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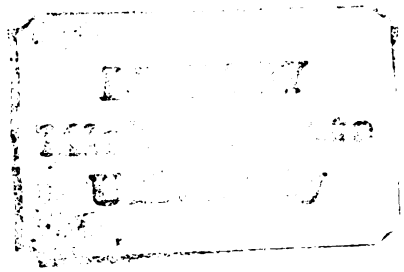

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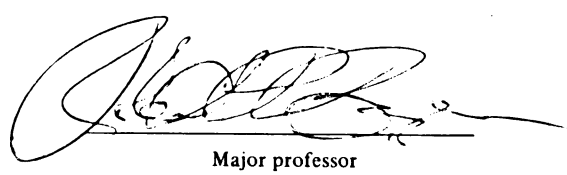
A Heuristic Study
of the Impact of the Critically Ill Neonate
Upon the Parent

presented by

Mary E. Robertson

has been accepted towards fulfillment
of the requirements for

M.A. degree in Child Development



Major professor

Date August 25, 1983

A HEURISTIC STUDY
OF THE IMPACT OF THE CRITICALLY ILL NEONATE
UPON THE PARENT

By

Mary E. Robertson

A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF ARTS

Department of Family and Child Ecology

1983

ABSTRACT

A HEURISTIC STUDY
OF THE IMPACT OF THE CRITICALLY ILL NEONATE
UPON THE PARENT

By

Mary E. Robertson

While neonatal intensive care has made tremendous strides in reducing the morbidity and mortality rates for infants, this has not occurred without many iatrogenic repercussions. Among other things, it has become apparent that this population is at greater risk for various manifestations of parenting dysfunction. In order to provide optimal care to the newborn and his family, detection and elimination of the basic causes of these disorders is essential.

This thesis was heuristic in nature and was initiated to explore the psychological affects of an ill neonate upon the parent. Based upon a comprehensive review of the literature as well as responses to a questionnaire by parents whose infant had required intensive medical care, research questions and possible interventions were identified for future study.

This thesis is dedicated to my mother, Marie Robertson, my friend, the late Charlie Doolittle, and to my husband, Robert S. Fox, who encouraged and supported me through their love and faith.

ACKNOWLEDGMENTS

I wish to thank Dr. Robert P. Boger and Linda Spence R.N. for all of their assistance, flexibility, and support in the writing of this thesis.

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CHAPTER I

Introduction

The growth of the Neonatal Intensive Care unit (NICU) would seem to be an excellent example of the physics principle which states that for every action there is an equal and opposite reaction. Sophisticated treatments and equipment have been developed which are geared to the unique needs of the neonate. Tremendous strides have been made in this field in reducing the morbidity and mortality rates for this population. In the wake of such accomplishments, however, have come many iatrogenic repercussions. In addition to the many physical problems which have arisen from current treatments, it has also become apparent that this population is also at greater risk for child abuse, non-organic failure to thrive and other manifestations of parenting dysfunction. It is essential that the treatment of these iatrogenic problems be directed at the cause and not simply at the manifest symptoms. In order to provide optimal care for the ill newborn and his family, conscientious monitering of policies, procedures, and existing modes of therapy must be maintained. Detection and elimination of these unwanted side effects of life sustaining treatments is essential. It is to this problem that this study was directed.

Purpose

A premature or critically ill infant has a major impact upon his parents. Most research has described this situation as a crisis for parents in terms of the immediate impact (Caplan, 1960; Caplan, Mason, Kaplan, 1965; Breslin, 1977).

This crisis is capable of eliciting a variety of somatic and emotional stress responses as well as a range of coping mechanisms. The impact upon families is not limited to the short term. If issues are not resolved completely, longer term repercussions are quite possible. Manifestations of maladaptive reactions of parents, such as child abuse and neglect and non-organic failure to thrive were noted to be more common in children who required intensive medical care in their newborn period than in the normal population (Ambuel and Harris, 1963; Elmer and Greg, 1967; Shaheen, 1974). Based upon these research findings, it becomes obvious that these families have special needs and require understanding of the problems that they face. The purpose of this study, therefore, was to identify the unique needs and concerns of parents who have a newborn admitted to a NICU as well as to explore those interventions which could be implemented to help parents to adjust this situation more effectively.

Significance

In the early days of neonatal intensive care, the medical dimension was given priority, with little concern directed to the emotional repercussions of the policies and procedures which were in effect at that time. Although today's NICUs are much more sensitive to the psychosocial needs of their families than were their predecessors, it is still necessary to maintain diligent monitoring of the effects of the care provided. This should be done both in relation to the long term physical and mental health impacts directly on the patient as well as the indirect mental health impacts on the family.

Research studies, studies which will be discussed in greater detail in chapter two, have shown the ill neonate to be at high risk following his/her discharge from the NICU for such manifestations of parent-child dysfunctions as child abuse and non-organic failure to thrive. The reasons for these phenomena

were, in the past, attributed to the effects of early separation of the mother and infant. More recently, multiple factors are recognized as being influential in this process. Whatever the cause, it is imperative that the factors which have influenced this trend be better understood in order that the goal of safe and conscienscious NICU care can be achieved.

While the incidence of child abuse in this population is increased, it must be remember that not every parent who has an infant in the NICU is a potential abuser. Indeed, most parents require only short term crisis oriented counseling rather than long term protective services intervention. Staff members in the NICUs need to be cognizant of normal stress and crisis responses as well as coping mechanisms of parents in this situation to enable them to effectively assist their families. Unhealthy coping during this time may delay successful incorporation of the infant into the family system. In order to provide this assistance to families, the staff must have a sound foundation of knowledge upon which to base their care. It is hoped that this study will provide such knowledge and, in addition, provide a basis upon which future research can be built.

Study Objectives

Early transactions are the basis for future relationships. It is essential that health professionals who work with families with infants in the NICU develop an understanding of how this situation alters the parent-infant transactional processes. It is also important to understand how the altered transactions will affect future family integrity and functioning. In response to this need, the following heuristic objectives were developed for this study:

1. To review available literature regarding the psychological and emotional effects on the parent who has a critically ill or premature infant in the NICU.

2. To review available literature regarding factors which affect long term parental response to a critically ill or premature infant in the NICU.
3. To review available literature regarding factors such as those interventions which may facilitate parental adjustment to having a critically ill or premature infant in the NICU.
4. Based upon the completion of objectives 1, 2 and 3, a questionnaire will be formulated to obtain parental responses to the NICU experience.
5. To formulate preliminary questions which can be used to develop hypotheses and programs for future research and evaluation.

Major Study Questions

To facilitate the exploration of the impact of the critically ill neonate upon the parents and the exploration of how health professionals might improve the services provided to facilitate parental adjustment, the following general questions were posed for neuristic delineation:

1. What are the psychological and emotional repercussions on family members of having a critically ill or premature infant in a NICU?
2. What are the factors which determine parental response to the admission of their child to the NICU?
3. What are the possible interventions which might be implemented to facilitate parental adjustment to having a critically ill or premature infant in a NICU?

