observers who may be anyone in the parents' environment who offers information about parent support processes. Key observer informants were the NICU Assistant Department Head, who has been involved in parent support work for approximately ten years, the current program nurse coordinator and the NICU social worker.

Data Collection Methods

The researcher was the key research instrument, as the researcher's abilities to develop trusting, informant relationships were necessary and directly related to the authenticity of the research (Spradley, 1979). Traditional field techniques, such as intensive interviewing, observation, and document inspection, were used to discover what was going on in the social setting. This researcher's clinical nursing experience in community and hospital-based parenting support interventions provided the sensitivity to parent support issues. This researcher's family and grief counseling skills were useful in forming relationships

within which informants could express negative feelings in an accepting environment.

Interviews

Ethnographic interview techniques were employed as the primary method of collecting information from the key informants about the processes of veteran parent support. Ethnographic interviews can be described as a series of friendly conversations in which the researcher slowly introduces new elements to assist the informants to respond as informants (Spradley, 1979). A Parent Interview guide was developed to focus the parent interview, based on Spradley's guidelines (Appendix A). This guide was developed to reflect the contents of the research questions, however, it was not used to determine the interviewer's exact questions or the sequencing of the content to be covered.

Parent interviews were either taped and transcribed or field notes were taken by the interviewer and expanded accounts of the interview were typed on computer discs. A summary sheet was completed by the researcher to summarize information on the informant.

NICU and volunteer parents had difficulty in identifying specific support processes during interviews. One strategy that proved to be helpful was having volunteer parents focus on recreating an incident in detail as opposed to identifying what they thought was helpful. On occasion, the researcher would be in the clinical setting and this re-

creation could occur immediately after an incident. Phone conversations and informal meetings of support parents that occurred when the researcher was in the clinical setting were also used as a source of data. Selected volunteer parents became very useful informants and would initiate contact with the researcher to share incidents. Another strategy that was helpful was increased involvement with the program nurse coordinator. The coordinator was asked to complete a brief summary of contacts with either the NICU parent or the volunteer parent (Appendix B). However, given the stressors of the position, these forms were often not completed. Therefore, the researcher was able to assume a supportive role for the coordinator as she implemented her role. Telephone calls and/ or face-to-face sessions with the nurse occurred approximately two or three times a month during the study period. These times were used to analyze selected cases that were either difficult or successful.

In order to secure information in a timely manner after the volunteer parents' contact with a NICU parent, a one-page family contact summary sheet was developed to be completed by the volunteer parent immediately after the contact. This form was used to record specific information about the support contact by the volunteer parent following a phone call, home visit, group or other contact. Data were requested on the nature of the interaction, the topics discussed, the support parent's feelings about the contact and other information (See Appendix C). Volunteer parents

completed 144 forms representing their support for 29 families.

Observation

Opportunities for direct observation of interaction between the volunteer parents and NICU parents were very limited. On the occasions when the researcher was in the clinical setting at the same time as the volunteer and new parent, the volunteer was asked whether she would mind if the researcher was in the nursery. The volunteer mothers chose to debrief the parent contact with the researcher immediately following the interaction as opposed to direct observation. The volunteer mothers stated that they would feel more comfortable with the NICU mother if the researcher was not present.

The researcher was able to observe veteran parents and NICU parents in group settings. Groups of NICU and veteran parents were observed in a volunteer parent's home, a hospital setting and a school setting. The researcher was also able to watch the processes of parent support between the veteran parents, all of whom are former NICU parents, at their monthly group meetings over the course of a year.

Document Inspection

Document inspection was utilized to review the files of each volunteer's caseload of families, the family contact summary forms and the program coordinator's contact forms. The researcher received written notes and letters from some parents who had moved away from the community. Demographic

data that were collected from parents as part of the larger study were used to describe characteristics of parents.

The researcher also kept a notebook to record feelings and thoughts about researching the processes of support in the NICU setting. Occasionally the researcher's reflections were taped and transcribed with the interview data.

Data Collection Plans

A data collection plan was designed and modified to include the collection of data from volunteer parents, NICU families who experienced parent support, and observers of the relationships. The initial study proposal indicated that the study would be carried out during the time period of the NICU/PPP demonstration project, September 1984 to September 1985. Because of delays in collecting comparison group data and operationalizing the program in the clinical setting, volunteer parents did not begin to receive referrals until March 1985. Volunteer parents had difficulty articulating support processes during interviews conducted during the first six months in which they were implementing the support role. They had one or two cases to describe, and little feedback from the NICU parents as to what was helpful. Most veteran parents were reluctant to refer their NICU parents for interviews because they felt their families were still stressed with the infant's care.

Funds for continuation of the demonstration program and a more comprehensive, long term evaluation extended the research from September 1985 until March 1987. A decision

was made to continue data collection over the extended time period of the study. This proved to be a valuable opportunity, since it was not unusual for the support relationships to vary considerably over the first year post infant discharge. Many relationships that volunteer parents thought were completed were renegotiated when specific family stressors affected families later in the first year. Volunteer parents and NICU parents were also better able to discuss the supportive relationships given some distance from the immediacy of the crisis event.

The additional evaluation funds made possible a one-year, post discharge home visit to all NICU families. In order to limit intrusion for the NICU families, the researcher used the home visit opportunity to gather information from all of the NICU families about their experiences in the support program. Thus, two home visitors, a master's prepared nurse clinical specialist, who was not the researcher, and a master's prepared social worker, were trained to ask specific questions regarding the support relationship and explore with the parent perceived processes of support as part of the home evaluation. The home visitors had some difficulty scheduling visits with the NICU parents because of the families' changing schedules or being unable to locate the family. However, 21 NICU parents were visited and a two to three page summary report for each family was completed for the researcher. A total of 49

parents, 21 NICU parents and 28 volunteer parents, were identified as informants.

Volunteer and NICU parents were selected for intensive interviewing after the preliminary analysis of the 21 families and coordinator's records, along with direct input from the program coordinator. These parents were asked to participate in a further interview either by home visit or telephone. Parents were hesitant to have the researcher visit. This seemed to be related to the difficulty parents had in identifying and expressing support processes in general. Many did not feel that they could add to the information that they had given to the home visitor. All of the parents contacted after the initial home visit preferred telephone interviews; these were scheduled at a convenient time. The choosing of a telephone interview for a mother of an infant that may have more challenging caretaking demands and other children to care for, or who may be back in the labor force, seemed related to a reluctance to schedule another activity. It was also easier for a mother to share with the interviewer by phone that a particular predetermined time was not good and the mother felt comfortable in postponing the conversation to a more convenient time. The contrast between the welcome acceptance of the researcher to the homes of the volunteer parents and the more limited response of the NICU parents was striking and reflects the advantage of developing relationships with informants.

Since most interviews were conducted when the NICU-involved infant was approximately one year of age, selected NICU mothers whose infants were approximately 6 months of age were also interviewed. Overall, these interviews were not as descriptive as the 12 month interviews although the content of support processes was similar.

The proposed data collection plan and the modifications of that plan that were used in each category of informants, are summarized in chart form (see Figure 1).

Data Analysis

Data analysis was accomplished using constant comparison methodology until the core variable, or basic social process, was identified and the propositions or research questions were generated (Glaser and Strauss, 1967). In constant comparative methodology, each incident is compared with other incidents, or with properties of a category, in terms of as many similarities and differences as possible (Glaser and Strauss, 1967). A process of open coding was used, whereby data were examined line by line and processes were identified in the data. Data were coded, compared with other data and assigned to categories. The major task of the researcher was to code the data into categories, and then define, develop and integrate them into a framework. Data collection and data analysis were conducted simultaneously.

Concept development was accomplished by reduction, and theoretical sampling of the literature and the data to

<u>Informant</u>	<u>Data</u>
VOLUNTEER PARENTS	
1. Volunteer Contacts 144 reports on 29 families	Summary of each contact (see Appendix A)
2. Support parent group 10-15 parents/meeting 2-3 hour sessions 12 sessions	4 videotapes fieldnotes
3. Intensive interview 4 mother/father couples (conjoint interviews/home) 4 mothers (in home) 2 mothers (in hospital) 1 mother (in school setting)	audiotape/transcribed
4. Phone interviews 4 mothers	fieldnotes
NICU PARENTS	
1. Home Visits 21 mothers	2-3 page summary
2. Intensive Interviews Hospital Interview 1 mother	fieldnotes
Telephone Interview 5 mothers 1 father 3 mothers (out state)	notes/transcribed
3. Program Evaluation questionnaires 15 parents	
4. Parent Group Meetings 1-hospital 1-home settings 1-school setting	fieldnotes
HEALTH PROFESSIONALS	
1. Interviews PPP program nurse coordinator NICU head nurse PPP Social Worker Social Worker-School Program Nurse Consultant (Utah) Program Nurse Consultant (Washington) Director of Parent Care, International President of Parent Care	
2. Group meetings with PPP program staff 12 sessions	

FIGURE 1: DATA COLLECTION FROM INFORMANTS

expand and enrich the emerging categories. Reduction means that categories were compared in order to cluster in similar sets. Theoretical sampling is a process of seeking out informants to gain data needed to complete or saturate a category or categories (Swanson, 1986). The literature is also used as data and a means of identifying possible comparison groups when research resources are limited.

This procedure resulted in the identification of being with/creating mother, a basic social process, and accompanying preliminary processes. Concept modification and integration was accomplished by using the procedures of theoretical coding and memoing. An emerging conceptual framework was developed from the processes and variables.

In the analysis of qualitative data, the major tasks of conceptual development follow a repetitive, cyclical pattern (Spradley, 1979). Therefore, the researcher has developed a flow chart that depicts the major activities that were followed in order to identify and develop the basic social process and the conceptual framework. This chart also includes the location of the particular aspect of the development within this dissertation (see Figure 2).

Reliability and Validity

Reliability and validity can be enhanced in qualitative research, although these issues are not addressed in the same manner as in quantitative studies. Qualitative researchers have developed "rough analogues" to quantitative measures of reliability and validity, usually referred to as

<u>Chapter</u>	<u>Data Analysis Process</u>	<u>Outcome(s)</u>
Four	Initial Codes	
	1. Coding 2. Categorizing 3. Clustering	3 Clusters of social support informational emotional role
Five	Conceptual Development: Phase I	
	1. Social support typologies 2. Support concepts	person specific boundary being like self-esteem
	Category Reduction	
	1. Coping with NICU 2. Caring for preterm infant	
	Conceptual Development: Phase II	
	1. Caring 2. Mothering	boundary becoming mother preterm mothering
	Raising the Level of Abstraction	
	1. Being with 2. Becoming Mother	
	Conceptual Development: Phase III	
	Making Comparisons: being with/becoming mother	
	1. Professionals 2. Others in social network 3. Other NICU parents 4. Other experienced helpers	not being with similar being with /creating role
	Raising the Level of Abstraction	
	1. being/with 2. creating mother	
Six	Identification of the Basic Social Process	
	1. being with/creating mother 2. identification of properties 3. identification of subprocesses 4. identification of preliminary processes 5. conditions for being with/creating mother 6. conditions for not being with/creating mother 7. identification of variables	
Seven	Integration into an emerging conceptual framework	
Eight	Generating research questions and propositions	

FIGURE 2: DATA ANALYSIS FLOW CHART

establishing adequacy of evidence and credibility (Chenitz and Swanson, 1986). Denzin (1970) applied the concept of validity to qualitative research and suggested that the following factors may threaten internal validity: history, subject maturation, subject bias, subject mortality, reactive effects of the researcher, and changes in the observer. Attempts to minimize these threats were accomplished by: a) using multiple sources of data, b) delaying completion of the analysis until volunteer parents were more aware of their role and NICU parents had sufficient time to have reflected on their experience, c) striving to maintain diversity in informants, d) noting the participants versus nonparticipants, e) describing the researcher's relationship with the informants, and f) recording notes about the researcher to monitor changes in the researcher.

External validity refers to the generalizability of the results to other populations (Denzin, 1970). In grounded theory, external validity is dependent on internal validity (Chenitz and Swanson, 1986). The greater the range and variation sought during theoretical sampling the greater the likelihood of negative cases being addressed. Study of diverse cases was made possible by the researcher's access to program staff and records and the home visit assessment of the majority of program participants.

Reliability usually refers to the accuracy of the measuring instrument over time (Kerlinger, 1973). Exact

replication of a grounded theory study is not possible. The test for reliability in a grounded theory study is through the use of the theory and its applicability to similar settings and to other types of problems over time (Chenitz and Swanson, 1986). Although the conceptual framework seems useful in explaining some similar problems identified in the widow support literature, testing the reliability of the emerging theory will require further research.

Protection of Human Subjects

Safeguarding informants' rights, interests and sensitivities was a critical element of the research project. Volunteer parents were given an explanation of the research at the completion of the preparation program and given an opportunity to ask questions about the project. Each parent was given an envelope with the consent forms and an explanation and directed to mail back the consent forms if they chose to be in the study. Parents were asked not to return the envelopes in group meetings as that might inadvertently put group pressure on parents who might choose not to participate. Parents were assured that their participation or non-participation in the research would in no way affect their participation in the hospital program. It was explained to parents that the hospital coordinator would not know which parents had chosen not to participate and the information would not be used as a means of evaluating the support parent in that role.

NICU parents assigned to the PPP support parents had

all signed consent forms to participate in the larger study prior to contact. An additional form was used to acknowledge their agreement to participate in the intensive interviews. A project media consent form was used to permit any audio or video taping of data. (See Appendix D)

Limitations of the Study

The following statements describe the limitations of this study.

1. The majority of the informants of this study were participants in a Perinatal Positive Parenting (PPP) demonstration program for parents whose infants were hospitalized in an NICU setting. The program includes a period of veteran parent preparation for the support role and utilizes a half-time program nurse to coordinate and supervise parents; therefore, veteran parents from this program may not be representative of all NICU veteran parents.

2. Although informants from other NICU programs were identified and interviewed as a way of further testing the concepts, limited resources prohibited extensive testing in this manner.

3. Because the researcher is a nurse, and the veteran parents know the researcher as a nurse involved in the development of the support program, they may have withheld information about the support process that would reflect in a negative manner on their own parenting behavior.

4. Because the researcher had the opportunity to develop more trusting relationships with the volunteer parents and little opportunity to develop such relationships with the NICU parents, volunteer parent perspectives are more represented in the data.

CHAPTER FOUR

DATA PRESENTATION: DISCOVERING THE CATEGORIES

The purpose of this chapter will be to describe the initial study findings by addressing research question one: What is involved in veteran parent support relationships initiated in an NICU setting? Coding, the initial phase of the grounded theory method, is the process of categorizing and sorting data, and the means for developing the analysis (Charmaz, 1983). Guided by the researcher's ecological perspective, contextual features of the support involvement were also coded. The following aspects of involvement in veteran support relationships appeared repeatedly and will be described in this chapter: processes of helping parents meet, the parent support relationships, processes of parent-to-parent support relationships. This chapter includes direct parent quotes that clarify and enrich the description of program involvement. Quotes from the data are indicated by the use of boldface type and the source is further identified as either NICU or volunteer parent or a nurse.

Processes of Helping Parents Meet

Parents whose infants have been admitted to the limited access environment of the NICU have a difficult time meeting other parents who have shared a similar parenting situation, especially during the initial crisis days in the NICU. In the particular hospital where this study was carried out, a concern of NICU staff was the lack of professional involvement in helping parents meet. Thus, efforts were being made to expand the professionals' role in connecting parents. Four professional activities were discovered that were focused on helping parents meet. These were: a) informing about the program, b) encouraging parents to participate, c) matching parents, and d) supporting volunteer parents.

Informing About the Program

Because the informants in this study were parents participating in a demonstration evaluation program, the mechanisms for NICU parents being referred to the program were determined by the research protocols. Because of the necessity for parents to sign consent forms to participate in this program, the nurse program coordinator contacted the parents on an individual basis, and spent considerable time with parents for the purposes of establishing a relationship with the parents and explaining the program to parents. The nurse often spent time with the new mother assessing her needs and acting in a supportive manner. Without this personal relationship with the program nurse coordinator, it

was felt that it would have been intrusive to ask parents to agree to participate in the research. Parents were told that they might participate in only those aspects of the program, such as visits, calls, or educational meetings, in which they felt comfortable participating. It must be noted that this particular system of referral is expensive in terms of professional time and energy, and it has not been continued in this particular hospital after the research ended.

If a mother delivered outside the NICU hospital and her baby was transported into the hospital, she was routinely asked by the transport team if she would like to talk with an experienced NICU parent. However, in a critical care situation, the opportunity for the program referral is often jeopardized by the immediacy of other demands. An NICU mother, who was identified by staff as a mother who really enjoyed the program, discussed her referral to the program.

The NICU transport team came to the hospital...I first saw a video, then they asked me if I wanted to talk to a support parent, and then my baby was wheeled in so I could see her for the first time and they were taping everything and preparing her for transport...I didn't want to talk with anyone, just leave me alone and let me figure it out...I worried that a support parent may force you to talk. (NICU mother)

This mother was later called by a support mother and ended up having a very positive, long term relationship with the support mother. She never recalled signing a consent form for the referral; she assumed her husband must have been

asked at the NICU hospital and agreed to the program. This same mother stated:

You have to make a decision--it's a hard time to make a decision...if I wanted support later, who would I have called ?...she (the support mom) will always be my friend forever, we still keep in touch 18 months later.
(NICU mother)

In those programs that are based in other community helping agencies, or those whose services are primarily organized and delivered by parents with consultation from professionals to serve a community need, access becomes a more complex issue.

Encouraging Parents to Participate

NICU parents who are in crisis usually have a difficult time making decisions about what kinds of help they need, or mobilizing the energy needed to seek resources that they feel may be useful. For them to initiate the process of gaining access to an experienced NICU parent is almost impossible, unless such a parent already exists in their usual social network. Parents who were directly contacted by the program nurse coordinator during the demonstration period, and asked in a caring, non-threatening manner if they would like to participate, with few exceptions, agreed to talk to a parent.

The nurse in this particular program often encouraged new parents to take advantage of the opportunity to talk with a support parent. Indeed, the lack of requests for an experienced parent in the program that was in operation prior to the demonstration program was felt to be due to

asking parents this question as a part of a series of routine assessment questions.

It is too hard for parents to make a decision during the first few days. I like to tell them that I would like to have one of our experienced NICU parents stop by to talk with them. Would that be okay? I tell them that experienced parents are an important part of our NICU team who can best understand what they are going through. I give the support parent credibility and I hardly ever get turned down. (NICU head nurse)

The coordinator also acknowledged that she did not encourage all parents to participate especially if the new parent appeared to have adequate support or too many other demands. Information was left with parents that described how they could contact the program coordinator if they decided to have contact with an experienced parent in the future.

Matching Parents

Parents who agreed to participate in the program after a visit from the program coordinator were then referred to a veteran parent. This referral was based on the matching of specific characteristics of the mothers, and the veteran mother's indication of the types of mothers that she would be comfortable serving. The matching characteristics included: infant health problems, infant caretaking problems, maternal health problems, maternal demographic characteristics (race, age, marital status, socioeconomic status), geographic location of residence, and family composition. Ideally as many characteristics would be matched as possible. However, there are many factors that can impair an optimal referral. Ability to reach the

volunteer by phone, the number of available volunteers who can provide support, and the willingness of the volunteer to take a family are all factors that determine which volunteer is assigned to an NICU parent.

In reality, there were situations where parents were matched based on which volunteer parent was available regardless of other matching characteristics. This may be a problem that was unique to a program during the early phases of initiation, where the demand for services may outweigh the number of trained volunteers. However, when faced with the dilemma of getting service for an NICU family, the program coordinator might be faced with persuading a veteran parent to take on an additional family. This puts the coordinator in a difficult position, and the match becomes a "better than no service" match.

Supporting Volunteer Parents

One of the most important role functions of the program coordinator was that of providing timely, accessible support to the volunteer parents. Being available to talk with volunteer parents about concerns related to their role, to the needs of the particular family they were serving or their own family health concerns enhanced the participation of the volunteer family. In a related study (Roman, 1986), 44 percent of the volunteer mothers (N=19) surveyed indicated that they received support for their own family problems to a great degree. Those volunteer mothers who had the most frequent phone contact with the program coordinator

had the most involved relationship with their NICU families. In order to support the NICU mother, the volunteer mother has to have access to support for herself.

The Support Relationship

There was great variability in how the support relationship was operationalized depending on the personal characteristics and life contexts of the participants in the support relationship. A description of who makes support contacts, modes of contacts, and the nature of the contacts over time will be reported.

Who Participates in Support Contacts

Descriptive characteristics of the veteran parents and the NICU parents were available for the parents involved in the demonstration program study (Roman, 1986). A summary of the reported characteristics is given here to describe parent participants.

Veteran parents. Nineteen mothers and nine fathers participated as veteran support parents in the demonstration program study. Volunteer mothers ranged in age from 23 to 38 years with a mean age of 30.8 years, standard deviation 3.86. Over one-half of the mothers were over thirty years of age. All of the mothers had completed 12 years of school, with a median level of education 12.5 years. Five mothers (26%) had completed 16 years of education. Three mothers were currently in school.