Operational Definitions

For the purpose of this study, the following were used as the operational definitions:

Critically ill infant. This term was used to apply to any infant whose condition warrants admission to a neonatal intensive care unit for treatment other than for brief observation.

Neonatal intensive care unit (NICU). The NICU is a highly specialized nursery, equipped and staffed to handle the unique needs of the critically ill and premature infant. The NICU is also referred to as a high risk nursery, a level three nursery, or a tertiary care center.

Regionalization. This is a system of perinatal care which was organized to distribute services in a balanced and coordinated fashion. Maternal-child care is provided in each designated region in three levels; level 1 being routine care and level 3 being intensive care.

Gestational age. This term refers to the conceptual age of the infant. This is determined prenatally with ultrasound, amniocentesis, or by date of the last menstrual period. Postnatally, the Dubowitz or Ballard exams are used. A classification system based on gestational age is used as follows:

Premature - Less than 36 weeks

Term - Between 36 and 42 weeks

Postmature - Greater than 42 weeks

Low birth weight. Low birth weight refers to an infant which is born with a weight less than 2500 grams, regardless of maturity.

Family. For the purpose of this study, the family will be defined as "a bonded unit of interacting and interdependent persons who have some common goals and resources, and for part of their life cycle, at least, share living space" (Andrews, Bubolz, Paolucci, 1980, p. 7).

Parents. For the purpose of this discussion, parent will refer to the infant's biological mother and father.

Distancing. An event or situation which serves to create emotional space or distance between two individuals.

Support system. The network of resources, emotional or physical, that an individual or family has available to them from their family, peer, or social environments.

Environment. The physical, socio-economic, and psychological space which encompasses a system.

Transaction. A reciprocal, two-way communication process which can occur between individuals or systems.

Conceptual Framework

An ecosystems model of human development and functioning was used as one part of the conceptual framework for this study. This model was used as it has the benefit of being able to combine physical, economic, social and psychological data, all within the same framework. It allows ready conceptualization of the family system, its subsystems and its suprasystems. Thus, it provides one with a comprehensive approach with which to view the transactions between families and their environment.

Basic to the ecosystems approach is the concept of the family as a social system. The family is a dynamic system, always acting and reacting to inputs from within and without the system, in an attempt to maintain its internal equilibrium. It operates on a feedback model, where inputs from the environment are received by the system and are then evaluated, integrated, and possibly, assimilated. Based upon its conclusions, the family system then makes an appropriate response (output) into the environment. This feedback process reflects the flexibility and adaptability of the family system. The feedback process is essential to the maintenance of a family systems internal equilibrium.

The importance of maintaining equilibrium will be discussed further in the discussion of crisis theory, which follows. In a sense, crisis can be defined as a state of disequilibrium which results when normal efforts to maintain homeostasis fail.

The family system has several characteristics which should be briefly discussed. First, the family system has boundaries. These boundaries range on a continuum from being very open to being very closed. This is often referred to as the permeability of the boundaries. Boundaries assist in the maintenance of the system's equilibrium by regulating the flow of resources in and out of the system. In other words, they serve to maintain the family's integrity.

A family system is comprised of subsystems. The subsystems may be the individual members or a combination thereof. Examples would be: the husband, the husband-wife dyad, or the husband-wife-mother-in-law triad.

Another characteristic of the family system is that it is guided by rules. This is true even of the most disorganized system which can be classified as a family. The rules are the conscious or unconscious directives for the organization of the system. The rules are reflected in communication patterns, roles, behavior, and power structures. The rules are based upon the norms and values of the system.

The final characteristic of the family system which is important to this discussion is that of energy. Energy is critical to every system and is required for its functioning. Energy here refers to food, fuel, money and information as well as emotional energy. A family must have the means to provide itself with energy in order to maintain independent functioning.

The system and its subsystems are two levels of the ecosystem. A third must also be discussed. The suprasystem is the environment in which the family system exists. It can be further broken down into other independent systems

such as the physical environment or the social and cultural environments. There is, as mentioned earlier, a reciprocal interaction and transaction between the system, the subsystems, and the suprasystem. Bronfenbrenner (1979) emphasizes the importance of considering the transactions between the various levels of the ecosystem when considering human development. He also feels that the human organism and the environment equally contribute to the process of development. Both must be given due consideration when considering the impact of any given event upon the system.

The ecosystem theory is a comprehensive and holistic base utilized as a part of the conceptual framework in this study. The second major component of the framework used in this thesis is the crisis theory.

The word crisis is widely utilized in our society. It is used to describe anything from a natural disaster to a set of lost keys. Crisis theorists, while making the definition more objective and, hence, more measurable, have allowed for this variability in their definition. Reuben Hill (1965) developed an equation which summarizes his crisis framework. This is: A (the event) $\longrightarrow$ Interacting with B (the family's crisis meeting resources) $\longrightarrow$ Interacting with C (The definition that the family gives to the event) = Produces x (the crisis). This is a most useful tool for professionals who work with families in crisis.

The event which precipitates the crisis is usually a situation for which the family was totally unprepared. It may be either situational or maturational. In some cases, the actual event may not be as threatening as some of the ramifications of the event. As Hill aptly put it, "the stressor event must be seen as a variable rather than a constant in family crisis research" (Hill, 1965, p. 35).

The impact of the event is seen as being dependent on two variables: the family's resources and the family's perception of the event. A family's crisis meeting resources are the physical and emotional tools which are available to

help resolve the crisis. If these tools are deficient or inadequate to meet the demands of the event, a crisis situation may ensue. Hill (1965) noted that persons of a low socio-economic status may be more prone to a crisis as a result of their limited resources. To these persons, losing little represents a very great loss. There is no buffer zone as they are already operating at a minimal subsistence level.

The impact of a crisis precipitating event is also dependent upon how the event is perceived by the family. This perception, or the meaning of the event, is determined by a variety of factors such as values, state of equilibrium and so on. The meaning of the event represents the reality of the event to the family.

What are the characteristics of a crisis? These were described by Rapaport (1965). A crisis is a temporary state. It is usually self-limiting. There are predictable stages which occur in a crisis. Various theorists have different names for these stages but they are all essentially the same. There is, first, the family's pre-crisis state of equilibrium. This is followed by the event or the precipitator. A period of disorganization develops at this time when previous patterns of coping are tried but found unsuccessful. This disorganization is reflected in the family's communication, coping styles, and interactions. Behaviors such as denial, somatization, withdrawal, and other stress responses are seen at this time. As the family readjusts to the changes that have occurred in their lives, a period of reorganization ensues. This phase varies in the amount of time it takes to reach it as well as in the degree of resolution which occurs. This resolution may be to the pre-crisis level of organization or it may be to an inferior or superior level. Ideally, a crisis is a call to growth and a higher level of functioning should be achieved. Most crisis theorists do not consider a crisis to be a negative event for this reason. Some of the developmental psychologists,

such as Erikson, use the idea of a crisis in terms of personality development (Levy, 1978).