NICU parents. The characteristics of the group of NICU parents who participated in the program are included.

These data were excerpted from program evaluation reports (Boger, Roman, and Haas, 1987). Of the 35 families who participated in the demonstration program, 29 mothers and 18 fathers returned demographic questionnaires at one month post discharge. Mothers' ages ranged from 17 to 35, with an average age of 26.8 (s.d.4.8). Fathers' ages ranged from 19-31 years with an average age of 28.8 (s.d.5.6). The average years of education for mothers was 12.7 (s.d. 1.27) and for fathers was 12.11(s.d./ .75). Seventy two percent of the NICU families earned \$24,900. or less and of that number 24 percent earned under \$10,000. Twenty four mothers were married and five were single at the time of initiation of the relationship. Twenty-seven caucasian and two black mothers were in the group of 29 mothers. All of the mothers had infants who were born less than 37 weeks gestation with a birthweight of less than or equal to 2490 grams yet greater than 1000 grams.

Mother and father support. Although the purpose of this investigation was directed towards experienced parent support, one of the important findings of this study is that parent-to-parent support is primarily a mother-to-mother support process. Although the majority of the parent volunteers participated as a couple, the father support parent usually had more limited access to the new NICU father or mother. Although there were instances of couples in group activity, couple hospital and home visits, and phone calls, these were more the exception than the rule.

Support fathers indicated a general reluctance on the part of many of the new fathers to have any one-to-one contact with them when offered.

Still, shy or bold, aggressive or not aggressive, men do not ask for help...if you have a problem, you untangle it yourself...you give support, you don't ask for support...you give guidance, you don't ask for guidance. (volunteer father)

You know, here is the wife, having children and she is sick and so on and he is out there battling, making a living, supporting the family and he is going to ask some other guy down the street for some help? That's not the way it works. In front of the wife, also? He is going to come and ask me for advice? (volunteer father)

It seems like the old saying, 'a man ain't supposed to have any troubles' and that's just the way they keep it. (volunteer father)

Yet, when such contact occurred, it seemed to be helpful for the new father.

I called three dads. I ask how they are doing. They say fine...thanks, goodbye. One dad really talked to me. His wife later told my wife that she had never heard her husband talk about the experience until she overheard us on the phone. (volunteer father)

I think that he (the new father) really benefitted from my husband being there and saying that it was hard on him and this and that...and when he (my husband) is with me, he picks up on things that I don't. (volunteer mother)

Although the support mother may not have much contact with the new father, the support the NICU mother receives is appreciated by the father.

The mother told me later that the dad was quite reserved, so I supported the mom, and my husband supported me--so I can support her. But, the father, in a way was supported, because when I met him for the first time, the baby was having a trach put in, he threw his arms around me and hugged me. (volunteer mother)

Thus, this study primarily reports the processes of experienced mother to new NICU mother support, in the context of a parent support program.

Modes of Contact

Experienced parents took the responsibility for making and maintaining contact with the new parent. As part of the demonstration program, volunteer parents were asked to visit the mother in the hospital during the baby's first few days of life, if the referral was made during this time period. Sometimes the volunteers just stopped in the mother's hospital room, but often they preceded the visit by a phone call to establish a convenient time. This was especially important for volunteer mothers who had to arrange child care and who lived a distance from the hospital. It was just as likely that the referral was not made during the mother's hospitalization and that the parents arranged to meet in the NICU and then go to the hospital coffee shop to talk. These visits also occurred in a community hospital where the mother was hospitalized at some distance from the NICU. A visit in the hospital with the new mother and visits to the baby and parents in the NICU allowed the experienced parent to begin to know the baby as well as the parents. Interest in the parents' particular baby by the experienced parent was a powerful affirmation of the importance of their unique baby in a crowded nursery setting.

Even if both parents in a family were volunteer parents, there was usually one mother-to-mother visit early in the relationship that focused on the mother's birth experience and what she was going through at the time. There were usually questions about the NICU and baby. Sometimes volunteers took educational materials or picture books that could be used to explain information, but these issues were more peripheral to the central issue of the mother's own experience. These visits are often described by volunteers as including hugging, crying and other sharing of intense emotional behaviors and feelings. These reports of personal closeness did not fit with usual models of distance regulation, and behaviors for initiating relationships with others (Hall, 1966; Kantor and Lehr, 1975;).

Out of the case records of 29 NICU families, 22 families were visited during the hospital stay, with an average of two hospital visits. About half of the volunteer parents made home visits, with a range from one to five visits, and an average of 1.6 visits per parent reported. Some parents, especially those in the rural areas, met in groups and even arranged social activities like picnics or Sunday afternoon get togethers with their families.

Although visits were an important component of the support relationship, the telephone served a lifeline function for the relationship. Telephone calls were used by the volunteers to check in with the mothers periodically,

offer the opportunity for support or help in getting resources, and to set up times for visits or other activities. Over ninety percent of the parents reported follow-up phone calls, with an average of 5.7 calls per parent. NICU parents initiated the calling less frequently, but some parents would do so when they needed advice, felt overwhelmed by their situation and needed to talk, or were feeling isolated from others who understood their situation. Volunteer parents occasionally sent notes of encouragement or cards to their families, reminding them that they were thinking of them and again offering further support if needed.

Nature of Contacts over Time

The timing of contacts was an important feature of the support relationships. There appeared to be a period of time surrounding the infant's birth and hospitalization where the new mother discarded usual distance regulation for new relationships and was open to establish a support relationship. This same phenomenon occurred at different points in time and was most likely associated with the infant's health or developmental crisis.

There also seemed to be a reoccurring theme that the experienced parent support was characterized by being timely, that is, it occurred when the parent needed the support the most and was not limited by institutional roles or rules for appropriate contact. There did not seem to be a predictable pattern to the unfolding of the support

relationship. The contact and intensity of the relationship expanded and contracted over time, depending on both participants in the relationship.

Most of the contacts occurred during the infant's hospital stay and during the first four to six months post infant discharge. Many parents reported that they stayed in occasional contact (approximately once or twice a month) during six to twelve months post discharge, while a few terminated the contacts after the first four months. In one of the rural areas, a volunteer mother had her mothers meet in groups about once a month in order to serve the number of mothers that she supported.

Processes of Parent Support

An initial searching phase of coding was used to identify processes that were fundamental in the ongoing relationship between experienced parents and NICU parents. Codes that reflected support processes were collapsed into three major categories of parent support processes. These broadly stated categories of support processes include: a) emotional supportive processes, b) informational supportive processes, and c) maternal image/role supportive processes.

Emotional Supportive Processes

A major group of parent-to-parent support processes seemed to cluster into a category of emotional supportive behaviors. The codes identified were: a) caring, b) talking and listening, c) understanding, d) encouraging expression

of positive and negative feelings: celebrating, hoping, laughing, crying, grieving.

Caring. Data analysis suggested that many NICU parents experienced social isolation as a consequence of their infant's hospitalization and the fact that the experienced parent contacted them was an important feature of the relationship. Many factors contributed to this experience of social isolation such as the limited access environment of the NICU, the lack of information about the NICU and preterm infants in the parents' usual support network and the isolation of the mother at home after the baby has been discharged. The fact that the experienced parent made the contacts and sought out the new parent, on a voluntary basis, was often interpreted as a caring message.

No one else calls you, either they don't know you delivered early or they don't know what to say and so don't call. The baby's birth is in the paper, and they know it's early, but I have to call them and reassure them that the baby is okay. (NICU mother)

When you need someone the most, you don't feel like talking. Well, my support mother would call and ask, "How's it going? Do you want to talk?" She asked about me "are you too tired to talk?" I've told her at times, I'm too upset to talk right now and she will say that's fine, she understands and I can call her anytime or she'll check back later. Even though I couldn't talk right then, I knew someone cared enough to call. She has a way of being gently persuasive, to help you talk. (NICU mother)

Doctors and nurses can be very supportive individuals, but let's face it, it's their job. A volunteer parent is helping because they want to. It is much easier to share with someone who is there because they want to be there. (letter from NICU mother)

When you've had a totally frustrating day: your toddler has been a discipline problem, your baby has been fussy and your spouse has been gone all day to work and

school, it is 9:00 at night, who do you call for some encouragement? Certainly not your obstetrician or the nurse who cared for you during labor and delivery. However, your support parent will most often be available to listen and care. (letter from NICU mother)

Talking and listening. Many NICU and experienced parents described the support role as being available for talking and listening when the NICU parent is ready to talk or listen.

They want to tell me why they thought they delivered early. They want to talk about themselves as persons and what they were dealing with. This talking about their experiences goes on for a long time. They still want to talk about it later, because nobody else wants to hear it anymore. (volunteer mother)

Our talk was more everyday, not so serious. She'd come and talk "other talk". It would be more about what you're feeling or information, it's everyday talk. (NICU mother)

I once called at 12:30 a.m. and my volunteer was courteous, caring and supportive even then. (NICU mother)

It was difficult for the NICU parent and the volunteer parents to describe what specifically they talked about together that made the new mother feel supported. One volunteer mother related a poignant example of talking with a new mother.

The mother called me at home the other night and told me that she was told by the hospital staff that her baby was dying and would not survive. I told the mother I didn't know what to say. Then we talked for about ten minutes. I called her later and asked her if she was going up to see the baby today, I asked if she wanted me to go up and meet her there. She said, well, if I had time. We decided I would come up (to the NICU) tonight. (volunteer mother)

This volunteer mother found it difficult to remember exactly what they talked about for ten minutes. But the fact

remains that many of them demonstrated willingness to talk to parents even when there is nothing that they could say.

The support parent is willing to listen to the bad things. (NICU mother)

They are bad news friends. (NICU mother)

The content of the parents' talking and listening seemed to cover a broad continuum. At one end point, there was the ordinary, mundane family-type talk that included such topics as coordinating family schedules, the weather, and children's activities. However, at the other end of the continuum, parents frequently talked about things that one parent suggested were things you would never ask anyone else. Volunteer mothers recorded on the family contact summary sheets that they talked with mothers about such things as : feeling angry towards other mothers and their babies who do not have problems; feeling depressed when things are starting to get better for the baby and others expect mother to be happy; learning to live with the fears (for your baby's life); sharing feelings about spouses' coping ability; talking about "feeling" all of the baby's painful experiences; and feeling bad about not returning to work. It seems that many of these topics reflect negative or scary feelings that a mother had about her experience. These topics may be difficult to share with others without feeling vulnerable that these feelings would be interpreted as not acceptable for a mother of a preterm infant. Parents also reported being able to talk about spiritual and religious beliefs with their support parents.

The mother (whose infant's prognosis was poor and the infant eventually died) told me she prays for her baby and has put the baby in God's hands. I told her I thought that would be the best place and I said I would pray for them too. Before we hung up, she told me that the Lord blessed her to give her someone like me. That's one thing we can share, our spiritual beliefs. Faith is very personal. You don't share with a lot of people, not usually professionals. (volunteer mother)

Volunteer mothers described their interactions with NICU mothers and other experienced parents :

I guess I let her be who she needs to be at that time, her baby was dying, but she was talking about rattles for her. That's okay. I let them guide the discussion, I don't have an agenda. (volunteer mother).

There is a trust that's there. We tell personal things and people understand. There is a permission to share. Other parents listen, they don't interrupt. They don't compare and they don't get distracted. (volunteer mother)

It's someone to talk to when you need it. Everyone else is too busy. Other friends try to understand our situations, but many of those friendships dissolve, it's like what happens to your group of single friends when you get married. Friends (old) don't understand the gravity of our situation (with a child with health and developmental problems). Who can parents talk to--no one is there. Professionals work 9-5, family crises occur 5-9! (volunteer mother)

Perhaps the uniqueness of the relationship lies in the fact that other persons in the family's environment, including professional staff and usual support people, are not able to talk and listen with parents in such a manner. An NICU nurse, who has observed parent support relationships for many years, indicated that social roles of parents and professionals influence interactions.

I think the depth of sharing a parent will do with someone who has been there is different. Parents can't tell the doctor that they are afraid. They say to the doctor what they have been taught to say to doctors. (NICU nurse)

Volunteer parents and NICU parents agreed that what is shared between parents is unique and special, however, they had difficulty in expressing what specific qualities make this so. Parents tended to report the overall feeling tone of the interaction and did not seem to be aware of the specific, subtle behaviors of other parents that made them feel like talking and listening to each other.

Understanding. Although professionals who work in the NICU get sensitized to their stressful work environment, the parent's first contact with the NICU is oftentimes overwhelming. Many parents brought to the unit their previous perceptions of adult intensive care. This included perceiving the unit as a place of death or disability, unless the advanced technology and highly skilled staff can reverse the anticipated outcome.

Professionals can't imagine what it is like to enter the NICU for the first time. The terror parents feel, they are terrified for their baby's life. There are few things that a professional can say to a parent that isn't interpreted by the parents to mean your baby is dying or will be brain damaged. Even something like "wait and see", which seems harmless enough, is interpreted differently by the parent. (NICU mother)

When your baby is in Neo you hear, 'this is the best place for her'; 'you're lucky you had her here or now.' I wanted someone to say 'yes, this is horrible, yes, this is scary'. (NICU volunteer mother)

Parents would often indicate that other parents can understand the complex feelings that accompany the infant's hospitalization in the NICU. If the parent's situation was similar to the experienced parents in other ways, this

appeared to enhance the NICU parent's feelings of being understood.

I think it helped that she had older children. She understood how hard it was to cope with the crisis of the baby's birth and still keep things going for my seven year old daughter when you're exhausted (NICU mother).

Even when the baby's medical condition became complex and ceased to match the volunteer's parenting experience, the parent's need for feeling understood seemed to supercede the need for specific parenting information related to the medical diagnosis.

We went out to dinner one night, before a visit to the NICU. I asked her if she would like to talk with another support parent whose baby had similar problems (this experienced mother's baby did not have a gastrostomy and tracheotomy). She said she wanted to stay with me. She told the program coordinator she wanted to stay with me because she knew I understood her feelings (volunteer mother).

Expression of positive and negative feelings. NICU parents often reported that they could turn to the experienced parent to talk about their feelings in an unguarded manner. Mothers often wanted to talk about what went wrong, the pregnancy, labor and delivery and themselves, and what it was like for them. Experienced parents often shared with the NICU parent the feelings that they experienced while their own children were in the unit, as a way of giving the parent subtle permission to verbalize the many scary feelings that accompany this event, in a non-judgmental atmosphere. Others were often hesitant to encourage the expression of positive feelings because they

felt this could falsely reassure the parent when the child's health and prognosis might be critical. Likewise, although professionals considered negative feelings, like anger, to be an appropriate grief response, parents who did not know the staff's expectations for parent behavior would hardly risk sharing negative feelings.

Parents reported the following feelings and behaviors that they often shared with each other: a) celebrating, b) hoping, c) laughing, d) crying, and e) grieving. A brief description of each of these feelings and behaviors will follow.

Positive feelings of hope, pride and joy were often shared by new and veteran parents. NICU parents indicated that experienced parents were the only ones who were willing to celebrate the baby's birth. A real loss for parents in the NICU experience was the expected joy, celebration and often ritual family behavior that accompany an infant's birth.

Everyone ignores that I gave birth, that it happened. The support parent was excited that we had her, whether she lives or not, the support parent is willing to listen to the bad things. (NICU mother)

Volunteer parents indicated on the contact sheets that they would hear from the NICU parent when the baby overcame a significant health obstacle or graduated to a nursery for less critical infants. In the periodic contact parents had with their volunteer, the baby's health and development were often topics that were discussed.

Even when the infant's prognosis for recovery was poor, support parents seemed to look for positive aspects in the situation. Hoping with the new parents for the baby's life and health and developmental outcomes was often described. The volunteer parent's very presence seemed to inspire hope for the new parent.

Parents can't give up hope. I know they (staff) are trying to help parents by giving them realistic expectations, but parents can't give up hope and continue. (volunteer father)

I take them balloons to put on the isolette. I tell them how good she looks today, how cute she is. (volunteer mother).

Parents also reported incidents where they were comfortable laughing with each other. Sometimes the laughing was over trivial things and other times related to serious concerns. Some have described this latter phenomenon in very stressed persons as black humor (Hutchinson, 1986).

She made me laugh, she would tell me stories about her kids, joke about all the tubes--it takes so many people to pick up one little baby--everything is so serious up there (NICU), it's nice to laugh just for a second. (NICU mother)

One volunteer mother described an incident of laughing with an NICU mother who had been told by staff previously that her baby would not survive.

Oh, we talk about everything, kids, family and then in the middle of that kind of conversation, she might say "would you visit the gravesite if your baby died". It was so startling, that I laughed and said, "I've never had a person close to me die, but when my dog died, I buried it in the backyard and visited the grave everyday. I probably would be crazy enough to want to do that" and we both laughed. I know it sounds crazy, but that's what we parents do, the mom bounces off her fears, anxieties and then watches to see what my reaction will be. (volunteer mother)

Many of the volunteer parents reported on the parent contact summary form that the NICU mother would cry with them and hug them, particularly on the early visits in the hospital. These behaviors indicated a closeness or proximity that was achieved in the relationship fairly rapidly. Crying was often mentioned by the NICU mother.

I met my support person twice in the hospital and cried with her, she reassured me. You're not alone when you find someone. Parents who have been through it, it's okay to cry with them. (NICU mother)

This ability to find an opportunity for emotional release with the veteran mother continued for some mothers after discharge. This was particularly true for mothers whose infants have demanding caretaking problems.

Right when he came home, he had bronchitis, pneumonitis, and had reflux (regurgitation of feedings) on top of that. The first four months I had to keep him inside constantly. She (support mother) would call and I would breakdown. (NICU mother)

Grieving behaviors, such as crying, anger, depression, sadness were reported to be shared between the mothers. Grieving behaviors may be more difficult for parents to feel comfortable expressing in the public environment of the NICU or with others whom they feel may not understand such behaviors. However, mothers did express these feelings with the support parents and often experienced parents reported that this occurred during the early visits.

Mothers whose children had a less favorable prognosis or who might experience a long period of illness before the baby eventually died, seemed to form close emotional

attachments with support parents that were linked to the volunteer's attachment to their baby.

Your support parent goes through it with you. They know about your baby. After my baby died at seven and one-half months, I didn't want to start a new relationship with a support parent whose infant had died. Personally, I want to stick with P. She knew my baby. A new support parent, they never knew your baby. I am sure P. felt bad too, we went through the good times and bad times. (NICU mother)

Program mothers whose infants have subsequently died all remained in the support relationship with the experienced parent for a time period after the infant's death. All of the support mothers were asked to come to the infant's funeral. The support mothers did attend funeral services, sometimes with the program coordinator or with their own families. On occasion, these former support relationships were transformed into a kind of friendship and this gave the mother an opportunity to talk about her baby with someone who knew the baby.

Informational Support

Sharing information was also a central feature of the support relationship. The content of information sharing between an experienced volunteer parent and a new parent often centered around the preterm infant; the NICU; the infant's health and caretaking; parents' relationships with other family members, friends, and professionals. After the infant was discharged, the content was often related to the infant's caretaking demands and integrating the infant into the family system. Informational support included the

following categories : a) sharing stories, b) explaining and interpreting and c) forecasting.

Sharing stories. The relating of stories about the volunteer parent's own NICU child was a potent source of information. Information was contained in words, and also pictures of the volunteer's own child that the experienced parent shared. Some mothers shared a diary or a picture diary that showed their child's development over time. The message was given subtly to new parents that although they may perceive an intensive care unit as a place of death or near death, it may also be a place where their infant may return to health. The volunteer parents who had access to professional supervision in a group setting with other volunteer parents generated a large quantity of experiential parenting information. These stories were often related generally to new parents to protect confidentiality.

Explaining and interpreting. Information that was shared during the early stages of the relationship was focused on explaining and interpreting what was happening to the preterm baby. Parents often took an educational pamphlet to the NICU parent or pictures of their own infant in the Isolette in order to talk about the treatment and monitor equipment. For example, oxygen level was a new concept for most parents. Parents wanted to know how oxygen helps their infant, what the numbers mean, is a particular number good or bad? Support parents did not give technical explanations, but shared their understanding of what "oxygen

level" means to them and other parents whose children have been on oxygen. They told parents how oxygen level must progress for the baby to get well and go home.

I would call her and say the baby's oxygen level is such and such. She would say it has to go down. She gave me information and would interpret for me. (NICU mother)

I said maybe this is a dumb question, but just once I'd like to know what every tube and wire is for. (NICU mother)

Forecasting. Support parents also prepared parents for the unpredictable pattern of getting well. One mother described her support mother as "forecasting". That is, she explained how a situation might proceed over time, including possible setbacks based on experiences with a variety of infants. Support parents used their own and other volunteer parents' experiences to share the specifics of how different infants may go through the NICU and the processes of recovery. As they matured in the role of support parent, parents became quite knowledgeable about a variety of ways infants and families managed the experience. However, they did not predict how the parent's particular infant would progress through the nursery and they referred specific questions to the health professionals. Thus, the new parents obtained an idea of some landmarks on the journey through the NICU. They gained information that they might not use at the particular moment, but would be there for them when they needed it.