The concept of a developmental crisis is frequently used when discussing normal life changes, such as marriage and childbirth. In fitting with the crisis theorists perspective, these situations call on the individual to respond to these maturational situations with increasingly complex coping mechanisms. As a result, the family and the individual's capacity to respond to future crises are increased and strengthened.

Reuben Hill's equation for crisis development stated two major factors which help to determine the family's reaction and adjustment to the stressing event: the resources for coping and the meaning attached to the event. There are several other factors which may also influence the family's adjustment. Family integrity, good intra-family relations, strong husband-wife relations, democratic authority lines, and previous success with crisis resolution were all factors cited by Hill as being associated with greater adjustment (1965). Going back to systems theory, these factors can also be related to the functioning of the system. Family integrity refers to the strength of the boundaries as well as the bonds within the system. Strong attachments within the family, husband-wife and parent-child, create a supportive environment which facilitates crisis resolution. The family's rules for functioning can also be seen as important to adjustment. If strong patterns exist prior to the crisis, they are more likely to support the family through the difficult period.

Those persons who are working with families who are experiencing a crisis, such as a premature birth, need to keep several points in mind. First, it is not uncommon for a crisis to reawaken unresolved issues lying dormant in a family or within an individual. In order for successful resolution of the current crisis to take place, these past issues must be identified and recognized by all the

involved parties (Lindemann, 1944; Rapoport, 1965; Hill, 1965; Parad and Caplan, 1960). There also seems to be agreement that the function of the professional in these situations is not to override the family's ability to help itself. Instead, the professional's role is to support and guide the family through its own crisis work (Lindemann, 1944; Hill, 1965). It may also be important to help the family to recognize any unresolved conflicts which are hampering current recovery. Availability and acceptance by the professional are two other tasks required of this role. Lastly, it is necessary to help some families to identify support systems which could bolster their resources both emotionally and physically.

Before concluding this discussion on the basics of crisis theory, it is important to review several points on one specific type of crisis, that of bereavement. The work of Erich Lindemann will be used as the basis for this discussion (Lindemann, 1965). The majority of Lindemann's work was based on observations and counseling done with bereaved patients. However, it was discussed that the "Grief Syndrome" is also seen in persons who are experiencing anticipatory grief. Lindemann describes a combination of psychological and somatic symptoms which result from the loss or perceived loss of a loved one. The symptoms vary in intensity and duration. Somatic symptoms such as tightness of the chest and throat, frequent deep sighing, anorexia, a feeling of emptiness, weakness, fatigue, and gastrointestinal symptoms were just a few of the more common expressed by bereaved persons. Psychological manifestations were described as feelings of "intense mental pain", altered sensorium, preoccupation, feeling distant or unreal, and, in some cases, guilt due to unresolved issues with the deceased.

It is important to include this discussion on grief and anticipatory grief responses as these are frequently encountered in the NICU. Parents focus on the helplessness and frailty of the infant and are unable to recognize the strengths

and, hence, potential viability of the neonate. Parents are also grieving for the hoped-for, healthy infant (Kennell and Klaus, 1982). This combination of losses of the family represents the crisis situation which will be the basis for the remainder of this thesis.

CHAPTER II

HEURISTIC EXAMINATION OF THE LITERATURE

The Tasks of Pregnancy

Pregnancy is often considered a mixed blessing by even the most enthusiastic parents-to-be. On one hand, there is great happiness and pride related to the event. Sollie and Miller (1980) conducted a study in which they attempted to explore the issues which surround the transition into parenthood for first time parents (n=120). In this study, they found four major positive and four major negative themes. The positive issues centered around the rewards and satisfactions associated with parenthood. Emotional benefits (joy, warmth, love, happiness), self-enrichment and development, a sense of family cohesiveness, and identification with the child were found to be the greatest rewards during this transition period.

On the other hand, the transition to parenthood was also draining to these couples. They cited the physical demands of the new baby as a major cause for this drain: the late night feedings, the lack of sleep, and the extra work involved. The changes which were required in the husband-wife relationship represented another major issue of this time. The third theme parents in this study referred to was the emotional costs of new parenthood. Emotional costs included such things as the increased responsibility and the worry that they would be unable to meet this heavy responsibility for another's life. The final

issue raised by these parents centered around lost opportunities imposed by the transition to parenthood. This was a reference to the loss of flexibility and to the restrictions imposed on their social life by the baby. Economic issues were also raised due to the limitations imposed on maternal work schedules and the extra expense of the child.

As seen from these comments of first time parents, parenthood is an event which demands changes in roles, relationships, time commitments, and in family structure. It calls for each family member to assume greater responsibilities within their system. Many first time parents worry about their ability to meet these responsibilities adequately. The family system must adapt to accommodate its newest member; its boundaries must be enlarged. The husband and wife relationship must be altered. Family dynamics in general must be changed as the infant becomes integrated into family boundaries and function. In addition to assuming the new or expanded role of parent, previous roles must be readjusted or given up completely. All of these tasks represent an often overwhelming amount of readjustment which must be accomplished in a relatively short period of time. It is for this reason that this period is often referred to in terms of a developmental crisis (LeMaster, 1965; Dyer, 1965).

A developmental crisis differs from the acute crisis discussed earlier only in that it occurs as a result of events which are common to almost everyone, i.e., starting school, leaving home, marriage, parenthood and retirement. These situations possess all the characteristics of a situational crisis except for one. They are usually not totally unexpected. They are, however, significant turning points which call for new skills and coping patterns; the old will no longer suffice. Equilibrium of the individual and/or family is disrupted. E.E. LeMaster attempted to explore the issue of parenthood as crisis first in 1957. His study (n=48) found that 83 percent of his sample perceived the event of their first child

to have been an extensive to severe crisis in their lives. This sample population felt that they had been totally unprepared for the realities of parenthood due to overly romanticized perceptions that they had initially carried into the event. LeMasters felt that this unrealistic ideal could have been a partial variable for determining the degree of crisis experienced by the new parents. This was substantiated by the responses of parents who did not experience what they perceived to be a crisis at this same time. These parents indicated that they did have realistic conceptions of what to expect of parenthood. However, the numbers in this subsample of LeMaster's study were too small to enable significant conclusions to be drawn. Indeed, an overall drawback of this study was the relatively small sample. The sample was also drawn from middle class, urban couples where the husband, at least, possessed a college degree. Dyer was able to replicate these findings in a similar study done in 1963. His sample (n=32) was done on a similar type of population.

As both of these studies were done on a middle class population, the generalization of these results is limited. While further research would be required to substantiate their conclusions, it seems reasonable to presume that the low income family would experience an even greater degree of crisis at this time due to the further strain upon already limited physical, financial, and emotional resources.