They can give you a forecast and tell you a situation over time. They also tell you experiences of other families they have worked with. (NICU mother)

I really felt the need to discuss my feelings with another mom who was ahead of me. (NICU mother)

Maternal Image/Role Support

The mother of a preterm infant has a more complicated task of defining a new parent self in an intensive care environment where she cannot take on the caretaking role she assumed would be hers. Thus, other supportive processes that merit attention are the behaviors that seem to cluster around the idea of maternal identity or self image.

A number of supportive processes were identified that relate to the mothering role. These include: a) parenting in the NICU, b) learning about a baby that is different, c) encouraging, d) reassuring, e) getting more help.

Parenting in the NICU. Parents discussed how to be a baby's parent in the context of the NICU. Since they had no past experience to prepare them for the role of parents of a hospitalized, critically ill infant, many new parents were overwhelmed and confused about what is expected of them as parents. Experienced parents told new parents the rules, how to talk to doctors, what questions to ask, and how to get help for their baby. After the baby's discharge from the unit, many experienced parents continued to teach new parents how to talk with health care providers and other professionals who may be involved in the infant's recovery and developmental evaluation. Parents reported that they have suggested strategies for new parents, such as taking a list of their concerns to the provider. They have role-played parent-professional interactions in order to reduce

some of the NICU parents' anxiety and have even accompanied the mother to clinic appointments.

Nurses know the answers, another mom can tell you what the questions are. Once we knew what to ask, the staff was great. We were "trained" really well. (NICU mother)

Learning about a preterm baby. Sharing information about how the preterm infant's behavior, health and caretaking needs differ from what the mother expects was an important support process. For example, a volunteer responded to a mother's worry about crib death and continuing apnea, periodic cessation of breathing, after the baby is home by explaining a pneumogram test that helps the neonatologist determine if a monitor is needed. Information sharing was particularly important for the parents whose infant is discharged with continuing health and caretaking problems. Feeding, especially reflux problems, and crying/fussiness problems were frequently reported as topics of concern for NICU parents on one-to-one visits and in parent group meetings. Developmental concerns and dealing with acute episodic diseases were also issues that were discussed with volunteer parents.

I talked with her about the baby not sleeping more than two hours at a time, she said she would get some information for me and get back with me. In twenty four hours she had information on helping premies sleep. I still keep the articles she gave me next to my bedside. This isn't stuff you call the doctor about all the time, she could help. (NICU parent)

Even if the volunteer mother did not have the information, the parent often felt comfortable in making the contact and beginning the search for information.

Out of the blue one day, my phone rang and I answered it and it was this (NICU) mother and she was worried about the baby. She said, "I didn't know who to call and I just knew that you'd have the right answer and I thought of you right away." I thought, I don't know the answer (laughing), but she trusted me enough to be able to make that first call to me. (volunteer parent)

After discharge from the NICU, volunteer parents often held or fed the baby. Sometimes they showed the mother, either directly or indirectly, some preterm mothering skills. The following paragraph is an excerpt from the researcher's journal after a parent group observation.

The new mother's baby was getting pretty squirmy and seemed to have a gas bubble or something that was making him a little uncomfortable. He was periodically spitting up some of the formula. After this went on for a while, they talked about him (baby) sometimes having stomach gas and being irritable. One of the support mothers asked to hold the baby. Without saying anything, she started very methodically rubbing the baby's stomach. I was aware that she was soothing the baby. The baby was relaxing and was much quieter. The mother asked the volunteer what she was doing. The volunteer shared that she had discovered with one of her baby's, that a particular pattern of rubbing the babies stomach in a clockwise position with the back of her two fingers and sort of squishing up his knees to his tummy helped. The baby's grandmother said, "whatever you did, it worked well, we knew he was uncomfortable before". They then asked the volunteer to show them again. (journal entry)

Encouraging. In recreating critical incidents with volunteer parents, it became apparent that experienced parents often acted in a role of encouraging the new mother, a sort of cheerleader, someone who gave the message to the new mother that you too can do it. One volunteer mother related an incident that had just occurred in the NICU with an NICU mother.

Parents are often afraid to talk to the doctor and nurse, they are afraid to tell the nurses things about

their baby. The mom saw that the baby had wet the Pampers (diapers) and it is important to keep the baby dry because the baby has a cast on. I said, "tell the nurse". A few minutes later, the nurse came over. I nudged the parent and she did tell the nurse. The nurse was responsive and changed the baby's diaper. Being in the NICU is like having a new job, you don't know the rules and you're scared. (volunteer mother)

Reassuring. Many of the volunteer mothers reported on their contact forms that they reassured the new mothers that their feelings and behaviors were normal. Somehow the fact that the support parent is or was like them was reassuring and offered an opportunity for social comparison. Feelings that were frightening or what the mothers might determine as not motherly were often discussed. The volunteers indicated that they tried to reassure mothers that other mothers felt like they did or experienced some of the same things. The fact that the experienced mother did survive a similar crisis was in itself reassuring.

When you see another parent who has been through what you are going through, it is reassuring to see them functioning. Like they were dressed, drove to the hospital, had makeup on. They talk about stuff matter of factly. (NICU parent)

An NICU nurse shared a comment that a new parent expressed to her after meeting with an experienced parent.

I don't know if my baby will survive, but after I talked to my support parent, I knew I would survive. (NICU mother)

Linking with more help. Parents often had to deal with other health and helping institutions in order to provide care for their infant. Sometimes the need was finding suitable child care for a preterm infant on an apnea monitor when a mother has to return to work. At other times, the

experienced parent took an active role in helping a mother obtain services for an infant who is struggling developmentally. Although there are health professionals in the NICU to help parents get the additional resources they may need to care for their baby, these services are dependent on the parent's readiness and openness to access these resources. Additionally, services to continue to help parents find resources after the infant's discharge are minimal in most acute care settings. Many parents have not been in a situation where they needed to look for resources outside of the family setting prior to the NICU and have few skills in dealing with other institutions. Experienced parents shared information on what resources might help the family, and how they could go about getting such help (people to contact, phone numbers, names of other parents who have used such services). They also conveyed to the new parents that it is acceptable for parents like themselves to ask for and use these services.

She started out with good support, his relatives, the church, but the relatives wanted her to shape up and get on with it, the church support burned out. Around ten months she looked and acted depressed, she called and said that she couldn't go it anymore. We talked about her alternatives (minister, doctor) but she said she couldn't make the calls. I said I can and called five or six places to get information. (volunteer mother)

Summary

The purpose of this chapter was to describe what was involved in veteran parent to new parent support initiated in an NICU setting. A description of the participants (the

veteran parents and the NICU parents), the characteristics and the context of the relationships were provided. Additionally, the results of the initial coding of support processes were identified and the reader was provided with examples from the study data. The chapter that follows will describe the focused coding of the conceptual development phase of the research.

CHAPTER FIVE

CONCEPTUAL DEVELOPMENT

The purpose of this chapter is to present a description of the conceptual development of NICU parent-to-parent support processes in order to assist the reader in understanding how the basic social process was determined. This chapter is organized to reflect consistency with the data analysis flow chart (Figure 2) that was presented in the methodology chapter. The conceptual development process included category reduction, recoding, comparing, and theoretical sampling. These were used to identify the basic social processes. Three conceptual development phases are briefly summarized: a) Phase I: Support Processes, b) Phase II: Caring and Mothering, c) Phase III: Making Comparisons. The summaries of these phases do not include all of the data or literature that was sampled during the development process. Excerpts from both sources are used only to assist the reader in understanding the development process leading to a concept. Consistent with Chapter 4, parent quotes are indicated in boldface type. Although these phases of

analysis appear as discrete sections, in the actual research process the breakdown is not as clear.

Conceptual Development Phase I: Support Processes

Coding of parent-to-parent support processes yielded numerous substantive codes that were clustered by the researcher into three groupings: emotional support, informational support, and maternal self image/role support as indicated in Chapter 4. In order to place the preliminary findings within the context of what is known about such processes, the literature in which authors included descriptions of actual support processes or a conceptual analysis of support processes was reviewed.

Typologies of supportive processes have been described in the literature and three typologies were reviewed for the purposes of concept development (Barrera, 1980; Gottlieb, 1978; Wortman, 1984). Gottlieb's typology of informal helping behaviors, developed as an outcome of a qualitative study of the informal helping behaviors extended to single mothers, was remarkably consistent with the initial categories discovered in this study. The two main supportive categories in Gottlieb's typology were emotionally sustaining behaviors and problem solving behaviors. Emotionally sustaining activities included such behaviors as talking (unfocused), reassurance, encouragement, listening, understanding, and concern. Problem solving processes included talking (focused), provision of information, referral processes and others.

The support process codes identified in this research were consistent with the processes reported in the typologies and do not clearly discriminate what processes are unique to the role of the experienced support parent. Cohen and Syme (1985) in an analysis of social support research, made the salient point that reviewing typology documents underscores how similar specific supportive acts or behaviors are when described out of context.

Next, exploration of the literature that described conceptualization of support processes was pursued in order to expand and raise the conceptual level of the individual processes. The literature was reviewed for conceptual articles that related to the three clusters of support processes: informational, emotional, and role processes. Selected conceptualizations advanced the development process. Emotional support, defined by Belsky (1984), was described as the love and interpersonal acceptance an individual receives from others, either through explicit statements to the effect or as a result of considerate and caring actions. This definition draws attention to the notion that emotional support is received from others, and implies that perhaps the supported person must open the boundary of personal space and actively receive intended support.

Wills (1982) described emotional support as having someone available with whom one can talk about problems. When people encounter threats to self esteem, that is,

occurrences that raise doubts about their own abilities, emotional support is especially useful (Wills). This description would suggest that the NICU mother, whose self esteem may be assaulted by her inability to carry her pregnancy to term and care for her infant after birth, may have particular needs for additional emotional support to maintain self esteem.

Studies that have attempted to measure both emotional and information support have found that these concepts are highly intercorrelated (Norbeck and Tilden, 1985). Wills (1982) believed that this occurred because the provision of advice may be perceived by the recipient as an expression of caring and concern by the other person. This may explain the difficulties in trying to separate the informational and emotional supportive processes of the volunteer parent and would strengthen the case for the development of a broader concept that includes both processes.

Even though I couldn't talk right then, I knew someone cared enough to call. (NICU mother)

The body of literature that described social expectation or comparison support, was useful in conceptualizing maternal role support. Cronenwett (1980) described comparison support as a person who helps you learn about yourself just by being someone in the same situation or with similar experiences; he or she is like you in some important way and you feel supported because you can share ideas and feelings with someone like yourself.

They are like me. They come to see the baby. They are like us. The nurse, it's her business, even a friendly nurse. (NICU mother)

The analysis of the social support research and review of the data directed further conceptual development by helping to focus the researcher's awareness on: a) the similarity of specific support processes and the need to further explore the unique contributions of NICU experienced parents, b) exploring the idea of experienced parents being more acceptable sources of support than others because they share similar parenting situations, c) the effect of likeness on new parent's willingness to receive support or open the personal boundary, and d) the idea of emotional and informational support being perceived as caring.

Category Reduction

Additional sorting of the codes enabled the researcher to collapse the codes into two major categories which seemed more support person specific. These categories were labeled: a) coping with the NICU experience, and b) caring for an NICU-involved child. However, further data collection and data analysis revealed that even in these two categories, the subprocesses of informational, emotional, and role support were overlapping and confusing.

Raising the Level of Category Abstraction

After extensive reviewing of the study data, it became apparent to the researcher that the data had been viewed and categorized from a health professional's perspective, that is dichotomizing the NICU experience and actual mothering

tasks. The NICU mother does not become a mother when she begins actual caretaking responsibilities of her baby, which usually occurs near or after discharge. It is more likely that once the mother delivers her baby and is unable to assume the expected maternal role, she begins the unsettling process of attempting to form a new mother role. Thus, the early categories were reviewed again and raised to a higher level of abstraction that includes two major concepts: a) caring about mother and b) helping mother to care for her preterm infant. These concepts were not bound by temporal or environmental characteristics. Thus, the concepts caring and mothering were further developed.

Conceptual Development Phase II: Caring and Mothering

Caring

Nouwen (1974) noted that the word care is derived from the Gothic "kara" which means "lament" . He proposed that the basic meaning of care is to grieve, to experience sorrow, to cry out with. Nouwen described the characteristics of a caring person as one who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not-knowing, not-curing, not-healing and face with us the reality of our powerlessness.

I met my support person twice in the hospital and cried with her, she reassured me. You're not alone when you find someone. Parents who have been through it, it's okay to cry with them. (NICU mother)

These descriptions of caring indicate a "with us" or presence and yet also do not imply "doing" or any specific

action. In fact it seems as if being comfortable with lack of action is necessary for the supporting person. Perhaps because the experienced parent is not involved in the treatment of the infant, or is not related to the parents, the parent can provide support by not doing. This description of caring was useful in further comprehending the difficulty parents have in trying to verbalize specific support behaviors. Perhaps by not doing anything other than being there, the volunteer parent supports the new parent.

Mayeroff (1971), in a conceptual analysis of caring, described caring as helping the other to grow. However, to care for other persons, it is necessary to understand those persons and their world as if one were inside it versus looking at others in a detached way from the outside. Being with was a phrase used by Mayeroff to describe a relationship where a person is with another person in his world, in contrast to simply knowing about him from the outside.

Mayeroff described persons being cared for as feeling they are not alone, feeling understood and feeling that the other knows what it is like to be them. The persons being cared for do not feel that they must conceal the true self by trying to appear better than they are, but can open up and let the other get close. Thus, the person being cared for experiences the other on the same level, a level of equality. This conceptualization also describes the boundary phenomenon of letting in or getting close. If

being with occurs when the participants in the relationship are equals, this may explain why NICU parents seem more willing to allow experienced parents to come closer to them.

It's a different kind of support. They ache like you. Other friends change the subject and walk away. (NICU mother)

Your support parent goes through it with you. They know about your baby. After my baby died, I didn't want to start a new relationship with another support mother whose baby died. I want to stick with her (the volunteer) because she knew my baby. I am sure she felt badly too, we went through the good times and the bad times. (NICU mother)

Other authors conceptualized this notion of being with someone as presence (Paterson and Zderad, 1976; Wilson, 1985). Paterson and Zderad (1976) defined presence as a mode of being available or open in a situation with the wholeness of one's unique individual being, a gift of the self which can only be given freely, invoked or evoked. Presence is characterized by a certain openness, a receptivity, readiness, or availability. Availability implies not only being at the others' disposal but being with them with the whole of oneself. These authors cautioned that visible actions or being attentive to another but refusing to give self did not signify presence. Presence is revealed subtly in glance, touch, and tone of voice.

L'Engle (1986) described compassion as meaning to share with another whatever it is that circumstances are bringing to bear on that other. She carefully distinguished that compassion does not mean to coerce or to manipulate as a

means of caring for another. When the helper attempts to coerce or manipulate, the other does not have to be involved with the one who is being helped. Compassion means to be with, to overlap, to share, no matter how difficult or painful it may be (L'Engle, 1986). L'Engle (1972) cautioned that compassion means to suffer with, but it does not mean to get lost in the suffering so that it becomes one's own.

These conceptualizations of caring and presence were helpful in exploring the boundary between experienced parents and new parents. If parents experience a state of being with that is different than others in the parents' network, perhaps this facilitates the receiving of emotional and informational support. However, there is the concern that experienced parents must carefully maintain their own boundaries so that they do not get lost in the new parents' experience.

Reviewing the data for instances where parents described the concept presence or being with was productive. Parents used the phrase, being with or variations of the phrase, such as being there or being for, on numerous occasions to describe how the support parent was with them at important times.

She can't get out very much. She has a three year old and a little baby and he is on oxygen and he can't be taken out. So I usually end up calling and seeing how she is doing and dropping in on her when she has some free time. Around Christmas, I went over with my son. Her little boy came out with a present for me. I felt awkward. She said, 'no, no I want to do this for you.' The card just made me want to cry. It was just about thanking me for being there when they needed me and being up at the hospital and that they didn't know what

they would do without the program and our help.
(veteran parent)

When we first brought our babies home to join their two year old brother, people kept saying, 'It will get easier'. Our girls are nineteen months old and I am still saying when? Support parents can become friends who are helpful for a long stretch of time, health professionals cannot. (letter from NICU mother)

Mothering

Two areas of literature were useful in further conceptualizing mothering: maternal role theory and mothering NICU children. Maternal role theory has been described for mothers of full term infants. No other role theory specific to NICU infants was uncovered, other than those reviewed in the classic studies reported in the preliminary review of literature chapter.

Maternal role. Role theory was useful in exploring the concept of mother. Using this framework, Mercer (1981) indicated that a woman defines her maternal role performance in interaction with her infant and responds according to her situational context, her perceptions of her past and present experience and her values. Maternal role attainment can be defined as a process in which the mother achieves competence in the role and integrates the mothering behaviors into her established role set, so that she is comfortable with her identity as a mother (Mercer, 1981). Maternal role attainment is described in the literature as a process occurring over the time period of the pregnancy until three to ten months postbirth (Mercer, 1981; Rubin, 1967). Mothering behaviors reflect a society's common beliefs about

what mothers should and should not do (Mercer, 1981). With the birth of the baby, the mother begins identifying her role-partner and assumes care-taking tasks (Rubin, 1967). In all roles, there is a role partner, and feedback from the role partner influences the process of role-taking. Benedek (1959), in her classic work on mothering, indicated that for mother, a good and thriving infant equals a good mother.

As a mother progresses through phases of maternal role attainment, she moves from adhering to rules and directions of others and adapts and evolves her own maternal role behaviors. The end point of maternal role attainment is maternal identity, a state where the mother experiences a sense of harmony, confidence, and competence in how she performs the mother role (Rubin, 1967).

Selected factors have been reported in the literature to have an impact on maternal role attainment. These factors include: maternal age, perceptions of birth experience (negative birth perception), early maternal-infant separation, lack of or conflicted support systems, self esteem, maternal illness, and infant illness (Mercer, 1981). Many of these factors are present for mothers whose infants are preterm and involved in intensive care.

The mother of the preterm and/or sick infant, whose infant is in a limited access NICU environment, has a more complicated task of defining a new mother self. The maternal role activities she had planned on assuming are being carried out by highly trained and skilled

professionals. The professional care giver becomes the primary source of information about her baby's care. The feelings of being watched and having her first attempts at mothering evaluated by professionals contributed additional stress for NICU mothers as they sought a maternal identity.

Parents have the feeling of being observed in the NICU at all times, every interaction you have with a professional or with your baby, it feels like there is a hidden agenda in every interaction...parents know they are being watched. I knew that I was supposed to act in a special way when they showed me my baby. (NICU mother)

Images of what mothers and fathers do is often transmitted through family beliefs and customs (Kantor and Lehr, 1975). Yet, NICU parents face uniquely contemporary problems. These problems are so new that families, friends and even professionals have not identified appropriate caretaking strategies.

My relatives didn't know what to say or do. I'm the only one in both of our families that has had a premie. I needed to help them (family members). My mother would die when the heart monitor would go off. My mother would say that he's going to die. (NICU mother)

We even lost friends over this. We couldn't take our child out. He is sick, we don't want to take him out. He's seeing a specialist for his lungs. We lost two or three sets of friends over him. We call our friends that we met through the NICU. (NICU mother)

Thus, the social context of parenting a recovering infant at home may be a source of stress instead of support for the mothers attempting to define a preterm mother role.

One author was particularly helpful in describing the isolated context in which all new mothers learn their new role in the 1980s (Dalley, 1981). With a high percentage of

mothers of infants and young children working, there is limited time and energy available for mothers to initiate and sustain relationships with other mothers for peer support. Even those mothers who work inside the home during their childraising years often find themselves isolated in neighborhoods where most mothers are working, and where few mechanisms exist to bring these mothers and children together. Dalley contended that this isolation of mothers increases the mother's exposure to experts and her dependence on them. Without previous experience and isolation from other mothers, mothering is done more by mental activity, conscious and striving, rather than by intuition and experience absorbed from other mothers over the years (Dalley).

Mothering an NICU involved infant. There has been little written specifically on the experiences of mothering NICU children. The research studies that are available on mothers of preterm infants are primarily focused on the mother's behavior as an interactional partner of the preterm infant and the effects of such interaction on the infant's development (Lozoff, 1977). Therefore, a broad search of literature that related to mothering infants with a life threatening health problem was pursued. The most useful sources identified were primarily books or other printed materials authored by parents or professionals who have had experience in parenting such children or providing support for parents. Many of the study parents included

descriptions of their own parenting experiences during the interviews and these data were also analyzed. In addition to information about mothering NICU infants from informants in the study, the researcher was able to locate a group of NICU parent newsletters from a national parent support group that included items written by parents for NICU parents.

Pizzo (1983) has published a volume describing parent-to-parent support based on interviews with a broad range of parents who were involved in parent programs. She reported that when a child's health or chance to survive is impaired by forces too imposing for a parent to combat, a person feels a burden unlike any other. She described the stress a parent feels as an experience of helplessness in a person driven by powerful impulses to help, and labeled it as a profound and special parent stress. NICU parent comments published in a support parent newsletter confirm her belief.