Erik Erikson also discusses the task of parenthood as a crisis in the "Generativity versus Stagnation" stage of life (Levy, 1978). Optimally, this crisis will result in growth and maturation of the parents as they work through the tasks of this stage. According to Erikson, adults are trying to generate meaning in their lives. This is accomplished through productivity in one's personal life, family, interests, and career. The opposite end of the spectrum is stagnation. If

an individual does not succeed in this stage, he is defined by Erikson as non-productive, non-directive, and without purpose.

In the above discussion, many of the similar concerns of both the mother and the father were discussed. It is also important to discuss the concerns of each individually in order to present a more complete picture of the state of the family at the time of the infant's birth.

Issues that the mother is experiencing during the pregnancy are often stressed more than those of the father. There are two probable reasons for this. First, the pregnancy has traditionally been the mother's domain. Fathers were never given their due in terms of their feelings or involvement in the pregnancy. They were the outsiders. Second, the pregnancy is physically more a part of a woman's lifespace. As a result, she must bear the brunt of many of the physical changes as well as the ways that these impact upon her life. As a result, the woman usually receives more attention than does the father. While this attention is usually positive and supportive in nature, mothers can also experience depression as a result. The physical manifestations of pregnancy, such as weight gain, nausea and fatigue, may enhance this depression (Osofsky and Osofsky, 1981).

Osofsky and Osofsky (1981) derived a list of major issues experienced by each parent in the pregnancy process. The list was based on their extensive clinical experience as well as on interviews with parents. One of these issues was given much attention in this and in other sources as well (Brazelton, 1981; Rubin, 1967; Kennell and Klaus, 1982). The issue was the reawakening of unresolved issues related to the mother's childhood and her relationship with her parents, especially her own mother. Other concerns which were cited by mothers related to the apprehension regarding their own safety as well as that of

the baby, the changing relationship with their spouse, concerns about changes in lifestyle and concerns about their capability to be a parent.

This work points out the fact that the nine months of pregnancy are important for the growth and development of the maternal role as well as for the development of the fetus. Reva Rubin (1967) discussed this complex problem of how mothers obtain the role of mother. Based upon her research, Rubin isolated five catagories of behavior which women seemed to experience as they strove to adjust to their new identity as a mother. Rubin's stages were not found to be mutually exclusive and often occurred simultaneously. Rubin did find, however, that certain categories of behavior were more predominant at given times during the pregnancy. Mimicry is the first such behavioral catagory and is seen more at the early stages of the pregnancy. Mimicry is defined as a "taking on" behavior, meaning that it is a more external type of action. The adoption of behaviors which are perceived as "pregnant" is mimicry. These include the wearing of maternity clothes, selective eating habits, and restrictive activities. The second stage, role play, is somewhat less symbolic. It is essentially trying the role on for size. Women who were at this point were noted to interact with children and even pets more at this time, testing their success with the maternal role. Fantasy, the next catagory of maternal role attainment behaviors, can occur along with other behaviors but is more pronounced as the pregnancy progresses. It is, in fact, internalized role playing. It allows exploration of the possibilities and potentials of the role, free of the bonds of external realities. The child is visualized at this time, both as the ideal child and as the "dreaded" child (premature, deformed, etc.). The fourth stage is when actual "taking on" of the role begins. This phase is called Introjection-Projection-Rejection (I-P-R). It is the process of evaluating role models and referents in terms of maternal behaviors and judgments, comparing these to one's own values system and making

decisions accordingly. This occurs both prenatally and postnatally. Examples would be breast versus bottle feeding, working versus not working, spanking or not spanking, and so on. The last phase is that of grief work, mourning for the previous role and identity. While the maternal role is being assumed, another must be discarded or adjusted. This was found to be a sporadic process, beginning at the time the pregnancy was confirmed and, in some cases, even earlier. Tentative resolution occurs usually about one month postpartum.

While the woman is adjusting to her new role as a mother, a similar process is happening with the father as he attains the paternal role. This is a subject which was largely ignored until recently.

Antle (1972) describes four major emotional components to the paternal pregnancy experience. The first of these related to the father's protective feelings toward the spouse or partner. These are stimulated, in part, by feelings of pride, wonder, and emotional closeness which can accompany the news of a desired pregnancy. Another type of emotion that may arise is related to the anxieties and concerns over the safety of the partner and the new baby. In addition to these concerns about physical well-being, many fathers are also worried about their ability to provide for the new baby. This is, in part, a financial concern but also includes issues related to doubts about their ability to be good fathers. Lastly, the father, as a result of all of the above, has increased dependency needs. He needs extra support to help him cope with his extra worries and concerns. This may come at a time, however, when his spouse is "turning inward" and wrestling with her own concerns. Depending on the strength of the relationship prior to this time, couples may either draw closer in response to concerns or distancing may occur. These emotional issues experienced by fathers were similar to those described in other studies (May, 1978; Oehler, 1981; Brazelton, 1981).

Osofsky and Osofsky (1981) also cited a few additional issues that men in their study identified as problematic at this time. Changes in their sexual relationship with their partners was a source of concern to many men. This change may have occurred as a result of fatigue or discomfort in the women. It also was reported to be a result of fears on the part of some of the fathers that they might somehow harm either their partner or the fetus. These changes in the sexual relationship may be occurring at a time when the father is feeling exceptional emotional closeness to the spouse or partner. This situation may result in distancing if ignored or not handled appropriately by the couple.

Also mentioned in the Osofsky and Osofsky study (1981) was an issue briefly touched upon earlier. Fathers are the less obvious participants in the pregnancy and parenthood experience. Consequently, they are likely to receive less attention than mothers. As mentioned, this is a time when the father is feeling especially isolated and vulnerable, requiring a little extra nurturance. This sense of isolation is important to the famiy unit. Family boundaries are an emotional as well as a physical entity. Due to a common feeling of ambivalence experienced by almost all parents, this isolation may cause significant disruption in the family system if it is not attended to appropriately.

Attachment

The previous discussion demonstrated that the pregnancy is a period when many physiological and psychological tasks must be accomplished by the family system. There is also one additional task which is occurring around this time which warrents a separate discussion. This is the process of bonding and attachment.

Criticism has surrounded some of the research on bonding and attachment in recent years due to problems with their methodology and/or interpretations.

It must be said, however, that despite any faults that exist in these studies, they have served an important role in society. Hospital policies related to the family have been drastically altered in response to studies such as those done by Drs. Kennell and Klaus (1982). The birthing process and the postpartum period have been put back into the family sphere. The medical profession now plays a more supportive role. Fathers in the labor and delivery rooms, sibling visitation, rooming-in and flexible visiting hours are the rule rather than the exception.

A review of current literature in this area can prove quite confusing. The terminology is often unclear and poorly defined. The terms bonding and attachment are often used interchangably. Also, many used small samplings and were poorly controlled for confounding variables (Gay, 1981; Lamb, 1982; Mitchell and Mills, 1983). Operational definitions are another source of question in many studies. For instance, is the length of breastfeeding or is the position of the mother with the infant truly a manifestation of either attachment or bonding?

Many have also questioned the results of these studies. Most would agree that there are short term changes which occur as a result of extended contact after birth (Chamberlain, 1982; Lamb, 1982; Siegel, 1982; Mitchell and Mills, 1983; Anisfeld and Lipper, 1983). The long term results are less conclusive. Few studies have followed the maternal infant dyad beyond the first twelve months. Those that have had relatively small sample sizes, limiting the generalizability of the results. For instance, Kennell and Klaus followed their 1972 study of mothers and infants through the first five years. The children were seen at two years and again at five years. Through attrition, their sample decreased from fourteen in each of the experimental and control groups to nine in the experimental and ten in the control. From this sample it would be difficult to attempt to make any major statements concerning long term results of the

study. On the other hand, one would not realistically expect to see any type of effect remain over such a long period of time without the benefit of some form of follow through programming. The stronger effects of the more immediate environmental and social variables would be expected to wash out any changes which did occur from these programs.

Bonding is a term popularized by Drs. Kennell and Klaus back around 1972 when the earliest major work on the subject was released. They defined bonding as "a unique relationship between two people that is specific and enduring over time" (1982, p.1). They used the behaviors of kissing, cuddling, fondling, and prolonged gazing as operational indicators of bonding. Kennell and Klaus state that "by general consensus a bond is a tie from parent to infant, whereas the word attachment refers to the tie in the opposite direction, from infant to parent" (1982, p.2). Gay, on the other hand, defines bonding as "a gradual continuing reciprocal process that incorporates the processes of acquaintance and attachment and links two individuals in a coordinated, constructive social relationship" (Gay, 1981, p.442). This definition differs not only in the timing of bonding, but also differs in that bonding is referred to as being reciprocal. Bronfennbrenner (1979) also suggests this idea of reciprocity in the early parent-child interaction. He suggests the possibility that the results of bonding studies are not a result of contact per se, but of the reciprocal transactions of mother and infant. Such semantic confusion regarding the term bonding brings difficulty to the interpretation of bonding studies.

The concept of a critical period is important to discussions of bonding as it is defined by Kennell and Klaus. The idea of critical or sensitive periods were derived from animal studies. In some species it is essential for mother and infant to be together for a critical period after birth or the mother will reject her offspring. Mitchell and Mills (1983) define a critical period as any time when

a living organism is more sensitive to environmental stimuli than at any other time. This refers to both positive and negative stimuli. Colombo (1982) recommended three criteria which should be used when attempting to define a critical period. They are: ability to distinguish precise onset and termination, ability to determine specific stimulus, and ability to determine the system being affected. According to these criteria, it is questionable if human bonding could qualify as a critical period as the timing is not proven. The existence of a critical period in either parent-infant or maternal-infant relationships is an issue much debated. This period has never been satisfactorily isolated in humans. The implications of this will be discussed later.

Attachment is the final construct that will be defined. Ainsworth (1979) defines attachment as "an affectual tie that one person forms to another specific person, binding them together in space and enduring over time" (Ainsworth, 1979, p.1). According to this definition, attachment is a reciprocal process. The purpose of attachment is to secure the proximity of the attached persons. Attachment endures separation over time and distance. Ainsworth states that there is a sensitive period for attachment; that qualitative and quantitative interactions must occur between an infant and its primary caretaker between one month of age and twenty-four months if attachment is to be formed (1979).

As a result of some of the inconsistencies presented above, many began to question the realities of the concepts of bonding and attachment. Some even advocated the total rejection of the theories. This is a bit extreme, however, and a more moderate stance is required. For the sake of clarity in the remainder of this review, the term bonding will not be used. Instead, attachment will be viewed as a continuum, beginning prenatally and continuing through the early years of the parent-child relationship. Support for this position will be provided.

Recent work on infants has altered previous misconceptions regarding infant capabilities. Most notable of these studies have been works of T. Berry Brazelton (1973) and Thomas, Chess and Birch (1977; 1979). The works of these researchers have had a tremendous impact in the area of attachment research. Brazelton, for instance, devised an assessment scale which clearly documents the infant's ability to respond and react to interpersonal and environmental stimuli. The infant is capable of eliciting and maintaining the proximity of the caregiver. He can be very selective in terms of what he attends to and what will be screened out (Brazelton, 1973). Based on these documented abilities, it would seem difficult to view either bonding or attachment as simple one way interaction.

This is also the implication of the research of Chess and Thomas (1977) and Thomas, Chess, and Birch (1979). They have isolated distinct patterns of temperament present very early after birth. These temperaments were distinct from the parenting patterns of the caregivers. In their study, these researchers found 40 percent of the children studied could be classified as "easy", 15 percent were "slow to warm", and 10 percent were classified as "difficult". Each catagory of temperament represented quite different patterns of behaviors and reaction patterns on the part of the infant. These behaviors elicited varied responses from the parents.

The studies demonstrate two points. As discussed earlier, the infant is not passive in the early acquaintance processes. The infant's behavior makes an important contribution and should not be discounted. The fact that the infant has a temperament that is discernible very early in life makes the possibility of a one way operation in any segment of the attachment process altogether less feasible. In other words, an infant cannot be considered a passive tabula rasa at birth. It can, and does, participate in transactions with its environment.

It is also important to realize that the human brain is both flexible and adaptable. It is not locked into specific, genetically determined behavior as would be seen in some of the lower orders of animals. In addition, especially from the ages from birth to about six years, the brain possesses a characteristic called plasticity. Plasticity refers to the ability of the developing brain to compensate for and make adjustments to early insults to its integrity. Therefore, a human infant who is separated from its mother during the immediate postpartum period is not likely to suffer irreversible consequences as a result. A lack in one area can be compensated for in another (Brierly, 1979).

The earlier discussion on the tasks of pregnancy pointed out that there are many reorganization and adjustment processes which are occurring at the time of birth. There has been research done which has identified that the attachment process may be an additional task which occurs at this time. Some researchers have begun to reevaluate the heavy importance attributed to the immediate postpartum period in terms of long term attachment. They argue that the parents have been forming attachments to their infants long before the birth has occurred. This has been occurring since the pregnancy was confirmed. This is not to discount the importance of the immediate postpartum period. This is when the family is united for the first time and is most certainly a very emotional and deeply personal experience. However, this experience cannot be taken out of the context of its place along a continuum. It is not a point in and of itself but a point in a far more complex process. Using this viewpoint of attachment as a continuum makes it far easier to reconcile that families who are separated after birth can form equally strong attachments (Osofsky and Osofsky, 1981; Oehler, 1981; Liefer, Leiderman, Barnett and Williams, 1982; Sameroff, 1982).