We were tortured by his suffering...I longed to put him back inside of me where he belonged...sometimes I wish he'd die so he would not suffer any more. (IVH parent newsletter)

Shock, helplessness. I would have traded places with him in a minute. I felt guilty--why us? (IVH newsletter)

Words cannot describe the feelings you have watching an innocent child being tortured. It was hell. (IVH newsletter)

Pizzo described a mother's "fractured self-image", an important characteristic of mothers with health impaired children (1983). This may be true especially true for mothers of preterm infants who report feeling guilt and shame that they have not been able to successfully nurture

the baby prenatally, and then continue to lack the competence to be able to assume a mother role for the sick infant. Caring for preterm infants is also difficult because of the infant's neurological immaturity which makes their cues for caretaking difficult for the mothers to "read". Preterm infants often cannot send the positive interactional cues that reward mother for her caretaking. Thus, mothers sometimes feel that they are not mothering appropriately and this feeling is often reinforced by family, friends and even professionals who are unfamiliar with mothering a preterm infant.

I felt like I was a totally incompetent mother, and I have an older child and have done this before. She (the public health nurse) made me feel like I didn't know anything. (NICU mother)

One of the most persistent themes in the literature written by parents is the idea of the overwhelming feeling of isolation and loneliness experienced by parents whose babies are different (Featherstone, 1980). Featherstone believed that pain isolates and the failure of others to understand parents' pain is particularly frustrating. This may be a perceived failure of others to understand on the part of the hurting parent or a real failure. The grief behaviors of people who are hurting also contribute to distancing and are hard for others in the parents' world to cope with and understand.

When your baby is in neo you hear, "this is the best place for her"; "you're lucky you had her here or now", I wanted someone to say "yes, this is horrible" "yes, this is scary". (volunteer mother)

I went to work and took candy and cigars and people would say your baby isn't due yet..I tell them she is in neo and preterm and everyone backed off...family and friends were not available...that first month was the worst...no one understood. (volunteer father)

I can't ever expect anyone to understand who has not gone through what I have gone through. (NICU mother)

The head nurse has come in to talk to me...I simply nod as she speaks...I sense she does not fully understand what is happening to me...the gray lady at discharge, she said she was sure he would be fine; they do wonderful things with the babies; God would take care of him...I nod, hoping to end the exchange, but think Lady, you just don't know the half of it.(NICU mother)

These feelings of isolation may also affect the marital relationship.

We have an excellent marriage, but we felt an isolation and pain so deep that sometimes we couldn't help each other. (NICU mother, newsletter)

It appears that a barrier to connectedness with others may be related to parents' beliefs that they must not reveal negative feelings about their situation (Featherstone, 1980). If parents believe they are not able to share feelings safely, this would contribute to creating distance with others. One mother, quoted in Featherstone, stated that the parent support group was the one setting where she was free to describe her feelings with total honesty.

Added to these psychological dimensions of isolation, is the real physical isolation of parents with newly discharged NICU infants. Most are infants with fragile health states, who cannot be exposed to others until they have developed some immunological hardiness to the environment.

Parenting a preterm infant after discharge from the intensive care unit has been described by NICU parents as coming home to fatigue, isolation and fear (Nance, 1985). Professionals agree that the preterm infant is a more difficult to parent child during the first year of life and often requires extraordinary amounts of the parent's time and energy (Goldberg, 1983). An increasing number of preterm infants have been reported to develop problems such as unique feeding, language delay, and neuro-behavioral or temperament difficulties during infancy, as well as learning problems and school dysfunction as they develop (Blackburn, 1987).

In summary, after exploring the concept of caring and mothering in the literature and the data, the following issues continued to be of importance:

1. Lack of well-defined maternal role expectations, in the NICU and after discharge.
2. Maternal isolation: physical, social, and psychological.
3. Coping with the powerful feelings that accompany a preterm birth and parenting experience.
4. The unique caretaking problems and the demanding caretaking role for selected mothers of preterm infants.
5. Caring as related to being with, a boundary phenomena.

Raising the Level of Conceptual Abstraction

Because the boundary issue was apparent in describing caring and also related to perceived maternal isolation, the concept of caring for mother was broadened to being with. The concept being with appeared to be more support person specific. Mothering a preterm infant was raised to the concept becoming mother as a way of focusing on the role in a more expanded way rather than limiting it to caretaking activities.

Conceptual Development Phase III:

Making Comparisons

One of the central mechanisms for clarifying concepts is the use of comparison. Thus, the researcher next explored differences between how support parents can be present or be with new parents in contrast to other persons who attempt to be supportive such as professional persons, family or friends. In order to pursue this conceptual notion, parents were asked to contrast parent support with support offered by professional and usual network persons during the NICU crisis and after the infant's discharge. Literature that related to parents' perceptions and professionals' perceptions of each other was also reviewed.

Parent Support and Other Support

Dillard (1974), in conceptualizing perception, uses the metaphor of looking through the lens of a microscope as an acquired skill. The analogy can be made that the NICU parent gets used to looking at professionals through a lens

that was shaped by personal experiences over the course of the parent's life. Many parents reported that they had clearly defined ideas about what they could expect from professionals who are caring for their infant.

Professionals are intimidating, there is a wall there, there has to be, the professional has to have the wall there or they will get burned out. (volunteer father)

The nurse is a potential threat to the parents. Maybe if you have a relationship that is ongoing with that nurse you may be able to discard your perceptions of her. Parents see each other as parents. With professionals, you never know when they are going to analyze you. (volunteer mother)

Doctors and nurses can be very supportive individuals, but let's face it, it's their job. A volunteer parent is helping because they want to. It's much easier to share with someone who is there because they want to be there. (NICU parent letter).

Who can parents talk to? ...no one is there...you are in the doctor's office five minutes, the Public Health Nurse comes out to check you out; Is the house clean?, Are you handling the child okay?, she judges and checks. (volunteer mother)

Professional staff were also able to describe how they feel parents relate to the staff.

I think there is a depth of sharing a parent will do with someone who has been there. It is different. Parents can't tell the doctor that they are afraid. They say to the doctor what they have been taught to say to doctors. (NICU nurse)

Parents reported that the process of sharing information is unique when compared with others who offer information support.

They listen, they respond, they don't interrupt, don't get distracted, there is a silence that is not awkward, it is a waiting. Like they want to draw more, unless you experience it you can't understand it. (volunteer father)

Professional caregivers often have to relate to others briefly, specifically, and sometimes intensely (Bellah et al., 1985). In an intensive care setting, often times these interactions are brief and hurried with the critical business of saving infant lives setting the pace of interactions with parents. Parents perceive that NICU professionals must save babies' lives, this is their priority, and parents' needs must always come second to the infants' needs in the NICU.

With the support parent, it is ok to cry, to be sad. It's not fair. I felt that I could let my guard down with her. The nurse gave me permission, but I just couldn't with her. (NICU mother)

Many NICU parents reported that they had difficulty getting support from their usual support persons during the NICU hospitalization because of the limited access to the NICU. Family and friends are often confused and hesitate to talk with parents about their baby's health and chances of survival. A critical feature that parents identified in getting support from veteran parents is sharing of a common language. When talking with experienced parents, new parents do not have to explain all the new language/terms that apply to the baby's health and treatment. Sharing a common language facilitates the process of communication during a stressful period of time for new parents. Thus, the contextual features of the NICU experience play a role in limiting parents' access to those who could offer emotional support and, therefore, make interaction more difficult.

Professional caregivers also get used to looking at NICU parents through professional lenses . These professional lenses are colored by professional role socialization, and the responsibilities of a contractual agreement to care. This was a noteworthy finding of the researcher. It was difficult to move between the clinical nursing role and the role of one who attempts to understand the parents' world. At different times, it was painful to be so close to the parents or frustrating to be with professionals who could not perceive the world of the parents.

Hutchinson (1986), in a qualitative study of neonatal intensive care nurses, addressed the processes NICU nurses use to cope with the stressors of caring for critically ill newborns. The central problem identified for the NICU nurses was related to the extreme violations of the ideal baby; this explains what nurses describe as the horror of caring for abnormal, incomplete, unappealing and dying infants (Hutchinson, 1986). The findings from this study suggested that nurses combat this horror by a process called creating meaning, that is reconstructing the NICU reality. The nurse creates meaning emotionally, technically and rationally. Hutchinson maintained that if a nurse uses only technical means, the nurse becomes a technician and will lack the humanness necessary for working with babies and parents. Thus, the way the individual nurses in the NICU cope with the stresses inherent in their jobs may facilitate

or jeopardize the nurse's abilities to be with parents in a timely manner.

Bogdan et al. (1982), in a qualitative study reported previously, described specific ways that NICU staff characterize and judge parents. Parents are identified as good, not so good, or troublemakers by staff. Thus it seems that perceptive barriers exist for professionals to be able to be with and understand new parents.

Veteran Support

The literature that described other experienced helper processes and programs was used as a source of comparison. The description of two support programs and identified support processes were helpful in furthering the identification of the processes of parent support. Two publications by Silverman (1970; 1986) documented the development of a widow-to-widow program over a ten year period. Another publication (Lifton, 1973) described a supportive intervention designed for returning Vietnam Veterans and the processes of support. These two sources were used to compare peer supportive interventions.

Silverman described the experienced widow-to-new widow relationship as primarily non-structured, long term interactions with the experienced widow acting in the role of an informed friend. The stated goal of the widow-to-widow support program was to change the widow's sense of identity to that of an unmarried woman. The NICU mother is also experiencing an abrupt role change from what she

expected. Whether the mother role was an unknown role or an expected role, once the baby entered the NICU the role drastically changed.

Silverman reported that the first question asked of the experienced widow is "what happened to you?" and the helper is prepared to tell her story. Knowing how the experienced widow has survived and how she has managed is important to the new widow. The new widow is then able to accept new information from the experienced widow because of the presence or unity that has developed between the women. This is similar to the experienced mother sharing stories and being with another.

Another similarity of the program description was the acknowledged loneliness and isolation of the widow experience. This is similar to the isolation of NICU mothers that often occurs and likewise addresses a boundary issue that is essential to the role.

Lifton (1973) studied the experiences of returning Vietnam Veterans and identified three factors in the helping situation that facilitated coping. These factors include: a) affinity: the coming together of people who share a particular personal experience, along with a perspective on this experience and who wish to make some sense of it, b) presence: a kind of being there, full engagement and openness to mutual impact, and c) self-generation: the need on the part of those seeking help to change or gain insight

to initiate their own process and conduct it on their own terms.

Lifton's study also addressed the notion of presence, a state of being with those who share a similar critical experience. His findings suggested that an active participation in creating the new role or response to the crisis event would be important.

This phase of making comparisons and further data recoding advanced the reconceptualization of becoming mother to creating preterm mother. Being with continued to be strengthened as a central process of parent support. Further development focused on the relationship between these two main concepts and the identification of a basic social process.

CHAPTER SIX

BEING WITH/CREATING MOTHERING:

THE PROCESS OF VETERAN PARENT SUPPORT

The purpose of this chapter is to present a description of the basic social process that explains and accounts for the variation of the phenomenon parent-to-parent support initiated in a Neonatal Intensive Care Unit (NICU). Thus, this chapter will address research question two: what is the central complex process that explains and clarifies the interaction between veteran support parents and NICU parents? Additionally, what are the supporting processes and the conditions under which it occurs?

A basic social process is a type of core category that accounts for change which occurs over time (Fagerhaugh, 1986). Participants in parent support relationships do not participate in the process of veteran parent support in the same way across time. However, the basic social process that is identified is fundamental, occurs over time and remains intact even when conditions vary the process considerably (Fagerhaugh, 1986). After the basic social process is identified, properties, or specific characteristics of the basic social process are described

and subprocesses or related processes are identified. Conditional variables that shape the basic social process are identified using constant comparative methodology as described in the methodology chapter.

Although a number of organizational directions could have been chosen for the presentation of the process of veteran parent support, the researcher chose the following format in order to make the presentation of the process more logical and understandable for the reader. A comprehensive description of the basic social process, **being with/creating mothering**, and the properties, or characteristics of this process will be reported. This will be followed by a delineation of the more specific subprocesses of **being with/creating mother**. Related processes that precede the occurrence of the basic process, labeled preliminary processes, will be identified and described. Lastly, conditions that enhance or limit the occurrence of **being with/creating mother** will be described as conditional variables that can be used to integrate the processes.

The Basic Social Process

Description of the processes of support that are unique to a veteran-new parent relationship was difficult for NICU parents, experienced parents and professionals involved in such programs. Other social support researchers concurred that the transfer of social support from helper to patient is so subtle, so hidden by cues, body language, and choice of phrase that it is unclear in most social support

assessments what message is being sent and what message is being received (Revenson, Wollman and Felton, 1983). Parents were urged to delineate further how supportive behaviors from an experienced parent differed from the supportive behaviors of professionals, family members, and others in the parents' social network. Volunteer parents were asked to describe, in detail, specific incidents of interactions that they had with new parents, so that subtle differences in support could be analyzed. These strategies were useful in discovering the phenomenon that appears to be the essence of veteran parent support. It is proposed that the explicit supportive behaviors of parent-to-parent support are embedded in a basic social process of **being with/creating mothering** that occurs between two mothers, who have experienced the birth of a critically ill infant who required neonatal intensive care.

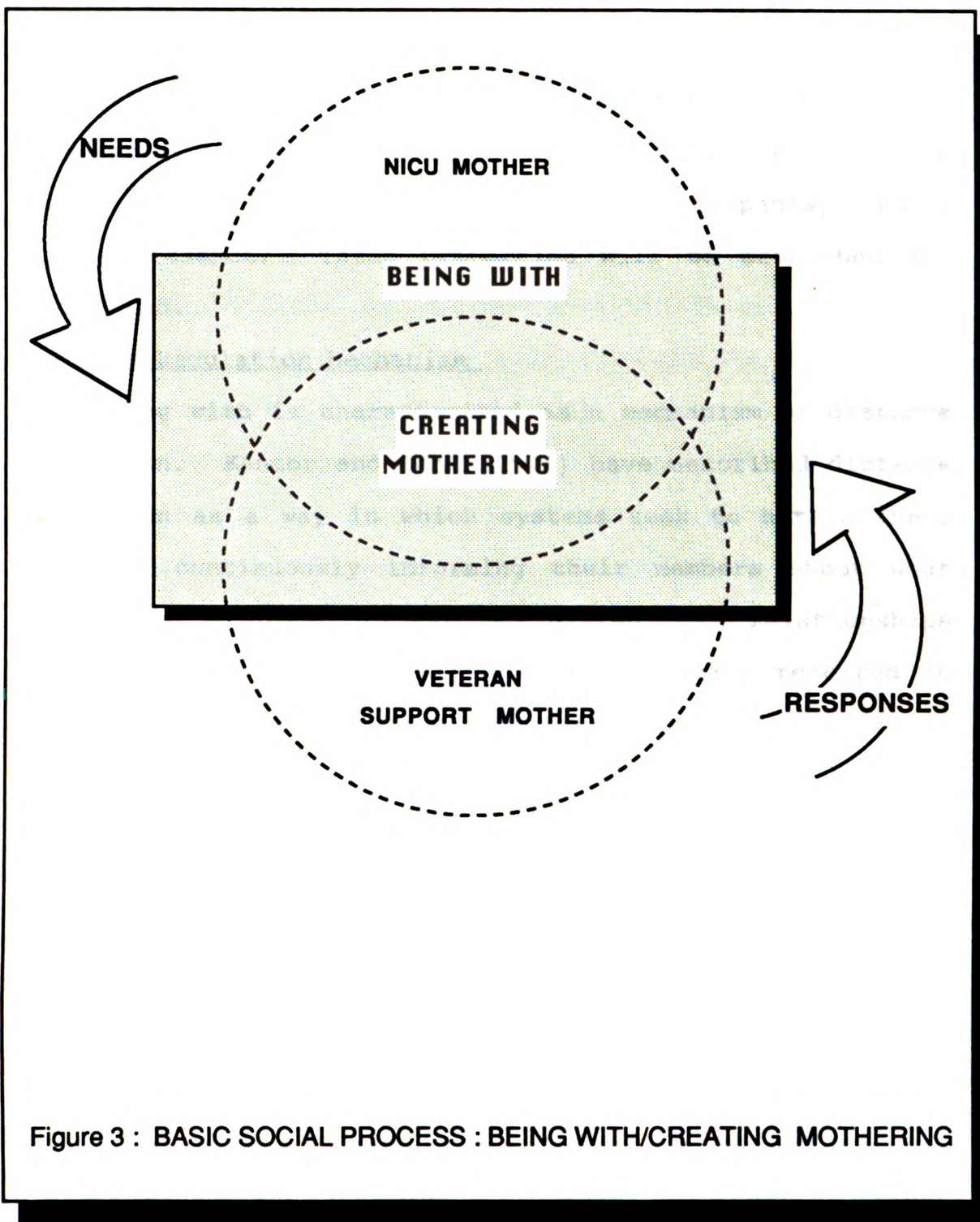
Being with/creating mothering is the basic social process that was discovered which links the substantive supportive acts that occur between an NICU mother and an experienced mother. **Being with/creating mothering** can be defined as a physical and/or psychological proximity between an experienced NICU mother and a new NICU mother that enables the new parent to cope effectively with the NICU crisis and create a comfortable, competent mothering role. **Being with** is a process where personal boundaries are momentarily opened by the shared, painful experience of the birth of a critically ill infant. The **being with** is the

openness that makes possible the supportive behaviors that are broadly conceptualized as **creating mothering**. **Being with/creating mothering** is a proximity phenomenon, a space that is non-threatening, non-judgmental, and caring, that enables the mother to see, hear and create for herself a new mothering style that is sensitive to the needs of her vulnerable infant (see Figure 3).

The process of **being with/creating mothering** has numerous specific properties that can be described and differentiated from the way professional or usual network helping persons support NICU parents. For explanatory purposes, properties of each dimension of the process will be described separately, although it is the researcher's belief that they do not occur independently of each other in the context of parent-to-parent support.

Properties of Being With

Being with is a spatial metaphor and can be used to indicate proximity. Proximity is a concept that has to do with very near or close distance (Webster's, 1985). Proximity can be used to describe physical proximity, that is, having to do with material existence or relating to the body, or psychological proximity, a feeling of closeness, intimacy, or connectedness to another. In a relationship, proximity is co-regulated by the participants of a social interaction. Proximity can be contrasted with the concept of separation, or distance. Not being with, as a spatial



metaphor could be used to indicate physical and/or psychological distance.

Properties of the concept **being with** include: distance regulating mechanism, transactional in nature, dynamic based on parental needs and responses, rooted in similarity of the participants, based on equality of participants, and a timely presence. These properties will be described and elaborated.

Distance Regulation Mechanism

Being with is characterized as a mechanism of distance regulation. Kantor and Lehr (1975) have described distance regulation as a way in which systems seek to attain their goals by continuously informing their members about what constitutes a proper or optimal distance in relationships among members. Other family researchers have referred to this process as separateness-connectedness (Hess and Handel, 1959), and closeness-disengagement (Olson, Russell, and Sprenkle, 1979). From an individual perspective of each mother, distance regulation could be viewed as a mechanism for determining how often, when, with whom, and how far should the personal boundary be opened in a critical, threatening situation. The occurrence of **being with** is co-regulated by the NICU mother and the experienced volunteer mother and shaped by the life context of each participant. Desired amount of time, level of intensity of interaction, intervals between occurrences, the regularity of interaction

are all features of **being with** that are co-determined by the participants.

Experienced parents seemed to be able to be physically and psychologically close with NICU parents soon after the parents have identified them as former NICU parents. Parents frequently reported hugging and crying even at the first contact with each other. There appeared to be a special permeability to the new parent's boundary for the experienced parent during the early days in the NICU. This closeness was not consistent with regular patterns of interpersonal distance assumed by two persons during interaction. Social distance is assumed to be approximately four to twelve feet, whereas intimate-personal distance is considered approximately one and a half to four feet (Hall, 1966).

Transactional in Nature

Of critical importance in conceptualizing **being with** is the acknowledgement of the property of the transactional nature of the process, that is, both the volunteer mother and the supported mother must actively open personal boundaries and receive the other's presence. In each episode of support, there appeared to be varying degrees of giving and receiving of support. Although this study focused on the supportive processes to the NICU parent from the support parent, support parents also received support in the relationship. In a related study, volunteer support parents indicated that they received personal benefits in

their support relationships (Roman, 1986). Some of these benefits were described as an increase in self esteem, feeling that what they were doing was important work, gaining new parenting information, gaining support for themselves from other parents, and working through their own feelings about the NICU.

Dynamic

Being with is a dynamic state of physical and /or psychological proximity, with varying degrees of closeness or intensity over the course of the relationship. Prior physical, psychological or social isolation appeared to increase the NICU mothers' motivation to open boundaries and **be with** the volunteer support mother. Likewise, mothers who felt connected to others and were able to use existing supportive persons in their environment found less need to develop an intensive relationship with the volunteer. The NICU mother's needs changed over time, often depending on her baby's health and development. The volunteer mother's responses were also determined by the stressors and supports in her environment. Thus, the relationship fluctuated over time and developed a special rhythm of its own, with periods of increased contact and intensity and periods of decreased contact and intensity.

Experience Rooted in Similarity

Another property of **being with** is the recognition that the participants in the relationship share some similar characteristics that help them identify with the helping

person. The most central characteristic of likeness between parents was the realization that they share a unique parenting situation, the critical illness of their infants at birth. A related characteristic seemed to be the status of the infant's health problems and growth and development. However, even when the course of the infant's recovery is not similar to the child of the volunteer mother, other characteristics of similarity, such as age, race, siblings, along with the mother's view that this is a positive experience, were related to the fact that the parents maintained the relationship.

Experience Rooted in Equality

Another property of **being with** is the lack of evaluative power on the part of the support mother that could attempt to control the parenting behavior or consequences of the new parent's behavior. The volunteer parent's nonjudgmental attitude appeared to be integral to the opening of the parent's boundary to experience **being with**. The two mothers created mothering responses based on information, the volunteer's experiential knowledge, and both mothers' hunches about what might work in a particular situation. The equality of the relationship allowed the mother to maintain self-esteem in a vulnerable parenting situation.

Timely Presence

NICU parents indicated that experienced parents listen when you really need someone to listen to your concerns.

They called when no one else would call you or wanted to talk to you. They listened when bad things happen. Experienced parents can be called at any time, even in the middle of the night. Parents also described experienced parents as not being distracted or interrupted by other more important things.

NICU parents sometimes talked about experienced parents being "there", as a variation of being with, as a way of expressing the actual presence of the volunteer at crucial times. Often "there" was in the hospital or NICU, yet parents would also describe the availability of the support parent even by their presence on the telephone as being "there".

Properties of Creating Mothering

The process of being with enables the support processes that could be described more as the doing of parent support, that is creating mothering. Creating mothering is a way of describing the aspects of parent-to-parent support that are primarily focused on the new mother's attempt to define or redefine her role, while her infant is hospitalized and at home post discharge, so that it is responsive to the needs of the NICU-involved child. The gerund creating mothering is appropriate to the conceptualizing of the uniqueness of each mother-infant dyad, and how that dyadic relationship is co-created by the infant, mother, and significant others including the support parent. Creating mothering is a way of acknowledging that reality is something that the mother

and others participate in making. **Creating mothering** focuses on the new mother and others creating a new reality after the birth of an NICU-involved infant. In the words of an NICU parent, this reality is can be described as "a new normal".

Creating mothering is not to be considered similar to the concept learning mothering. Dalley (1983) has urged a rethinking of the concept mothering that includes respect for women's nurturing feelings and behaviors combined with experienced mothering as opposed to exclusive dependence on learning mothering from professional parenting resources.

Properties of **creating mothering** include: a) grounded in shared experiential knowledge, b) self-esteem enhancing with respect and encouragement for the mother's strengths, c) sensitive to the needs of the mother and infant, and d) a past, present and future orientation. Each property will be described.

Grounded in Shared Experiential Knowledge

Parents share information about the unique mothering role in the NICU and the day-to-day activities of mothering a formerly NICU-involved infant. Because volunteer mothers are linked to a network of other former NICU mothers through participation in a support program, their experiential knowledge base can become extensive over time. Even if a particular mother is not familiar with a particular caretaking problem, she more than likely knows another

mother she can call for advice or to whom she can directly refer her NICU mother.

Self-Esteem Enhancing

Creating mothering is characterized by the way in which mothers encourage each other to cope with their infant's challenging care. They do not approach a situation from an evaluative perspective, questioning whether this particular mother will be able to care for her infant. This allows the new mother to feel some sense of safety in disclosing her fears about her abilities to care for her infant. The experienced parent then helps the new mother work out ways to gain some confidence in particular caretaking tasks that are worrisome.

Sensitive to the Needs of Mother and Infant

A mother who has published accounts of her experience in the NICU and the period after discharge reminds professionals that an infant's story ends for them when the infant leaves the nursery, but just begins for the parent (Eikner, 1987). This is especially true for parents whose children have ongoing problems. An experienced parent can share information about the baby's caretaking within a realistic framework for day-to-day care. Her advice is grounded in the daily caretaking realities of the mother. The experienced parent knows first hand the fatigue, depression, and anxiety that can accompany difficult caretaking situations. She can give the mother permission

to take care of herself and other family members or seek additional resources if the family system is overstressed.

A Past, Present and Future Orientation

When an experienced parent and a new parent create mothering, it is within a perspective that includes not only the past and present situation, but also a forward glance to future situations. Parents have described this phenomenon as forecasting, an ability to broaden the parents' views about parenting an NICU involved child, encouraging a future perspective. The experienced mother is an authentic source of anticipatory guidance for the rapidly changing developmental and caretaking challenges of the preterm infant.

Subprocesses of Being With/Creating Mothering

Subprocesses of the concept being with/creating mothering were also identified in the study in order to specify the unique characteristics of the support processes. The initial coded processes of support that were identified in the data analysis chapter were re-categorized to a more abstract level. These subprocesses include: a) confronting a possible future, b) forming an image of a good mother, c) learning about mothering babies who are different, d) caring for mother, and e) getting more help. (see Figure 4)

Confronting a Possible Future

One of the first pieces of information the support parents give the NICU parent is the subtle message that although they may perceive an intensive care unit as a place

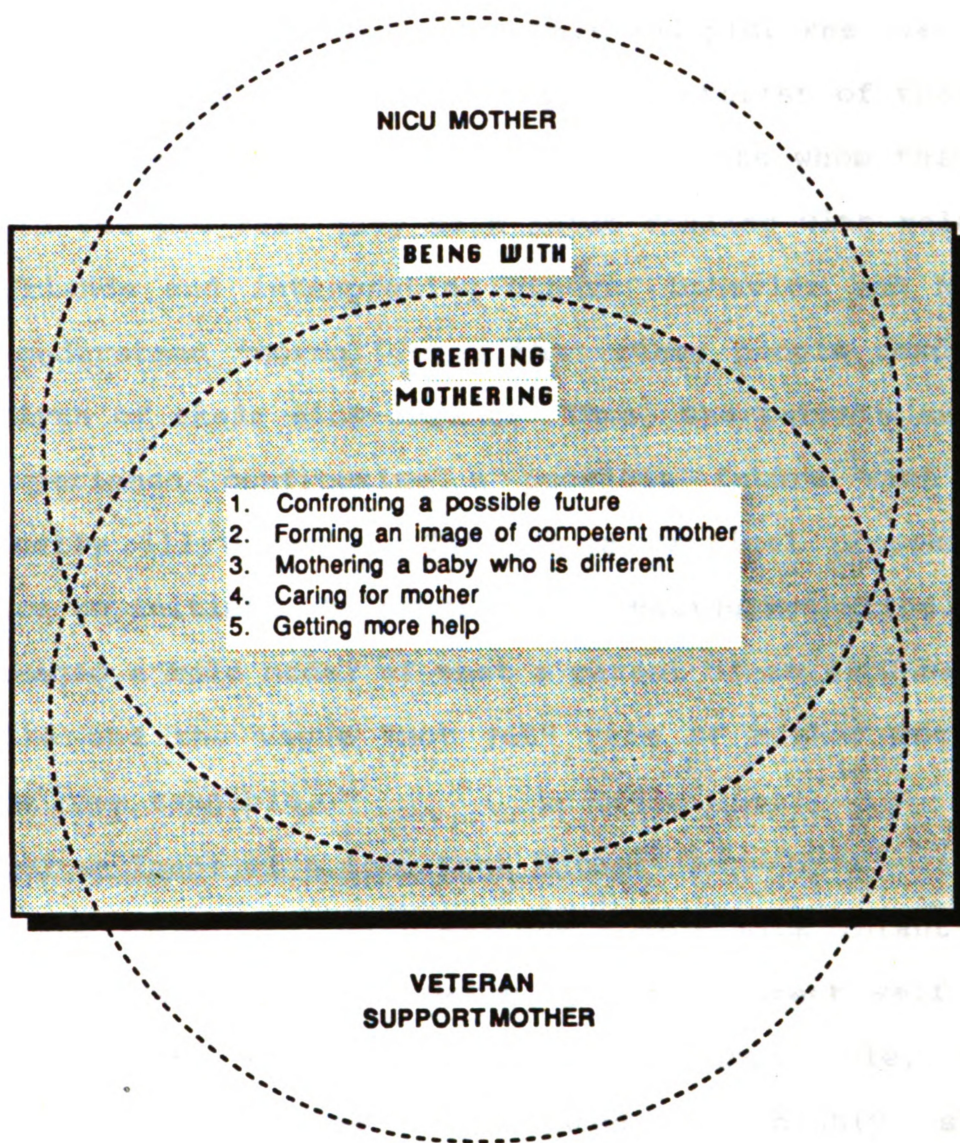


FIGURE 4: BASIC SOCIAL PROCESS WITH SUBPROCESSES

of death or near death, it may also be a place where their infant may return to health. Information is transmitted by words, pictures, and stories of the volunteer parent's own child. Volunteer parents often share pictures of their child when the child was in the unit and pictures over time, as the child has developed. They tell stories of their own experiences and those of other NICU parents whom they work with in the program. They talk about dealing with relatives and friends and interpreting others' behavior and helping them understand 'normal' ways that other people respond to the birth of their sick infant. Thus, the parents are able to experience confronting a possible future with their critically ill infant. This is a critical process that appears to initiate the process of **creating mothering**. They see imaged a role model of what a parent of an NICU baby may be like and the vague "not yet" role of mother becomes a little more tangible.

Forming an Image of a Competent Mother

The mother of the premature and/or sick infant has a more complicated task of defining a new parent self in an intensive care environment. Her planned role, infant caretaking, is being implemented by highly skilled professionals and she is unsure how a mother is to act when her baby is ill and in an Isolette. Three processes were identified that contribute to helping the mother form a positive self-image. These were a) expressing and ventilating positive and negative feelings, b) having

feelings normalized by authentic sources, and c) encouraging and reassuring mothering behaviors from an assets perspective. Parents share their fears and anxieties about their abilities to cope with the NICU experience and their competence to care for their infant. An experienced parent encourages the parent that she will in time be able to do what this parent has done, that is, become the primary caregiver for her infant, becoming mother of a preterm infant.

Mothering a Baby who is Different

The process of mothering a baby who is different includes learning about what is expected of mother in the NICU environment and how she might care for her infant in modified ways. An important part of mothering a preterm infant is learning the baby's behavioral cues for caretaking that differ from those of a full term infant. Storytelling of their own or others' experiences is a common way experienced parents share this information. Support parents are willing to forecast for the parents what parenting an NICU baby may be like for them in the nursery and at home. Forecasting can be defined as dealing with the invention of anticipations and identifies actions to use (Kalish and Kalish, 1985). It is most commonly used as a news or weather predicting image and contains both backward and forward looking perspectives (Kalish and Kalish). Support parents use their own and other volunteer parents'

experiences to share the specifics of how different infants may go through the NICU and the processes of recovery.

Caring for Mother

A central activity of creating mother is nurturing the mother herself. In a health care system, where professional attention is focused on the infant, the veteran parent easily identifies with all the physical, psychological and social stressors that the NICU mother is experiencing. The experienced parent almost always reported that she asked the mother "How are you doing?" NICU mothers described how they feel they can "breakdown" with the volunteer, but that she will try to "pump her up" again. The support mother's attempts at contacting the mother are perceived as a caring message.

Getting More Help

It seems that the support mothers are especially sensitive to the issues of mothers' fatigue and feeling down. Volunteer parents often reported that they would talk with mothers about how they could get more help. Although there are health professionals in the NICU to help parents get the resources they may need to care for their baby, these services are dependent on the parent's readiness and openness to access these resources. Additionally, services to continue to help parents find resources after discharge are minimal in most acute care settings.

Preliminary Processes

In examining the basic social process, being with/creating mothering in a holistic sense, processes were identified that precede being with/creating mothering for the NICU mother and the support mother. The preliminary processes for the NICU mother include: a) being alone, b) getting together, c) being like, and d) letting in. The processes of the veteran mother include: a) making connections and b) being open. Each preliminary process will be briefly described (see Figure 5).

NICU Parent

Being alone. A persistent theme in the data of both the volunteer parents and the NICU parents was the loneliness of the experience of having a newborn infant in the NICU. How isolated parents feel during the NICU crisis is co-determined by their personal resources and the supportive environmental resources that are easily accessible to them. These resources vary over time, therefore, a parent might be well supported during the hospitalization period, but then being alone may occur after discharge when such supports have fallen away. For parents to enter into a relationship with an experienced parent, usually the experience of being alone, either psychic or actual aloneness, precedes the need for such a relationship.

Getting together. NICU parents who are in crisis can have a difficult time mobilizing the energy needed to seek

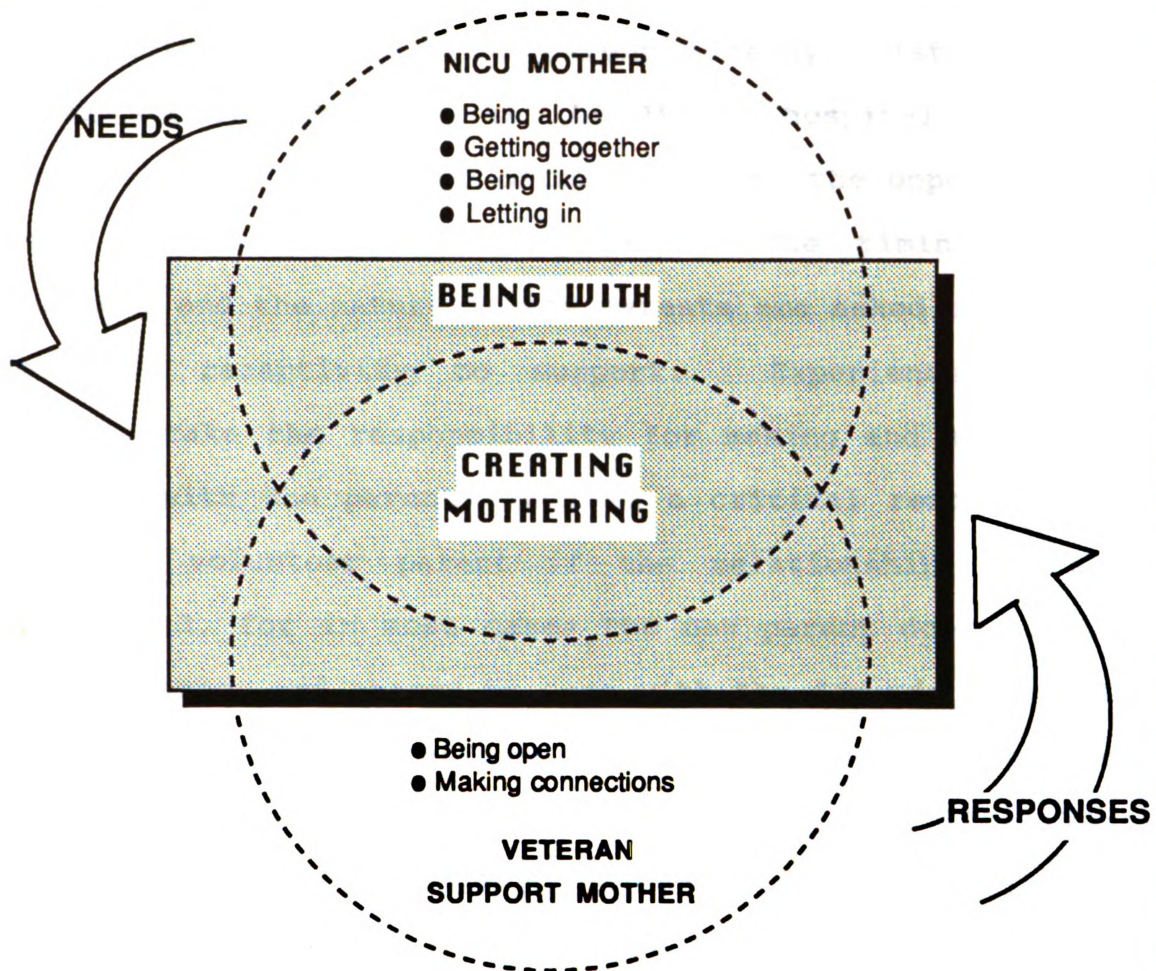


FIGURE 5: BASIC SOCIAL PROCESS WITH PRELIMINARY PROCESSES

resources or support. For them to initiate the process of gaining access to an experienced NICU parent is almost impossible, unless such a parent already exists in their usual social network. In the 1980s, hospital-based NICU parent support programs offered parents the opportunity to meet with an experienced parent. The timing of this contact, and the nature of how parents are asked affects the parents' receptivity to support. Experienced parents usually take the responsibility for making and maintaining contact with the parent. This is a critical responsibility for the volunteer parent if the relationship is to be maintained, for in most cases the new parent does not have the resources and energy to cope with the demands of getting together. However, the new parent must have the resources (transportation, child care for siblings, time if working) to follow through with the plans for meeting. Occasionally, mothers with limited resources were not able to cope with the demands of getting together.

Being Like. Being like is a process where the mother identifies characteristics of the support mother that are like her, or could be like her in the future. The most central characteristic of likeness between parents is the realization that they share a unique parenting situation, the critical illness of their infants and hospitalization in an NICU. There is an equality to the parent-to-parent relationship, the support parent has no power to judge the parent. Parents often state how others, especially doctors

and nurses, are not like them. Parents also report how different they feel from parents whose children have not been hospitalized in the NICU and suffered a life threatening illness.

There are many characteristics of "likeness" that parents find helpful in establishing a support relationship. Similarity in children's health status and treatment is important because the experienced parent can give specific health and parenting information. Age of the mother, race, socio-economic status, and education are all variables that have enhanced establishing the relationship. No one variable was identified as critical to the mother feeling the experienced mother is like her.

Letting in. Letting in is a process whereby the NICU mother opens her personal boundary and chooses to participate in a mutual sharing relationship with the experienced mother. This process is a critical dimension that precedes the being with between parents. There is a range of variability in letting in, such as mostly closed, slightly open. The timing and sequencing of letting in also varies. The mother may also select varying degrees of openness depending on the content of the interaction. Some mothers are willing to be open for the purposes of gaining information that will help them cope with the immediacy of the NICU experience. Others are willing to self disclose painful and frightening feelings to the veteran mother. For letting in to occur, there must be some kind of access to an

experienced parent. Some parents may be threatened by the intensity of a one-to-one contact and need a more informal access to experienced parents where they can evaluate for themselves if this contact will be helpful. Informal access, such as experienced parents' group meetings, or visiting and providing refreshments during usual parent visiting times are strategies that may affect this process for those parents with privacy needs or more limited social skills.

Volunteer Parent

Making Connections. In order for the volunteer parent to support an NICU parent, the volunteer parent must have access to information that the mother has delivered, the condition of the baby and the early prognosis, and where the mother is located so that contact can be made. It is helpful if this information can be made available to the volunteer parent in a timely manner, during the first days of hospitalization. The mother's hospitalization period is usually the time period during which she feels most alone, without her baby or the celebration with family and friends that accompanies a full term birth. If the contact is not requested by the parents during the early days of hospitalization, it is often difficult for the message of need to get to the program coordinator for a referral. Occasionally, a nurse will suggest an experienced parent and transfer the message to the coordinator, but that depends on

the time and energy resources of the nurse and the availability of the coordinator.

Once the support parent has received the referral, she has the responsibility to contact the parent as soon as possible. The timing of the contact is affected by many variables over which the parent may have little control. Most parents try to phone the new mother in her hospital room, but the mother's trips to the NICU can make this difficult. Some will stop by informally to try and meet, but this is not the standard procedure given the limits of the volunteer's time to arrange child care and travel to the hospital.

Being Open. The volunteer parent who accepts a referral has varying family, work and other demands on her time and energy. During the time period when she establishes a relationship with the new parent, her own family system is at a particular point in time in responding to their own stressors with varying amounts of resources available. Thus, her own willingness to be open to the new mother is a function of what is going on in her life at that particular moment in time. How much she is comfortable with sharing her own painful experiences or hearing and touching the pain of another mother depends on the supportive resources that are available to her at this time.

Conditions for Being With/Creating Mothering

Many parent and environmental variables shape the nature of the support relationship. In order to identify what factors or processes determine the nature of the relationship, the data from the twelve-month home visit summary reports and coordinator case records were coded and sorted into two groups. One group was characterized by parent dyads that were perceived by the coordinator as supportive, successful relationships. The other group of parent dyads were characterized as limited involvement support relationships. No one variable was found to predict the involvement of the parents in the relationship. However, in the process of comparing case reports of the relationships, specific conditions were identified which appear to facilitate the occurrence of being with/creating mother, these included:

1. NICU mother lacks accessible, acceptable social support.
2. NICU mother desires support and feels comfortable in social relationships (social ease).
3. Appropriate, sensitive linking of parents.
4. Both parents share similar characteristics (age, marital status, race, sex, family composition, religion, values).
5. Parents' infants share similar characteristics (NICU problems, treatments, severity of illness, days hospitalized, and developmental outcome).
6. Parents are in geographical proximity to each other, thereby avoiding using resources for transportation and long

distance phone charges, and having familiarity with local community resources.