Cranley (1981) performed two separate investigations to determine if parents do indeed form attachments prenatally. The position held in these studies was that the relationship could potentially begin as early as when the parents begin to desire and plan for a child. More commonly, a mother begins to form an attachment when she begins to feel a kinesthetic, intellectual, and physical awareness of the fetus. In her first study, Cranley interviewed thirty women during their last trimester and then again on their third day postpartum. These women were of mixed socioeconomic status and education levels. Fifteen of these women were experiencing their second child, eight were having their first baby and the remainder were having their third or greater. The results showed that 78 percent of these women engaged in behaviors or attitudes reflecting attachment to the fetus during the pregnancy. This prenatal attachment was found to be independent of antecedent and demographic variables. While there was also no association found between self-esteem or anxiety, the researcher did state that no inferences could be drawn from this as the women demonstrated an unusual homogeneity of high self-esteem scores. An interesting finding was that social support was positively correlated ($r=0.51$, $p \leq 0.002$) with maternal-fetal attachment. Stress was negatively related to attachment ($r=-0.41$, $p \leq 0.01$). While the sample of this study was small, the results bear consideration and warrant further study.

Cranley (1981) also studied prenatal attachment among fathers. In this study, a larger sample was used ($n=100$). Ninety of these expectant fathers were experiencing their first child, eight were experiencing their second, and for two, it was their third or later child. This study involved a questionnaire with two parts. The first was an adaptation of the Maternal-Fetal Attachment Scale, while the second part involved the Wapner's Marital Relationship Scale. The results indicated that fathers also demonstrated attachment behaviors

prenatally. A positive correlation existed between the fathers' perceptions of the strength of the marital relationship and paternal-fetal attachment ($r=0.5$, $p \leq 0.01$). The author cautions about making wide inferences from these data, as the majority of the fathers in this sample scored well above the mean on the Marital Relationship Scale.

While requiring further study and documentation, these findings do indeed seem logical. If attachment was not occurring during pregnancy, why would parents experience such strong grief responses with miscarriages and stillborn infants? One frequently hears pregnant women referring to their unborn using nicknames. They also often describe the en utero antics of their fetus (hiccoughing, kicking, turning) as intentional or playful. Consider, also, the extra care which many pregnant women exercise during this time. These are all manifestations of nurturant caretaking activities which reflect caring and concern for the fetus. The implications of this area are fascinating. Future research needs to explore this area further and evaluate the potential for interventions and programming. It may be that our attempts to decrease child abuse and neglect need to be started at this time in order to be more effective.

There is very little in human development which is dependent solely on one variable. The culture, society, peer and family systems as well as each individual's psychological and physiological make-up all interact and intertwine in the attachment process (Snyder, 1979; Sameroff, 1982). There are many antecedent variables which are present at the time of the infant's birth which will affect the parent's initial response to the infant.

This was a point recognized by Siegel, one of the researchers of the well respected Greensborough study (Siegel, 1982). This study involved 312 low income pregnant women who were randomly assigned to one of four groups. These groups were: early plus extended contact plus a home visit, early and

extended contact only, only a home visit, and a control group. Observations of attachment behaviors were observed at four and twelve months (Siegel, et al. 1980). Multiple regression was used to assess the contribution of certain antecedent variables such as marital status, education, parity, age, and the score of the Peabody Picture Vocabulary test. Their results showed that these antecedent variables had a greater impact on attachment than did any of the interventions. For example, at the four month evaluation, 22 percent of the variance for acceptance measures was accounted for by background variables (p 0.0001) while early and and extended contact accounted for only 2.4 percent of the variance in scores ($p \leq 0.04$), (Siegel, et al. 1980). The researchers attributed this to the fact that "the social, economic, and other stresses associated with the background variables are burdens, often intergenerational in nature that are not easily altered" (Seigel, Bauman, Schaefer, Sanders, and Ingram, 1980, p. 187).

A study by Anisfeld and Lipper (1983) adds an interesting twist to the early contact models for attachment. This study involved 59 women. Of these 59, 29 were given one hour of extra contact after the birth of their child. After that hour, they received no further extended contact. The control group received routine hospital care, which consisted of being briefly shown the infant and then separated until the time of the first feeding. Observations by a trained individual were made at two days postpartum during a feeding. The observer was blind to the status of the mother in the study. In agreement with other studies, there was a significant difference (at the $p \leq 0.05$ level) in affectionate/attachment behaviors between the two groups. Moreover, of the extra contact mothers, those who were classified as having low social support at the time of the delivery were found to have higher attachment scores. Social support was evaluated on the basic four criteria: marital status, whether or not a recipient of public assistance, whether or not a high school graduate, and

whether or not the father was in the delivery room. These criteria are somewhat similar to the background variables discussed earlier in the Siegel et al. (1980) study. Anisfeld and Lipper felt that the results of this study helped to define when early contact would be most effective. For instance, their data showed that women who had low social support at the time of their child's birth and received no extra contact had the lowest mean affectionate-contact scores (Mean score=23.0±6.9). Women who had low social support but who received the extra contact had the highest mean scores (Mean score=34±10.1). This interaction between social support and attachment was noted to be significant at the 0.03 level. Mothers who had social support at this time were not affected significantly by the extra contact (Mean score of mothers with high support and extra contact=30.2±9.7; Mean score of mothers with high support and routine care=29.4±7.3). Anisfeld and Lipper felt that this data indicated that women with low social support may benefit most from the effectiveness of early contact. This was also a finding seen in the Cranley study (1981) discussed earlier. The question might be raised as to whether it is indeed the extra contact which is promoting attachment in these studies or, as these studies indicate, if it is the level of support that a woman has available to her at this time.

This study has significance to the NICU staff as the characteristics used to define social support are similar to characteristics which define perinatal risk. Low socio-economic status, low education levels, non-white racial background are all related to a higher incidence of stillbirth, prematurity, toxemia, low birth weight, and other high risk situations. In addition, teenage mothers and mothers with high parity are more prone to perinatal difficulties (Osofsky and Kendell, 1973). Consequently, the NICU staff may see more mothers with minimal support systems as a result of the shared implications of these characteristics.

This would further add to an already complicated attachment process that NICU parents must deal with.

Based on the above discussion, the following will be used for future references to attachment. Parent-infant attachment will be viewed as a continuum which begins prenatally and continues to develop throughout the early years of the child's life. A variety of factors are believed to affect this development: the culture, the society, factors related to the pregnancy and delivery process, the parent's past and so on. The period immediately following birth will be viewed as important to the famiy, but not as essential in terms of attachment. A variety of other factors may compensate for its absence.

The Environment

The birth of a premature or critically ill newborn is, for most parents, the realization of many of their unspoken prenatal fears. It precipitates a wide variety of emotions and reactions. While the parents are most immediately concerned with their newborn's welfare, it is important to recognize that the NICU environment is impacting upon the family and is affecting their responses.