7. NICU parent's infant has a sudden change in health status or a potential or diagnosed developmental problem.

8. Both parents have the personal time and energy resources to follow through on meeting and establishing a relationship.

9. Father and/or significant others support the development of the relationship.

10. Mother is in stable health and not exhausted by infant's caretaking demands.

11. Mother feels insecure about mothering abilities.

12. Mother has difficulties relating to professionals but wants help.

13. Volunteer mother's belief system includes and values helping others.

14. Volunteer mother makes periodic contact with the new mother over the first year of life.

Conditions for not Being With/Creating Mother

During the data analysis specific factors were also identified that seemed to inhibit the development of the support relationship. These factors included:

1. NICU mother's usual support network contained individuals who were able to be with the mother (sometimes this was a family member, and in one case was a neighbor who had twins in the NICU in the past).

2. Access problems that included: transportation to the hospital or meeting places; sibling care; long distance phone expenses; scheduling problems with two families, family illness that prevents meeting.
3. Differences in personal characteristics that cause the NICU parent or the volunteer parent to see each other as "not like me".
4. Differences in the infant's condition and experiences that make the mothers feel they are not like each other.
5. Infant's developmental prognosis becomes less than optimal and resembles the developmental outcome predicted for the volunteer's child.
6. A crisis in the volunteer's own family limits the time and energy that can be given to the family.
7. The volunteer becomes "burned out" because of own family and/or NICU caseload families' demands.
8. The volunteer has a cluster of negative outcomes in families that she is supporting (such as death, divorce, developmental problems).
9. Mother's ill health or exhaustion from infant caretaking limits participation.
10. The volunteer mother does not maintain periodic contact over the first year of life.
11. Mothers previous experience with stressful life events.

Conditional Variables

In order that conditions for being with/creating mothering, and not being with/creating mother, could be

utilized for the development of a conceptual model, conditional variables were further specified. These variables were classified by the researcher as either personal or environmental variables and categorized as relating to the NICU mother or the volunteer support mother. Personal and environmental variables for each mother co-determined the level of involvement in the relationship over time, and the specific supportive processes that characterized the relationship.

NICU parent conditional variables are those personal and environmental characteristics that shape the parent's need for, desire for, abilities to participate in, and accessibility to participate in experienced parent support during an NICU crisis. Volunteer support parent conditional variables are those personal and environmental characteristics that shape the volunteer's response to the NICU parents' need for support. Personal conditional variables are those characteristics of the individual mother that may influence the mother's participation in the support relationship. Environmental conditional variables are those features of the participant's life context that affect the support relationship. A description of these conditional variables and examples from the study data follows.

NICU Parent Variables

Personal conditional variables. Personal variables that were identified in this study include: maternal illness, maternal age and development, prior parenting

experience, prior experience with crisis events, social ease and social competency skills and perceptions of professional support relationships. Maternal illness that affects physical well being can be a potent barrier to establishing a support relationship. One study mother, who delivered prematurely because of pregnancy induced hypertension, was not well enough to meet with the volunteer parent for the first two weeks of her infant's life and continued to have a difficult recovery. Although this mother did not use the support relationship during the initial crisis, her volunteer mother became a critical source of support when her family and church support fell away after the first three months. A mother who is in less than optimal postnatal health may have a more difficult time expending energy in establishing a relationship with a support mother. This mother may need sensitivity to her physical needs and recontacting at periodic intervals to assess her readiness for a support relationship.

The variable maternal age and development although seemingly an important variable in maternal role attainment (Mercer,1981), showed inconsistent patterns. One young, single mother with a conflicted family support network, but a strong peer support network of other single mothers, had limited contact with the support mother, except for medical emergencies related to the infant's care. The support mother was sensitive to the single mother's need for independence and the utilization of her peers with fullterm

infants for support. Yet, she was available to her when she needed someone for "like me" support, in medical treatment issues. Another group of young mothers who perceived health providers as authority figures used the support mother extensively during the NICU period. These relationships were maintained post discharge until the mothers felt comfortable in their caretaking role and others were also able to help with the infant.

Prior mothering experience diminished the level of involvement with the volunteer only if that mothering experience was with an NICU infant, or if the mothering demands of other children at home took priority over coping with mothering the hospitalized child. Prior experience in dealing with crisis events was an important variable in shaping some mothers' support relationships. One mother, whose own parents had died when she was a teen, felt she could cope with NICU crisis and minimally used the experienced parent support. However, near the infant's one year birthday, she responded to the volunteer's periodic contact because of her concerns about her infant's health and development. Her volunteer mother was able to act in an advocacy role for her to get a diagnosis of cerebral palsy and the necessary assessment and referral plan before the family's scheduled move out of the state. A mother, who had economic difficulties and other children to care for at home, appeared to be able to focus only on the immediate needs of other members of her family and did not participate

in the support relationship. When the baby recovered, she was able to assume the infant's caretaking needs.

Environmental conditional variables. NICU Parent situational variables that were identified in this study include: the NICU infant's health, developmental and caretaking characteristics, father's support for the experienced parent relationship, family boundary maintenance, social isolation, properties of the usual support network, perceptions of support network, other stressful life experiences (unemployment, a health crisis of another family member), access issues (geographic isolation, long distance phone) and previous family association with the volunteer parent.

The acuity level of the infant's health status in the NICU may intensify the mother's need for emotional support. If the infant has a more positive prognosis for surviving intact, is of heavier birthweight and longer gestational age, and anticipated hospitalization is short, the mother may need emotional support during the first few days and then focus on informational support to cope with the NICU and prepare for the infant's discharge. If the infant's life is in jeopardy, and the infant's eventual developmental outcome unclear, the mother may use the parent support relationship extensively for emotional support until the infant's condition is more stable. An unusual diagnosis and/or treatment and caretaking procedures may also influence the use of the support relationship, if the

volunteer mother has "like" experience. Since the infant's health and development status show much variability over the course of the first year, the support relationship also reflects this uneven pattern if the support mother has maintained even limited periodic contact by the phone or mail.

The infant's caretaking needs also influence what kind of support may be useful. Many parenting difficulties are tied to feeding and sleeping problems that accompany preterm delivery. It is difficult to find helpful information to cope with these daily activities. Because of their experience and access to new caretaking strategies through the NICU, volunteer parents are often used by the mother to figure out new parenting strategies. This is especially true, if the mother is not getting adequate rest herself because of the caretaking demands.

The father's support for the experienced mother's involvement with the family is another situational variable. Mothers who were not married to the baby's father or were in the process of working out a satisfactory relationship with the baby's father were inclined to use the support relationship until such a time when the relationship with the father stabilized. A father, who encouraged the mother to spend time with the experienced mother and who defined this source of support as unique and something he is not able to offer, shaped the mother's access and use of the support relationship. Some study fathers reported actually

being the person who encouraged the mother to participate in the program at a time when the mother may have been ambivalent about the decision. Volunteer parents acknowledged that in some positive relationships, although they had not met the father, the father would respond in a warm manner when answering phone calls.

Although the father is an important person in determining the openness of the family boundaries to allow the support relationship between the mothers, other family members also can affect the relationship. One volunteer mother reported very positive interactions with the new mother until the father and the mother's own mother happened to be in the mother's hospital room during a visit. The volunteer mother indicated that it was clear her presence was a threat to other family members and the relationship diminished quickly after the visit. On the other hand, a few volunteer mothers reported very positive attitudes from the infant's maternal grandparents for the support relationship. In some instances the volunteer parent had occasion to support the grandmother, who then encouraged her daughter to use the support mother. One grandmother came to support group activities with her daughter because the baby's father was often working and the mother reported he was not at ease with other parents. This grandmother expressed appreciation that such a program existed at this time, unlike her own experiences with premature infants in the past.

Social isolation , especially isolation caused by geographic location, affected the level of involvement in the support relationship. Mothers in rural areas approximately 30 miles from the NICU were very responsive to participation. Without program structural support, they began meeting in groups because there were too many new mothers for the few trained volunteer mothers in this area to handle. The volunteer mothers would periodically invite the new mothers, fathers and babies to an evening or weekend afternoon get together to talk and share snacks. These families in particular may extend the relationship to other social activities like picnics or camping. One of the first needs that volunteer mothers expressed was for any possible financial reimbursement for long distance telephone charges. New parents also expressed the concern that even though the volunteer mother assured them they could call collect, they did not feel comfortable doing so, although they desperately needed to talk with someone.

Social isolation of new NICU mothers can also be caused by the health problems of the infant postdischarge. Apnea difficulties, feeding problems, respiratory problems, increased susceptibility to infectious diseases all contribute to keeping mother housebound. Some mothers had planned on returning to work after the birth of their babies and these plans changed temporarily until the infant's health stabilized or adequate child care could be found.

Properties of the mother's usual social support network and their perceptions of the network members also shaped the nature of the relationship with the support parent. If the extended family network was close by and was able to meet the emotional needs of the new mother and help her locate parenting resources, then it was easier for the mother to get most of her needs met in well-established family relationships. Some of the mothers even expressed how their families were with them through the experience. For other families, the NICU experience was stressful and grandparents who were grieving themselves had difficulty in supporting their own children. Family support networks which may be functional for other family crisis events may be conflicted as a result of the lack of experience with the preterm infant parenting and fear for the infant's life. Some grandmothers were reminded of their own experiences with preterm births and infant deaths and were unable to support their daughters, while others used past negative experiences to support their daughters and focus on the positive benefits of new technology.

Friendship networks and work associates also affected the relationship. Many parents indicated their friends had no understanding of the NICU experience for parents, and many were not even parents themselves. These parents turned to the support parents for emotional and parenting support. If NICU parents did have persons in their friendship network who did have NICU experience these resources were used in

place of increased involvement with the volunteer. One mother had a neighbor who had twins in the NICU in the past and the proximity of this mother made her a rich source of support over the first year of the infant's life.

Other stressful life experiences also affected the support relationship. One mother was hospitalized for emergency surgery and had an extensive recovery time while her infant and other children were cared for by relatives. Another mother's husband died of seizure disorder during the infant's first year of life; still another mother's husband had heart surgery. These additional family stressors consumed time and energy the family might have allocated to the support relationship. When these stressors occurred early in the support relationship, they tended to distance the volunteer parent.

Access difficulties also limit the support relationship. A few NICU mothers did not have telephone service. Thus, the volunteer would have to make surprise visits to the mother and baby at home. When the mother was not home, it was hard to keep the volunteer motivated to contact the mother. Young mothers frequently changed their residence and this also made accessing the mother more difficult. Long distance telephone costs were also a barrier, especially for the NICU mother because reimbursement mechanisms were not available. If the mother lived more than 30 miles from the volunteer mother, home visiting became almost impossible for the families.

Volunteer Parent Variables

Personal conditional variables. How the volunteer reads or interprets the NICU parents' responses is likewise shaped by personal variables of the volunteer parent. Parents who were most active in the support role appeared to have well developed social skills, were at ease with others during the volunteer training sessions, and related well with the program nurse coordinator. There were also some volunteer parents who were by nature more shy and reserved around others. However, many of these quiet parents were able to develop productive, sustained relationships with families, especially those with multiple problems. They were conscientious about regular contact, listened carefully to new parents and were a calming influence on the new parent. As there are many types of NICU families, there appears to be a need for a range of volunteer parents of different personality types. One characteristic that seems to stand out as a necessary social characteristic is the ability to self disclose in a comfortable, sensitive manner. Parents who were in this particular program were all interviewed by professional staff prior to beginning the training program and shared their own experiences in group settings. It is difficult to determine if the parent volunteer self-disclosure skills were enhanced in the parent group training sessions.

A genuine interest and need to serve others is a personal characteristic that affects the volunteer mother's

commitment to maintaining the support relationship, even if the new mother has difficult life circumstances. This need to serve was often linked to religious beliefs of caring for others. Volunteer mothers often stated that the helping role also assisted them in "redoing" their own experience now that they have experience and new information.

Time and economic resources affected the volunteer parents' support relationships. Time is needed to make repeated contacts by phone because the parents are often difficult to reach while the baby is in the NICU. One of the characteristics of experienced parent support as contrasted with other forms of support is the availability of parent at a particularly stressful time. Being with and being there at a time that is most urgent is a characteristic that NICU parents identified of their support parents. Thus, availability, or interruptability, or willingness to drop everything and talk or come is a time resource that affected the relationship. Time became a difficulty for some volunteer mothers who returned to work and tried to maintain support contacts. Maternal employment did affect the time and accessibility of the volunteer. Economic resources are also needed to pay for child care and transportation expenses to visit the new mother in the hospital and at home, and also participate in the volunteer group meetings and activities. Some families would also invite their NICU family for meals or coffee that would increase expenses.

Maternal health problems affected the volunteer mother's ability to participate in the support relationship. Three of the volunteer mothers experienced unplanned, high risk pregnancies and at different times in the pregnancy were confined to bed. If the support relationship was diminishing, the volunteer mother terminated the relationship or the coordinator transferred the family to another volunteer. A volunteer mother who is pregnant and trying to maintain her pregnancy; may find it nearly impossible to deal with issues of preterm birth without jeopardizing her own fragile well-being.

Environmental conditional variables. Support for the volunteer mother's role from her own spouse was an important environmental variable affecting the support relationship. Mothers whose husbands attended the parent training sessions, participated in monthly meetings or verbalized their spouse's support were most active in the volunteer role and continued to participate in the role over longer periods of time. One mother, who was caring for an infant with a terminal prognosis, reported how much she needed to share her feelings about the situation with someone and get support to continue with this family. Her husband was an easily accessible and effective source of support.

Health problems in the volunteer's NICU child also affected the support mother's accessibility to the new mother, unless these problems were acute in nature and resolved quickly. If a new developmental problem or

diagnosis for the volunteer's own child was received during this time, this also stressed the support relationship. Some health problems in other family members also required the volunteer's time and energy.

Other family stressors also affected the emotional and physical availability of the support parent. Four parents experienced temporary unemployment which limited the mothers' support involvement. Eight families moved into other housing in the area. Some health problems in other family members also required the volunteer's time and energy with seven families reporting a serious illness and/or accident of a family member during the course of the study. Of those families who were described as high involved families (over 100 hours/18 month period), two families who had experienced additional family stressors and had very stressed NICU families, requested a temporary leave from the program to settle things in their own lives (Roman, 1986). This phenomenon of volunteer burn out continues to reappear in the subsequent program, although program staff members are assessing volunteer parents carefully and counseling "break periods" for high involved parents.

NICU family parental marital difficulties and/or the infant's health and developmental difficulties also affected the support parent's response. If the NICU parents were having marital difficulties, volunteer parents had to work hard to not get pulled into the conflict while maintaining a supportive relationship with the mother. Support parents

did attempt to talk with parents and make appropriate referrals, but when the outcome was separation or divorce, it was hard for the support parent not to feel she had failed to make things better or fix things. Thus, it was hard to go on to the next family. One mother had worked over a six month period with a young mother who ended up divorcing, yet kept her enthusiasm for program involvement until one of her other "great" mothers unexpectedly left her family, including two other children, and eventually divorced. This event coincided with an infant death, from sudden infant death syndrome at four months of age, in one of her other "good" families. These experiences were associated with the volunteer mother's withdrawal from supportive relationships for a time. A great amount of support parent involvement is necessary when the infant has a prolonged hospitalization or course of disease. A few volunteer mothers assisted mothers whose children were described as terminal and who did eventually die over the course of the relationship. Although these experiences were not viewed as negative by the volunteer mothers, they did require enormous amounts of physical and psychological energy, and affected the relationships the volunteer had with other families. If things were going well in the other families, and they required only moderate involvement, these cases could be a source of positive energy for the volunteer mother. If others were difficult families, the needs of the

mother whose infant was dying were seen as more legitimate by the volunteer mother.

The nature of the volunteer parent's caseload of families at any given point in time was critical to each support relationship. When a volunteer was dealing with a difficult NICU family situation, or multiple difficult situations, it was hard to see the rewards of her efforts. A family situation in which the family was receptive to the volunteer, coping well, with an infant whose outcome was positive could restore the volunteer's enthusiasm for her work. The programmatic difficulty is in predicting family situations at the time of matching families.

The volunteer parents' own social network also seemed to influence the support relationship. Volunteer parents who were isolated themselves sometimes were more involved with the parents in their support relationships. Volunteer parents who had large active support networks of their own, sometimes had to limit the intrusion of the NICU families' needs for social contact. One support mother stated clearly, "we're not doing this to make new friends, I can hardly see the ones I have".

Social ease and competencies are other related personal variables that appear to determine the nature of the support relationship. Characteristics of a person with social ease are: one who is easy to be around, can adjust to almost any situation, likes people, and is willing to be open with people (Ford, 1985). Social competence skills may

include language, motor, coping, assertive, and role-taking skills (Ford, 1985). The parent's ability to attract, mobilize and sustain relationships are all dependent in some ways on the parent's own social skills.

Summary

In summary, the basic social process of experienced parent-to-new parent support initiated in the Neonatal Intensive Care Unit that was central to an emerging theory of veteran parent support was a process of being with/creating mothering. Properties, or characteristics of the process were identified. Subprocesses of the basic social process further delineated the process. Preliminary processes that are linked to being with/creating mothering were described. Conditions of being with/creating mothering and not being with/creating mothering were summarized. From this, specific conditional variables were labeled so that an emerging conceptual framework could be developed.

CHAPTER SEVEN

EMERGING CONCEPTUAL FRAMEWORK

In the progression of grounded theory methodology, concepts are identified, developed and then integrated into an emerging conceptual framework at the conclusion of the data analysis. The purpose of this chapter is to present a conceptual framework of veteran parent support which emerged from the descriptive analysis of the study data presented in chapter six. Specific information from the research data to support the emerging framework was described in chapter five.

Overview of the Conceptual Model

Because they feel alienated in a strange, unfamiliar environment and overwhelmed by the expectation of death or disability of their infant, parents whose children are hospitalized in the Neonatal Intensive Care Unit (NICU) have sought out parents like themselves for support. Yet the unique, supportive processes that characterize parent support relationships have remained obscure and difficult to articulate for parents and professionals involved in such programs. It is proposed that the difficulty in

interpreting such supportive relationships has been that the supportive behaviors are embedded in a basic social process of **being with/creating mothering** that occurs between two mothers.

Being with/creating mothering can be defined as a physical and/or psychological proximity ,between an experienced NICU support parent and an NICU parent that enables the NICU parent to cope with the NICU crisis and create a comfortable, competent mothering role. **Being with/creating mother** provides a space that is non-threatening, non-judgmental, and caring that enables the new mother to see, hear and create for herself a new mothering style that is sensitive to the needs of her vulnerable infant. The processes and conditional variables that modify the process of **being with/creating mothering** that were identified in the study were integrated and a proposed model of the processes of volunteer parent-NICU parent support is presented in Figure 6. The components of the' model will be briefly summarized here.

The Basic Social Process: Being With/Creating Mothering

Being with is a spatial metaphor and can be used to indicate proximity. **Being with** is a space, where the boundaries of each individual are open enough to overcome the isolation and feelings of aloneness that accompany the experience of parenting a critically ill infant. **Being with** is a dynamic state of physical and/or psychological proximity, with varying degrees of closeness or intensity

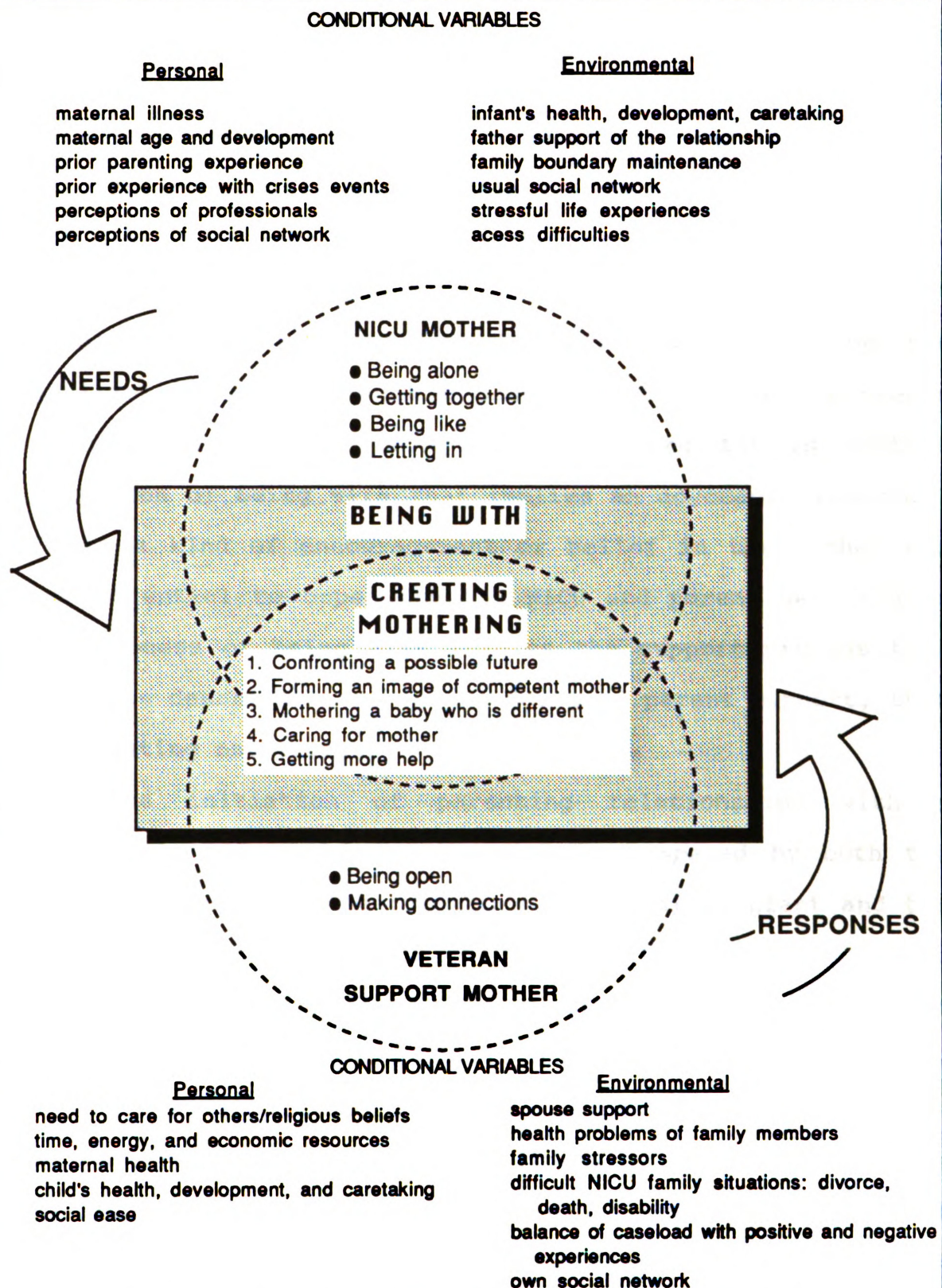


FIGURE 6: EMERGING CONCEPTUAL FRAMEWORK OF VETERAN PARENT SUPPORT

over the course of the relationship. The state of being with fluctuates over time, with periods of increased contact and intensity and periods of decreased contact and intensity.

Being there is a variation of the notion, being with, and a way that parents express the presence of the volunteer parent at crucial times. Oftentimes, there was in the hospital or home, yet parents would also describe the availability of the support parent event by their presence on the telephone as being there. Being for is another variation of being with that implies an advocacy dimension. It is a kind of encouragement or belief in the mother and her potential to cope with the NICU and parent her infant. The process of being with enables the support process that could be described more as the doing of parent support, that is creating mothering.

The initiation of parenting relationships with a critically ill child in the NICU is hampered by both the characteristics of the premature and/or sick infant and the stressful environment in which this interaction must be initiated. Additionally, mothers often report feeling guilt and shame at their inability to nurture the baby prenatally and their continued lack of competence to assume a caretaking role for their critically ill infant. The feelings of being watched and evaluated by professional staff add to the isolation of the NICU parents and encourage the drawing of boundaries that isolate parents further from needed support. Creating mothering is a way of describing

those aspects of helping that are primarily focused on supporting the new mother's attempt to redefine her role, responsive to the needs of the NICU-involved child.

The gerund **creating mothering** is appropriate to the conceptualization of the uniqueness of each mother-infant dyad, and how that dyadic relationship is co-created by the infant, mother, and significant others including the support parent. **Creating mothering** rather than learning mothering indicates respect for women's nurturing feelings and behaviors which are combined with experienced mothering support and professional support.

The process of **being with/creating preterm mothering** is co-created by the NICU mother and the support mother and shaped by the life context of each participant. The NICU mother's needs and the support mother's responses determine the relationship that changes through time. Characteristics of the process, such as desired level of time, level of intensity of interaction, intervals between occurrences, the regularity of interaction are all co-determined by the participants' needs and responses.

Properties of Being With/Creating Mothering

Specific properties of the concept **being with/creating mothering** were identified in the data analysis. For explanatory purposes, the properties are described for each dimension of the process separately. However, the researcher believes that the processes occur together in the

process of veteran parent support. The properties of being with include:

- 1) distance regulating mechanism
- 2) transactional
- 3) dynamic based on needs and responses
- 4) rooted in similarity
- 5) equality
- 6) timely presence

The properties of creating mothering include:

- 1) shared experiential knowledge
- 2) self-esteem enhancing
- 3) sensitive to needs of mother and infant
- 4) a past, present and future perspective

Subprocesses of Being With/Creating Mothering

Being with/creating mothering is a transactional process that can be further distinguished by the delineation of five specific subprocesses. The subprocesses that emerged from the study data included: a) confronting a possible future, b) forming an image of a competent mother, c) mothering babies who are different, d) caring for mother, and e) getting more help.

Preliminary Processes

The process being with/creating preterm mothering is preceded by specific preliminary processes for each mother. For the NICU mother, four processes precede being with: a) being alone, b) getting together, c) being like, and d) letting in. For the support mother, two processes precede

being with: a) making connections, and b) being open. Although each process contributes to the occurrence of being with/ creating mothering, letting in and being open are critical processes for the NICU parent and the support parent respectively. All of the preliminary processes are related to the phenomena of boundary regulation and distance regulation and are co-regulated by both parents in the relationship.

Conditional Variables

Personal and environmental variables for each mother co-determine the level of involvement in the relationship over time, and the specific supportive processes that characterize the relationship. NICU parent conditioning variables are those personal and environmental characteristics that shape the parent's need for, desire for, abilities to participate in, and accessibility to participate in experienced parent support during an NICU crisis. Volunteer support parent conditional variables are those personal and environmental characteristics that shape the volunteer's response to the NICU parents' need for support. Specific conditional variables are depicted in Figure 6.

Summary

In summary, the basic social process of NICU volunteer parent-to-NICU parent support initiated in the Neonatal Intensive Care Unit that was identified in this study is a process of being with/ creating mothering. Characteristics

of being with/creating mothering and specific subprocesses were reported. Preliminary processes for both the volunteer and NICU mother were identified. Personal and environmental variables that shape the support relationship were described. An emerging conceptual model was presented that integrates the processes and the variables that modify the relationship.

CHAPTER EIGHT

SUMMARY AND IMPLICATIONS

The purpose of this study was to discover and describe the processes of veteran parent-to-new parent support initiated in a Neonatal Intensive Care Setting, using grounded theory methodology. In this chapter, a summary of the research and the emerging conceptual framework of veteran parent support processes will be provided. Consistent with the outcomes of grounded theory research, this framework will be used to develop research questions and propositions for future research. Thus, research question three will be addressed: What propositions or research questions can be generated from the concepts and the emerging theory for future research? Implications for future research methodology and for the conceptual development of support will be described. Additionally, study implications for the professional support role with families of NICU-involved infants will be presented.

Summary of Research

Professional staff in the Neonatal Intensive Care Unit (NICU) have been concerned with the needs of parents of the

critically ill and/or preterm infant and have sought ways to help support the family during this stressful period. One strategy that health care providers have found to be useful is the development of supportive relationships between experienced NICU parents, whose infants have previously been in the unit, and parents whose child is currently in the unit. Although there has been considerable interest in the development of such programs, there has been little research about the processes of parent-to-parent support or the child and family outcomes of such an intervention. This research, a qualitative study of parent-to-parent support processes, was a component of a comprehensive project entitled "NICU/Perinatal Positive Parenting: a research demonstration parent-to-parent support program for high risk families whose infants are hospitalized in the Neonatal Intensive Care Unit". The purpose of the study was to document differences between treatment and comparison group parents on parental well being and maternal-infant interaction outcome measures (Boger, Roman and Haas, 1987). Additionally, a descriptive study of volunteer parents and their perceived effects of program participation (Roman, 1986) and this study of the processes of parent support were conducted. Data for this qualitative study were collected from 21 NICU parents and 28 volunteer NICU parents over a two year period (1985 to 1987), using primarily ethnographic interviews, program documents and limited observations.

Veteran Parent Support: A Model

Grounded theory methodology was used for the description of the unique, supportive processes that characterize parent support relationships. From these processes, a basic social process was developed and properties of the process delineated. Conditional variables were identified and the concepts and processes identified in the study were then integrated and a proposed model of the processes of volunteer parent-NICU parent support was developed (Figure 6).

Being with/creating mothering: the basic social process. The supportive processes that occurred between a veteran parent and an NICU parent emerged as embedded in a basic social process identified as **being with/creating mothering**. **Being with/creating mothering** can be defined as a physical and/or psychological proximity between an experienced NICU support parent and an NICU parent that enables the NICU parent to cope more effectively with the NICU crisis and create a comfortable, competent mothering role. **Being with** is a state in which the boundaries of each individual are open enough to overcome the isolation and feelings of aloneness that accompany the experience of parenting a critically ill infant. **Being with/creating mothering** is a dynamic state of physical and/or psychological proximity, with varying degrees of closeness or intensity over the course of the relationship. **Being with** provides a space that is non-threatening, non-

judgmental, and caring that enables the new mother to see, hear and create a new mothering style that is sensitive to the needs of her vulnerable infant. **Being with** is a oneness with the other, which momentarily opens boundaries that separate the mothers.

The gerund **creating mothering** is appropriate to the conceptualization of the uniqueness of each mother-infant dyad, and how that dyadic relationship is co-created by the infant, mother, and significant others including the support parent. **Creating mothering** rather than learning mothering indicates respect for a mother's nurturing feelings and behaviors which are combined with experienced mothering support in addition to professional support. **Creating mothering** is a transactional process between an experienced support mother and an NICU mother that includes specific subprocesses: a) confronting a possible future, b) forming an image of a competent mother, c) mothering babies who are different, d) caring for mother, and e) getting more help.

The process of **being with/creating mothering** is co-created by the NICU mother and the support mother and shaped by the life context of each participant. The NICU mother's needs and the support mother's responses determine the relationship that changes through time. Characteristics of the process, such as desired level of time, level of intensity of interaction, intervals between occurrences, the regularity of interaction are all co-determined by the participants' needs and responses.

Preliminary processes. The process **being with/creating mothering** is preceded by specific preliminary processes for each mother. For the NICU mother, four processes precede **being with**: a) being alone, b) getting together, c) being like, and d) letting in. For the support mother, two processes precede **being with**: a) making connections, and b) being open. Although each process contributes to the occurrence of **being with/ creating mothering**, letting in and being open are critical processes for the NICU parent and the support parent respectively. All of the preliminary processes are related to the phenomena of boundary regulation and distance regulation and are co-regulated by both parents in the relationship.

Conditional variables. Personal and environmental variables for each mother co-determine the level of involvement in the relationship over time, and the specific supportive processes that characterize the relationship. NICU parent conditioning variables are those personal and environmental characteristics that shape the parent's need for, desire for, abilities to participate in, and accessibility to participate in experienced parent support during an NICU crisis. Volunteer support parent conditional variables are those personal and environmental characteristics that shape the volunteer's response to the NICU parents' need for support.

Future Research Directions

. The outcome of a grounded theory study, an emerging conceptual model about the problem under study, can be used to develop research questions and propositions. Research questions and propositions for future studies were generated from the proposed conceptual model and are presented.

Proposed Research Questions

A difficulty in understanding support processes initiated in the NICU was compounded by the lack of knowledge about the parenting experience of families of NICU-involved infants. Of concern is that parents who are most stressed with infant caretaking demands have little energy to make their needs known to both formal and informal support systems. These parents are likely to have difficulty participating in research evaluations and thus most likely are not represented in study samples. Qualitative research methodologies, where relationships are established with informants, would be useful in order to study high risk parenting situations. The findings of this study suggest the following future research questions:

1. What is generally involved in becoming a mother of an infant who is critically ill at birth and hospitalized in a NICU setting?
2. What are the specific processes of becoming a mother of an infant who is critically ill at birth and hospitalized in a NICU setting?

Information was limited that described the role of fathers in a support parent program. Inadequate amounts of data were available to conceptualize the father's role in this study. However, there was enough information to suggest that father-to-father support does occur for some fathers, when volunteer fathers are persistent in their attempts. As this study was being completed, the researcher began receiving information from father volunteer informants on father support. Volunteer fathers indicated that creative ways to involve fathers are needed because a mother support model will not work for fathers. Proposed research questions include:

1. What are the experiences of fathers whose infants are critically ill at birth and hospitalized in an NICU setting?
2. What happens when an experienced NICU father gets together with a father whose infant is hospitalized in an NICU setting?

The findings of this study and the related descriptive study of volunteer parents (Roman, 1986) suggest that volunteers experience growth as an advantage of participation in the program. Qualitative methodology may be useful in identifying the subtle ways in which the veteran parent is affected by participation. Future research questions could include:

1. What do volunteer parents perceive as changes in their own life which they attribute to participation in the support role?

2. How do these changes relate to volunteer parents' ability to function in the support role?

Proposed Research Propositions

Propositions for future quantitative research can be generated from relating conceptual units of the emerging model. Statements of propositions seem the appropriate level of generality for an emerging theoretical framework and will be used. A propositional statement sets forth the general value of one unit that is associated with a corresponding general value of another unit (Dubin, 1978). Every proposition has the potential to be turned into numerous hypotheses by employing empirical indicators for the named units. Propositions can be generated from combining units of the emerging conceptual model and proposing relationships. Although numerous propositions could be developed from the model which emerged, proposition development was limited to three focal areas: a) factors associated with participation in a support relationship, b) factors associated with the level of parent involvement in the support relationship, and c) factors associated with potential maternal and infant outcomes. In order to derive propositions, components of the conceptual model can be depicted as independent variables with the three outcomes as dependent variables. The researcher proposes a comprehensive evaluation of parent-to-parent support testing proposed propositions controlling for level of involvement and program intervention. The propositions that are listed are

not inclusive of all propositions that could be derived from the conceptual components of the model.

Propositions about participation. Propositions related to predicting whether an NICU parent will participate in a support relationship were developed using the preliminary processes of the model and are summarized in these categories.

Being Alone: The NICU mother's social, physical and/or psychological isolation are associated with the mother's willingness to participate in a parent-to-parent support relationship.

Getting Together: The processes that are used by professionals and volunteer parents to link NICU parents to an experienced parent are associated with the parent's willingness to participate in a support relationship.

Being Like: The number of mother and infant characteristics that are similar to the characteristics of the volunteer parent are related to the mother's willingness to develop a relationship with the support mother.

Being Like: When an infant has caretaking difficulties related to the illness and/or developmental prognosis, matching mothers on the infant characteristics rather than matching on the mother's characteristics is associated with increased participation.

Making Connections: The volunteer mother's own resources and demands are associated with the amount of time and energy she is able to invest in contacting the NICU mother.

Being Open: The volunteer mother's own personal and family resources and demands are associated with the willingness of the parent to be emotionally available to the NICU parent's stress.

Propositions about level of involvement. Level of involvement in the support relationship may affect the potential outcomes of the parent-to-parent support intervention for both the volunteer and the NICU parent. In the related study of volunteer parents (Roman, 1986) level of involvement was defined as an estimate of the amount of time that volunteer parents and NICU parents spend in program activities. From this estimated time, level of involvement was categorized into three levels, high, moderate and low levels of involvement. NICU mother, volunteer mother and infant variables were identified that characterized each level of involvement. These variables are presented in propositional form.

High involvement relationships: High involvement parent-to-parent support relationships are associated with: critical health status and demanding caretaking difficulties for the infant; few supports, isolated, and open boundary for NICU mothers; and a need to care for others, social ease, time and energy resources, and no access barriers for volunteer mothers.

Moderate involvement relationships: Moderate involvement parent-to-parent support relationships are associated with: short period of critical, then stabilized. health status,

some early caretaking problems for infant; few supports, or many supports but not mobilized, open boundary, short term need for immediate crisis support and initiating mother role for NICU mothers; and social ease, moderate time and energy resources, some access barriers for volunteer mothers.

Low involvement relationships: Low Involvement parent-to-parent support relationship are associated with: short term stay in NICU, quickly stabilized health, few caretaking challenges for infants; good existing support system or lack of such a system, ability to mobilize resources, boundary semi-closed, uneasy in social relationships for NICU mothers; and own stressors make time and energy resources scarce, respects mothers needs for non-support, access barriers which affect involvement for volunteer mothers.

Propositions about potential outcomes. Because the processes identified in the study are related to caring for mother and mothering a baby who is different, it could be hypothesized that potential outcomes of the intervention are related to mother's well being and her mothering abilities. The analysis of the study data suggests that maternal self-esteem, maternal self-image and maternal physical and psychological health may be potential well being outcome variables.

Maternal outcomes: Participation in a veteran parent support relationship is associated with increased maternal self-esteem, more positive mood states and fewer indicators of maternal health problems.

Since an important component of the support process is discovering how to mother a baby who is different, this finding would suggest that better maternal sensitivity and perhaps better reciprocal interactions with the baby may be an outcome. Additionally, if the baby is getting developmentally appropriate caretaking from a mother who feels comfortable in her mothering role, then it may be hypothesized that the preterm infant's vulnerable health and developmental status, given the absence of congenital anomalies or birth trauma, may be associated with the mother's program participation. The literature also supports the notion that maternal support affects mothering abilities and child outcomes (Boger, Richter, Kurnetz and Haas, 1986; Pascoe, 1984).

General Proposition: Participation in a veteran support relationship is associated with maternal role attainment.

General Proposition: Participation in a veteran support relationship is associated with the quality of maternal infant transactions.

General Proposition: Participation in a veteran support relationship is associated with the health and developmental status of the preterm infant.

Study Implications

Implications for Using Methodology

Qualitative methodology was useful in discovering the subtle aspects of veteran parent-to-new parent support processes with parents whose children were hospitalized in an NICU. Qualitative methodologies are especially suited for situations where parents may feel hesitant to disclose feelings or beliefs that may reflect in a negative manner on their parenting abilities. Informant relationships were established with volunteer parents because of the clinical role in which the researcher was also functioning at the time of the study. Research access to NICU families during the first year was more limited and might have been enhanced if the researcher had clinical access to such families where relationships could also serve the parent's needs as well.

Parents in this study showed much variability over the course of the first year of the infant's life. It is suggested that a longitudinal qualitative study of parenting NICU-involved infants would be useful. Awareness of the changing nature of support relationships as described in this study was related to the lengthened evaluation period.

Implications for Conceptual Development of Social Support

The development of veteran parent support programming for those parents whose infants are, or have been, hospitalized in a Neonatal Intensive Care Unit has occurred in the context of considerable research interest in social support as it affects health and well-being. The findings

of this study support the notion that social support is a multidimensional concept. The processes of veteran parent support are consistent with other well-accepted definitions of social support. Most social support theories include the categories of emotional, informational, and material support (Wortman, 1984). Because most of the informants in this study had adequate material resources, there was not enough information to conceptualize material support as a central component of the process. However, data collected from the few participant mothers from low socio-economic groups suggest that these needs must be addressed prior to informational or supportive needs.

The findings of this study would suggest that the specific giver of support, in this case the experienced NICU parent, is a critical factor in the kind of support that is exchanged between parents. There appears to be a boundary crossing phenomenon, or enhanced accessibility to the NICU parents, that other persons who have not experienced such a critical event do not readily achieve. The process "being like" appears to ease the parent's boundary so that information and emotional supportive resources can flow. Professional support persons, although they may use similar supportive behaviors, are often perceived by the NICU parents to be in an evaluative role that colors the relationship and the potential positive effects of support. Subprocesses such as confronting a possible future and forecasting mothering are examples of processes that reflect

the specific giver of support. The contrast in specificity of support processes that relate to the giver of support is apparent when compared to more general typologies of supportive processes (Gottlieb, 1978).

There was much variability in the timing of the need for support for NICU parents. Parents who had good support systems to cope with the crisis of the NICU appeared to need more short term informational support that helped them learn the role of being parents in the NICU setting. If these parents' support systems fell away after a period of time, the parents might respond to a later invitation for support. If the falling away of support coincided with emergent developmental problems with the child, the need for support increased. Parents whose children were in more critical health states or had more serious, long term health problems used the support parent for emotional support and for forecasting mothering and the relationship was continued later into the first year of the infant's life. Thus, the kind of support and the timing of support varied with the changing needs of the NICU family. Therefore, research must carefully document at what specific points in time support is most effective, or what variables affect the timing of support.

Implications for Professional Support Role

This research draws attention to rethinking appropriate and acceptable roles for health care providers in supporting parents of NICU children. Although professional staff

define their responsibilities to include the parents of infants who are hospitalized in an NICU, parents report that they do not receive the support needed to cope with this event (Blackburn 1986). An important insight for the researcher was the fact that NICU parents did not expect the professional staff in the NICU to be a primary source of emotional support. Most parents felt that the NICU staff's central responsibility must be to the demands of the infant's treatment and caretaking. They seemed to realize that staff energies are limited in an intensive care environment and fear that staff may "burn out" if they are burdened by the parents' needs.