Intensive care units have been criticized since their inception in the 1960s. This criticism stems from all the negative stimuli to which the patients, their families, and the ICU staff are exposed. While these units are providing the intense technology that many persons require to sustain their lives, much is lost in the process. An individual loses his/her identity, is separated from his/her loved ones, is deprived of sleep, and is exposed to a wide variety of noxious stimuli. It is not surprising that patients in the intensive care units do lose contact with reality, unrelated to their clinical diagnosis, and develop a syndrome called "ICU Psychosis" (Gowen, 1979).

Neonatal intensive care units differ from adult ICUs in many ways, but they also experience many similar problems related to the negative

environmental stimuli. The most widely identified environmental problem of theNICU has been that of noise pollution. NICUs, as a rule, require a greater number of personnel than do most other hospital units to be considered safely staffed. This, combined with the noise emanating from the equipment and alarms, produces a disturbing clamor. This has been a source of much concern as research into environmental hazards has shown noise pollution to be detrimental to both physiological and psychological well being. Noise levels in both adult and neonatal intensive care units have been documented to reach unhealthy levels which can cause both temporary and permanent manifestations of hearing loss, hypertension, sleep disorders, and other stress related responses (Falk and Woods, 1973; Woods and Falk, 1974; Miller and the American Academy of Pediatrics Committee on Environmental Hazards, 1974; Price, 1976; Long, Lucey, and Phillip, 1980). The noise affects patients, staff, and visitors, all to varying degrees. In a study by Falk and Woods (1974), these stress responses to the noise levels in adult ICUs were examined. They noted such physiological responses to noise as the activation of the pituitary/adrenal axis, vasoconstriction with elevated blood pressure and tachycardia, and an increased secretion of a variety of hormones. While these responses are normal and essential adaption reactions which help the body cope with stress, persistence of the stressor can eventually lead to decompensation of the body as a whole (Falk and Woods, 1973; Selye, 1976). Psychological responses to sensory overstimulation, such as anxiety, depression and irritability, can accentuate the physiologic responses. The environment of the NICU is likely to have negative impacts upon the parents much as it affects patients and staff. There has been little, if any, research done to document the existence of these effects on the parents. However, research that would assist in the identification of any contributions made by the

environment to the parents' comfort and anxiety may prove to be an important step toward change in this area.

Several researchers have investigated noise levels in the NICU. In the Falk and Woods (1973) study, noise levels were measured at various high risk areas of the hospital, including inside of isolettes in their NICU. The mean noise level inside of the isolettes in this study was 74.5 dB using a linear scale and 57.7 dB on an A-scale. For comparison, a normal conversation would be 50 dB(A), a noisy office, 70 dB(A), and a noisy factory, 80 dB(A), (Woods and Falk, 1974). Chapman, Bess, and Peck (1980) found the mean overall noise level in isolettes in their study to be 77.4 dB. Striking the side of the isolette produced peak ranges of 130-140 dB. Merely closing the door to the storage area below most isolettes created a peak amplitude of 114 dB. Anagnostakis, Petmezakis, Messaritakis, and Matsaniotis (1980) and Bess, Chapman, and Peek (1979) used similar formats in studying noise levels inside NICU isolettes. They measured the added noise of various types of equipment used in the NICU. The mean ambiant noise levels inside the isolettes was 55.0 ± 1.0 dB(A) and 55.4dB(A) respectively. Use of a respirator increased the mean values to 65 ± 1.7 dB(A) and 60.0dB(A) respectively. In the Anagnostakis study, it was also found that infants inside oxygen hoods with humidity and a flow of 5 liters per minute were exposed to 75 ± 1.5 dB(A). Crying could add another 10dB(A). Both of these research groups recognize several facts: 1) adult safety levels cannot be generalized to infants; 2) adult safety levels are based upon only eight hours of exposure and infants can be exposed for periods of days to months and; 3) many of these infants are being given ototoxic drugs which can potentiate the effects of noise levels. Both of these research groups also concluded that the possibility for hearing damage and physiologic disruption are very real.

There is a paucity of research which has actually measured the physiologic response to noise in the premature or ill infant. Long, Lucey, and Philips (1980) conducted one such study in this area. While the sample was quite small (n=2), the results were alarming and do indicate the need for further research. The infants in their study were monitored for intracranial pressure, oxygenation levels and other general vital signs concomitant with measurements for ambient noise levels. A fall in oxygenation, a rise in the intracranial pressure, and increases in heart and respiratory rates were noted when loud sudden noises were perceived by the infants. This reflects that physiological responses do occur. This study lends support to the belief that sudden, loud noises can be a potential precipitator of intracranial hemorrhage a major cause of morbidity and mortality in the premature infant.

There are countless machines and monitors used in the neonatal intensive care units. While their use is vital to the care of the infants, there is usually some risk to their use. These invasive types of equipment carry the inevitable worry of iatrogenic complications, either trauma, infection, or both. These risks must be weighed against the benefits of the equipment's use.

In addition, there are always the psychological risks. Equipment on and around the infant can be a barrier to parent-infant interaction. It can obstruct a parent from completely visualizing the infant, as in the bases of bili-masks, oxyhoods, heat shields, and the securing tapes for the endotracheal or nasogastric tubes. It can inhibit a parent from touching or holding an infant as in the cases of IV's. On a very small infant, ekg leads, amboards or dressings can cover a significant portion of their body, limiting the areas where a parent can touch or stroke the infant. Extra equipment may also reflect the need of the infant for extra support, and consequently may be seen by the parent as a greater degree of illness and threat of death.

The use of equipment in the NICU is not decided indiscriminately. It is often a physiological necessity. In the premature or critically ill neonate, handling must be kept to a minimum. It has been documented that these infants cannot adapt physiologically to handling (Long, Philip, Lucey, 1980). The use of moniters, infusion pumps, and other types of equipment allows for the minimal handling of these infants. This could prove life-saving as recent research has documented that even some normal care-taking activities, such as diaper changing, cause hypoxia in an unstable infant (Speidel, 1978; Long et al., 1980). While the infant's health and future well being are, of course, the first priority in this situation, it does indeed represent a further limitation of parent-child interaction.

The NICU Staff

The NICU staff is an important component of the environment which surrounds the infants and their families. How the staff responds to the needs of these families will play an important role in how the family will adjust to this situation. The staff, however, is also much affected by the NICU environment. As a result, burnout is a serious problem in these units.

Burnout is defined as "a loss of motivation for creative involvement" by Marshall and Kasman (1980, p. 1161). This is both a physical and psychological problem for the staff. Physical problems include fatigue, a decreased sense of well being, and increased absenteeism related to psychosomatic complaints. Emotional problems include hostility and negativism, feelings of helplessness and isolation, and depression. These are reflected in a wide range of behaviors at the work place.