Some of the professional persons who were interviewed for this study raised the concern that NICU families are coping with a crisis and they feel the need to protect the family from the intrusiveness of others. Yet realistically NICU staff do not have the personal or environmental resources to provide such support. This study identified the issue that parents may not find the support offered by professional staff acceptable.

One of the concerns most frequently vocalized by professionals about parent-to-parent support is the worry that experienced parents will fail to deal constructively with parents' anger, escalate the issues and exaggerate the professional and parent differences already present in a stressful environment. Harrison (1985), in an analysis of

the concept anger attempted to reframe anger from a negative connotation to a more positive view. She described anger as a feeling-signal that all is not well in our relation to other persons or groups, and that such persons are demanding acknowledgement from us, asking for recognition of their presence and values. Harrison suggested that in such a situation, persons can ignore, avoid, condemn, blame, or act to alter the relationship towards reciprocity, beginning a real process of hearing and speaking to each other.

Health care providers in the NICU often seemed to use the process of diagnosing parent's anger as opposed to listening and resolving difficulties. NICU parents related that they had difficulty expressing anger to professionals, although veteran parents in the study program were given permission to express angry feelings to program professionals in group settings. From such exchanges, a sub-group of veteran parents and professionals formed a committee to deal specifically with unresolved issues that related to parents' experiences.

The findings of this study stimulated the following questions: is it realistic to expect the professional staff to provide all of the support that parents require? Are they best able to provide the type of support needed? Although a further analysis of professional roles is beyond the scope of this discussion, the study findings suggest that NICU professionals share the responsibility for caring and parenting support with both professional and lay

providers. An NICU mother commented to the researcher that a veteran support mother does not replace the support that the mother receives from professionals; both are necessary. Additionally, it seems fruitful to begin to develop programs that strengthen the environment in which these families live with their vulnerable infants. This means redefining professional role responsibilities; developing para-professional and volunteer support roles; creating models of health delivery in accessible, acceptable locations; and designing reimbursement mechanisms for professional staff and operating expenses that are critical to support the caregivers.

If professionals collaborate with experienced parents, other questions must also be asked. What is the role of the professional? Should support parents be trained, supervised and supported by professionals? In a related study, a majority of the veteran mothers identified the program nurse coordinator as an important source of support for their own family health concerns (Roman, 1986). Because volunteer parents are themselves NICU parents and may still be considered at risk for parenting difficulties, the role of the professional is crucial in safeguarding family health of both the NICU family and the volunteer family. In order to maximize participation for all participants, it is suggested that professionals in experienced support parent programs use: a) careful assessment of the strengths and needs of families who volunteer for a support role, b) provision of

group preparation sessions prior to implementation of the support role for the purposes of: 1. allowing the former NICU parents to form peer support relationships among themselves, 2. gaining experience in supporting each other, 3. giving parents access to the most up to date health and developmental information on preterm infants from professionals and experiential knowledge from peer NICU parents, and 4. assessing which families may need further access to parenting resources themselves (thus serving as a second order health intervention), and c) professional supervision and support to the volunteer parent for the caseload of families that are being served.

For the 40 bed NICU in this study, a half-time professional coordinator was hired for the demonstration program and the position increased to a full time position as the program was expanded to serve all families in the nursery. If the program attempts to reach mothers who may be reluctant to participate, and if volunteers are recruited from non-traditional volunteer mothers such as low socioeconomic or adolescent mothers, this allocation of professional time would likely be inadequate.

Having professional staff whose position is defined primarily as serving the needs of parents manage a parent support program has been the desire of many of the health care professionals that were interviewed. When NICU staff attempt to add the responsibilities of coordinating a support program to a regular position, they cannot have the

time to match, support and monitor parent support relationships. This aspect of program implementation is critical to insure the health of both NICU and veteran families who may have children at risk.

Conclusion

This study documented the processes of veteran parent support initiated in a Neonatal Intensive Care Unit. Analysis of the data suggests that experienced mothers of preterm infants are important sources of information and support for new mothers who are coping with such an experience. Experienced mothers do not appear to replicate or replace professional support, but offer a unique, credible and often needed resource to new parents. However, accessing an experienced mother of a preterm infant, given the structures of the health care delivery and community settings, often proves formidable. The current pattern of family reliance on health care professionals for parenting support and the professional's self perceptions of parenting expertise add to the difficulty of getting such support. It appears that new health structures and professional and non-professional role reallocations will be necessary to advance parent-to-parent support for high risk families. However, the processes of parenting support that emerged in this study may not be as unique as one might believe. Perhaps this study draws attention to a resource that mothers from

previous generations used before parenting support was formalized in professional roles and carried out in complex health care settings, such as the NICU.

A brief historical review of parenting support uncovered a useful perspective in which to view this research. In 1957, a respected pediatrician, Winnicott, cautioned professionals to hesitate in giving advice to parents about parenting and life processes. He was concerned that as doctors and nurses became increasingly concerned with psychology, or the emotional, feeling side of life, they may fail to realize that they were not experts in psychology. Once health professionals stepped out of their domain of expertise, they often do not realize that their authoritarian posture has been carried with them as they advise parents. Winnicott's advice to professionals: those who find themselves stepping outside their special skill can perform a valuable function if they can immediately stop giving advice (1957).

Almost thirty years later, Pizzo (1983) asserted that most professionals now currently believe that they are more competent than the average parents and that assessment of parental competence is a continual judgement that professionals make about parents. Bettelheim (1987) concurred with this perspective and returned to Winnicott's manuscript for the concept of "good enough mother" in order to again caution both professionals and parents. Bettelheim believed that to be a "good enough parent" one must be able

to feel secure in one's parenthood, and one's relations to one's child. One must feel so secure, that while one is careful in what one does in relation to one's child, one is not overanxious about it and does not feel guilty about not being a good enough parent. Bettelheim (1987) believed that mother's errors are compensated by what the mother does right, and feeling secure in her mothering role is of utmost importance.

Bettelheim (1987) also acknowledged that raising a child is a creative endeavor, an art rather than a science. The research reported in this dissertation supports this notion. Creating mothering for the preterm infant is a process that occurs between a mother, her preterm child and others in her environment, including experienced parents who have parented a baby such as hers. It is a process that is grounded in a philosophy of helping a mother to create mothering sensitive to the needs of both her vulnerable infant and herself. It is a process that attempts to make the mother feel good about herself, which is a more important goal than even the sharing of any information that may help. Although this philosophy can be applied to all parents, it is critical for mothers who begin their mothering experience with what Pizzo (1983) termed "fractured self-esteem".

A veteran NICU volunteer mother appeared to be able to cross personal boundaries to be with NICU mothers in ways that few other supportive persons were allowed. The new

mother participated with the experienced mother and others in creating mothering that was realistic in terms of the needs of all family members, that was "good enough" mothering to anticipate successful outcomes for mothers and infants.

APPENDICES

APPENDIX A

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NICU/PPP Interview Guides**I. Introduction**

- A. Self:** Nurse, work with parents with NICU infants, parent-to-parent support groups, interested in studying what it is like for parents
- B. Explanations**
 - 1. Project--NICU/PPP purpose, part of an evaluation.
 - 2. Questions--purpose of the interview, want to understand what the experience of NICU is like for new parents, how they think support parents can help new parents.
 - 3. Recording--taking notes while we talk, confidentiality, consent forms, and taping, if possible.
 - 4. Native language--helpful for us to know how NICU parents talk (e.g. "feeders and growers").
 - 5. Interview--will last 1-2 hours, depending on parents' needs, interruptions to care for infant or other family members are fine. Tell interviewer when they are tired and want to quit. May bring up painful memories; it's not unusual to get teary.

II. Parents' own perceptions of the NICU experience:**PROBES...**

****I've never had the experience of having my own infant in the NICU. Could you describe the main things that happen to parents when their baby is in NICU?**

****What was that period of time like for your family?**

****How was it when you brought your baby home?**

****Can you describe an incident that really stands out in your mind? Most remarkable?**

****How do NICU parents describe _____?**

****You say you felt _____ (overwhelmed, stressed, anxious), can you give me an example of a time, situation, or happening when this occurred?**

****Can you say more about the feeling _____?**

III. Parents own experience with getting some support or help from others while in the NICU or at home:

PROBES...

****Were you able to get some support or help from others when you were in the NICU?**

****Who was available to help you?(Own family member, someone you know that had a premature infant? A neighbor? Church?)**

****How was this person helpful? Can you describe an incident that shows how someone was helpful?**

****How did someone being helpful affect your family?**

****Were you able to talk to a parent who had previously had an infant in the NICU? How did that go for you?(If "yes" go to IV., if "no" skip to V.)**

IV. Parents' perceptions of their support parent relationship:

PROBES...

****What was it like to meet the support parent? Do you remember what it was like for you when you first knew that it was possible to meet another parent with this experience? How did you feel? How about the other members of your family? How was the meeting with the support parent arranged? Can you describe that visit/call?**

****What happens to a new NICU family and a support parent when they get together? On a typical visit, what would I see? What would I hear? What would I feel like?**

****If I were listening to veteran parents and new parents talking about their experience among themselves, what would I hear them discussing?**

****Who in your family would meet with the support parent(s)? How did your family decide who would meet with them? Would you have liked it differently? How? What could have helped that occur?**

****Did your relationship with the support parent make it easier for other members of your family? Did it make it harder?**

****How is support from an experienced parent different from support from others (family, health providers)?**

****Can you describe an incident that shows how the support person was helpful? What specifically did the support parent do or say? What were their behaviors?**

****Can you remember an incident when it was awkward between you both? When you didn't feel better, or maybe not so good, about your relationship? What do you think that was about?**

****If you could tell your support parent exactly what you wanted them to do, what would you tell them? When would you want to see them? What would you want to happen?**

V. Implementing the Support Parent role:

PROBES...

****I've never had the experience of having my own infant in the NICU and then volunteering to help other families. Could you describe the main things that happen when a support parent contacts a new NICU family?**

****How do you meet? How is it arranged? What does it feel like in the beginning?**

****How do you feel when you get a call from the coordinator?**

****Describe a typical first visit. How does this compare with your experience with family X?**

****What happens when you get together with family X? What would I see? What would I hear? What would I feel like?**

****Can you describe an incident that really stands out in your mind?**

****How do you think that you have been helpful to this family? Is there anything that you have been worried about in your helping role? Have you ever worried that what you say or do made the family worse? Did you check that out with the family?**

****What things happen that make you feel good about being a support parent? Describe a situation where you felt just "great" with an NICU family. Do you want to work with another family? What keeps you going (wanting to help others)?**

****Do you ever feel like you want to stop? Do you ever feel that it's taking too much of your energy? How do other family members feel about your time and energy being with an NICU family?**

****What do you think the experience of support is like for the new NICU family? How would they describe the time you have together? Do you think that they feel you are helpful? Have they shared with you any examples of when you have been helpful? How would new parents say it?**

At 3 month interview only:

PROBES...

****How do you feel about your relationship with the NICU family now? Has your relationship changed since we last talked? What do you think has caused those changes?**

****Describe for me a typical contact that you might have with your NICU family. What would I see? Hear you talking about? Feel?**

****Have you made any plans to continue the relationship? In what way? Have you made any plans to finish the program relationship? How was this decision made?**

****How do you feel about stopping the relationship?**

****What do you think was the most important thing that you did for this family, or happened to your family? What was the thing that you wished you had been able to do differently, or wanted to happen differently?**

****Think of an experience when you felt _____ (better, sad, happy, hopeful). What was happening between you and the NICU parent?**

VI. Closing the interview:

- A. Thank them for their valuable input and time.
- B. Reassure them of your confidentiality.
- C. Discuss any additional times for them to have more input or finish some ideas and concerns (may suggest they jot things down for the next visit).

APPENDIX B

VOLUNTEER CONTACT SUMMARY FORM

Contact type:

Visit _____

Phone _____

Other _____

Site:

Today's date:

Written by:

Amount of Time :

1. What were the main issues or themes that struck you in this contact:

2. Summarize the information that you got (or didn't get) on each of the target questions you had for this contact:
 - A. Parent's own experience:

 - B. The veteran parent support role:

 - C. Other concerns:
3. Anything else that struck you as interesting or important in this contact:

4. What further questions do you have for the next contact:

APPENDIX C

NICU PARENT NAME: _____

VOLUNTEER (NAME): _____

CODE # _____
(Evaluation Specialist will fill out)**FAMILY CONTACT SUMMARY SHEET**

Date: _____

TYPE OF CONTACT:
VISIT: HOSPITAL HOME
TELEPHONE:
OTHER:

PERSONS PRESENT DURING CONTACT:

Infant's current health condition:

Did you have a chance to interact with the baby? How did that go for you? Did you observe the parents and the baby together? Describe:

What did you talk about with the parents?

Any PPP activities accomplished? Written materials (name)? _____
Films/Tapes?

What did you learn about the family during this visit?

How did things go for you on this visit? What do you think you gave the family? Is there Anything you're unsure of or would have liked to have done differently?

Plans for Next Visit: Any further concerns or issues that you want to deal with at the next contact?

SIGNATURE OF VOLUNTEER PARENT: _____

(Use reverse side if necessary)

APPENDIX D

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
238 ADMINISTRATION BUILDING
(517) 355-2186

EAST LANSING • MICHIGAN • 48824-1046

March 3, 1987

Ms. Lee Anne Roman
Institute for Family & Child Study

Dear Ms. Roman:

Subject: Proposal Entitled, "Demonstration of the Perinatal Positive Parenting Program With A Subpopulation of NICU-Involved Parents at the Butterworth Hospital, Grand Rapids, Michigan"

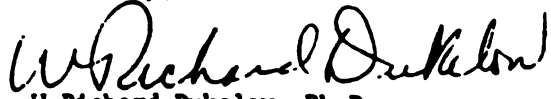
UCRIHS' review of the above referenced project has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this project at its meeting on March 2, 1987.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to March 2, 1988.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,


W Richard Dukelow, Ph.D.
Acting Chairman, UCRIHS

jms

cc: Dr. Robert P. Boger

**NICU/PERINATAL POSITIVE PARENTING
IN-HOSPITAL PHASE
CONSENT FORM**

Name _____ Room No. _____

I understand that Butterworth Hospital is sponsoring an investigation of Neonatal Intensive Care Unit parent-infant interactions being directed by Dr. Robert P. Boger, Ph.D. from the Institute for Family and Child Study at Michigan State University.

I understand that a trained volunteer will visit with me for the purpose of sharing materials especially designed to provide new parents with information about the behaviors and capabilities of infants. The project has been explained to me and I understand the explanation given.

I understand that I am under NO obligation to participate in this program, and that if I choose NOT to participate, that this will NOT affect my care at Butterworth Hospital.

I understand that all information that I give will be treated CONFIDENTIALLY and that my name will NOT appear on any written records or reports.

I give my permission to allow project staff to review my and/or my infant's medical records with regard to material which is relevant for project evaluation.

I understand that I am free to discontinue my participation in the program at any time WITHOUT penalty from Butterworth Hospital, my doctor, or project staff. I also understand that I may REFUSE to answer any question asked of me.

I understand that my participation in the program does NOT guarantee any beneficial results to me or to my infant.

I understand that, at my request, I can receive a summary of the research findings of this project after my participation is completed.

Infant's Name _____

Date of Birth _____

Signature of Physician _____ Date _____

Signed (Parent) _____

Date _____ Age _____

Hospital Number _____

Signed (Parent) _____

Date _____ Age _____

Signed (Witness) _____

Date _____

**NICU/PERINATAL POSITIVE PARENTING
IN-HOME FOLLOW UP PHASE
CONSENT FORM**

I understand that Dr. Robert P. Boger, Ph.D. from the Institute for Family and Child Study at Michigan State University is conducting a study of Neonatal Intensive Care parent-infant interactions. This project will be conducted at my home.

I understand that someone from Perinatal Positive Parenting may call me after I have been discharged from the hospital. They may call or visit to gather follow-up information on my interactions with my infant, my perception of my infant, and my attitudes and knowledge of the perinatal period. I further understand that contacts may be by phone, by mail, or in my home by a trained observer from Michigan State University.

This project has been explained to me and I understand the explanation given.

I understand that I am under NO obligation to participate in this program.

I understand that all information that I give will be treated CONFIDENTIALLY and that my name will NOT appear on any written records or reports.

I give my permission to allow project staff to review my and/or my infant's medical records with regard to material which is relevant for project evaluation.

I understand that I am free to discontinue my participation in the program at any time WITHOUT penalty from Butterworth Hospital, my doctor, or project staff. I also understand that I may REFUSE to answer any question asked of me.

I understand that my participation in the program does NOT guarantee any beneficial results to me or to my infant.

I understand that, at my request, I can receive a summary of the research findings of this project after my participation is completed.

Infant's Name _____

Date of Birth _____

Signed (Parent) _____

Date _____ Age _____

Hospital Number _____

Signed (Parent) _____

Date _____ Age _____

Signed (Witness) _____

Date _____

CONSENT FORM**for Selected NICU Families Participating in Qualitative Evaluation at
Butterworth Hospital**

I understand that a study of NICU-involved families is being conducted at Butterworth Hospital, under the direction of Robert P. Boger, Ph.D. from the Institute for Family and Child Study at Michigan State University.

I understand that information on all my family members will be collected utilizing medical records, family assessment tools, and contacts with family members and professionals providing service to the family. This information will be regarding events and activities of family members related to the premature birth and subsequent experiences.

I understand that my family members and I will be visited in the hospital and at home for interviewing of family members and observation of family interactions. Individual family members, including children, will have the opportunity to decline participation in this research.

I understand that I am under NO obligation to participate in this program.

I understand that all information that I give will be treated CONFIDENTIALLY and that my name will NOT appear on any written records or reports.

I understand that I am free to discontinue my participation in the program at any time WITHOUT penalty from Butterworth Hospital, my doctor, or project staff. I also understand that I may REFUSE to answer any question asked of me.

I understand that my participation in the program does NOT guarantee any beneficial results to me or to my infant, or any other family member.

I give my permission to allow project staff to review my and/or my infant's medical records with regard to material which is relevant for project evaluation.

I understand that, at my request, I can receive a summary of the research findings of this project after my participation is completed.

Infant's Name _____
 Date of Birth _____
 Signed (Parent) _____
 Date _____ Age _____
 Hospital Number _____
 Signed (Parent) _____
 Date _____ Age _____
 Signed (Witness) _____
 Date _____

NICU/PERINATAL POSITIVE PARENTING
VOLUNTEER PARENT CONSENT FORM

NAME: _____

I understand that Butterworth Hospital is sponsoring a study about Neonatal Intensive Care Parent Support programs being directed by Dr. Robert Boger, Ph.D., Director of the Institute for Family and Child Study at Michigan State University

I understand that information I gave on the NICU/Volunteer Profile may be released to project staff in order to be included in a descriptive study of volunteer NICU parents.

I understand that a record may be kept of information that I share verbally or in writing with the NICU/PPP Project nurses about my concerns and feelings about the implementation of the volunteer support role, unless I specify that a particular segment of information may not be used for study purposes.

I understand that I may be asked to participate in additional interviews about my role as a volunteer support person and I may refuse to do so at any time.

I understand that all information that I give will be treated CONFIDENTIALLY and that my name will NOT appear on any written records or reports.

This project has been explained to me and I understand the explanation given.

I understand that I am under NO obligation to participate in this study and that if I choose NOT to participate, this will not affect my participation in the Volunteer Support program at Butterworth Hospital.

I understand that I am free to discontinue my participation in the study at any time WITHOUT penalty from Butterworth Hospital, or project staff. I also understand that I may REFUSE to answer any question asked of me.

I understand that, at my request, I can receive a summary of the research findings of this project after my participation is completed.

SIGNED (Parent) _____

DATE _____

SIGNED (Witness) _____

DATE _____

NICU/PERINATAL POSITIVE PARENTING
HEALTH CARE PROVIDERS CONSENT FORM

I understand that Butterworth Hospital is sponsoring a study about Neonatal Intensive Care Parent Support programs being directed by Robert Boger, Ph.D., Director of the Institute for Family and Child Study at Michigan State University.

In my role as a health care provider, I have contact with parents whose infants are/or have been hospitalized in the NICU and parents whose infants have been discharged from the NICU who function in a volunteer support parent role.

I understand that the parents who are participating in this study have signed consent forms indicating their permission for the collection of information from medical records and from professional persons providing services to the study families regarding parent support processes.

I understand that I will be asked for my perceptions and observations of the processes of NICU parent support by persons from the research project. I understand that my interview may be audio and/or videotape recorded and I permit the tape or transcript of the interview to be used for research and/or educational purposes.

I understand that all information that I give in an interview about my perceptions and observations of the processes of NICU parent support will be treated **CONFIDENTIALLY** and that my name or those of the NICU parents will **NOT** appear on any written records or reports.

I understand that, at my request, I can receive a summary of the research findings of this project after my participation is complete.

SIGNED: _____

DATE: _____

SIGNED (Witness): _____

DATE: _____

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