Causes of burnout in the neonatal intensive care unit have been studied extensively. While there are many reasons for this problem, several themes were recurrent throughout these studies. Emotional reasons were cited as one of the

major causes for burnout in nearly every study (Marshall and Kasman, 1980; Astbury and Yu, 1982; Gribbons and Marshall, 1982; Frader, 1979; Jacobson,1978). The death of an infant was also cited in each of these studies as being highly stressful. The death of an infant is a seeming paradox and is often difficult to accept. Death also has the added implication to some medical personnel of reflecting failure on their part (Marshall and Kasman, 1980). Ethical issues were also a source of high anxiety for the NICU staff members, for they must repeatedly question their efforts in light of the patient's quality of life. This is especially true when "chronic" or long term patients are involved (Astbury and Yu, 1982; Gribbons and Marshall, 1982; Marshall and Kasman, 1980; Jacobson, 1978; Frader, 1979).

Nurse-physician relations were also high on the nurses' lists as a source of chronic stress (Jacobson, 1978; Gribbons and Marshall, 1982; Astbury and Yu, 1982; Schmidt, 1977). This was usually as a result of a lack of role clarification. Neonatal nurses are highly specialized. This, combined with their experience, places them in a rather unique position. They have a greater responsibility for their patients than do some nurses in other units. Problems arise when either one or two situations occur. Physicians may ignore the nurses' competence and knowledge or, in reverse, may shift their own responsibility onto the backs of the nurses (Schmidt, 1977; Gribbons and Marshall, 1982; Jacobson, 1978).

Understaffing and overwork are common complaints of NICU nurses and physicians. Due to burnout and a high staff turnover, it is often difficult to maintain enough nurses to safely staff the units. Orientation to these units is, of necessity, extensive. This decreases the rate at which departing nurses can be replaced. As a result, overtime and heavy patient assignments are the rule rather than the exception. This is a very stressful situation for these nurses and given the unstable nature of the patient population, frustration rises with the

knowledge that safe, comprehensive care is not being maintained (Jacobson, 1978; Astbury and Yu, 1982; Gribbons and Marshall, 1982; Walker, 1982; Schmidt, 1977; Jones, 1982).

The type of care provided in the NICU is family centered, meaning that the care extends to the parents as well. This can become a stressor in itself if parents are responding to the situation with anger, denial, or hostility. Also, many parents who have infants in the NICU were high risk to begin with, often with problematic or variant life styles. It can be stressful to deal with such families day after day (Marshall and Kasman, 1982; Marshall and Kasman, 1980).

Jones (1978) also studied the stress responses of the nursing staff in the course of a total environmental analysis of two neonatal intensive care units. Using a standardized psychological evaluation (Warheit-Schwab Survey) and open-ended interviews, Jones found that NICU nurses exhibited significantly higher levels of depression, psychosomatic symptoms, anxiety and mood disorders as compared with the general population (significant at the 0.05 level). It is not known, however, if these difficulties were present prior to the time that these nurses began working in the NICU or if these were incurred as a result of the nature of the job. Jones also noted that the nurses experienced very intense emotions related to changes in their patients condition. She identified much ambivalence on the part of the nurses regarding their jobs. Many of the factors cited by the nurses as leading to job satisfaction were also the same as those reported as creating dissatisfaction. An example of this would be the unpredictable nature of the job. This unpredictability is seen as both stimulating and stressful by the nurses.

While the discussion thus far has mainly dealt with nursing issues, it must be recognized that the neonatologists also experience burnout. While many of the stresses are the same, physicians do have their own unique set of problems.

One author summed up the neonatologist's problem when he said, "The relentless load of responsibility which cannot be shared, the anxieties of making life and death decisions almost every day and the concern over long term handicaps in the survivors eventually over the years take their toll." (Walker, 1982, p.86).Signs of this toll are reflected by avoidance, inflexibility, resistance to change, and in the more severe instances, abandoning the field (Schmidt, 1977).

The staff's tension is bound to be perceived by the neonates and the parents as well as be transmitted to them. In addition, the staff's stress levels may reach a point where it begins to interfere with their ability to help others. Also, the continuous exposure to this perpetual stress of the NICU environment may desensitize the staff and, hence, they may be unable to anticipate or recognize reactions of the parents. Most NICUs are committed to family centered care. In order to meet this commitment, the staff must "heal itself" and develop some mechanism which will help to control the effects of stress and burnout. It is essential that the care of these infants and their families is not compromised.

Parental Reactions

The antenatal period has been described as a time when parents are psychologically developing and readjusting their lives to accommodate their new roles as parents. Even those who have experienced this with earlier pregnancies must undergo this process again (Osofsky and Osofsky, 1981). Birth of a premature infant interrupts this natural development. The crisis of premature birth delays resolution of the tasks of pregnancy until resolution of the crisis of the early birth has been resolved. In addition, the special needs of the premature or critically ill newborn may aggravate parental concerns over parenting capability. Financial concerns are also accentuated. Above all, of course, is the concern for the infant's well being.

After giving birth to an ill neonate, parents describe a wide gamut of emotions including grief, guilt, and anxiety. These reactions have been described in literature dating as far back as the turn of the century (Silverman, 1979).More "recently", there have been the works of Prugh (1953), Caplan, (1960), and Kaplan, Mason, and Caplan (1965). While these works are widely quoted in current discussions of parental reactions, it must be remembered that the NICUs discussed in these studies were vastly different from the NICU of today. The most important difference is that parental visitation was not an accepted practice at that time. Visits were limited to viewing the infant from the windows of the nursery until it was time to prepare for the discharge.

The works of Caplan, Mason, and Kaplan (1960, 1965) on premature birth and the family were all a part of a larger study on the effects of stress on the family. Caplan (1960), for instance, looked at thirty families in depth to determine if a healthy versus unhealthy resolution of the crisis could be predicted based upon certain clusters of behaviors. In this exploratory study, it was found that a certain degree of accuracy in prediction was possible. It was found that cognitive grasp of the situation, how feelings were handled, and the provisions for help in resolving the crisis were most helpful in predicting resolution. Parents who had successful crisis resolution tried to maintain a cognitive grasp of the situation, maintained a conscious awareness of unpleasant emotions and actively sought help from family, friends, and the professional staff of the unit. Unhealthy resolution was reflected by denial and avoidance of information which might force acknowledgment of the severity of the situation. Emotions were surpressed and, as a result, aggressive outbursts, non-specific tension and meaningless activity in non-related areas was commonly manifested. An inability to ask for help was commonplace and dysfunctional communication patterns between the parents were noted.

Kaplan and Mason (1960) discussed maternal reactions to the premature birth. They emphasized the initial shock that most women feel. These researchers proposed four psychological tasks which they felt were necessary for mothers of premature infants to work through in order to successfully master the crisis. The first was anticipatory grief. This involved acknowledgment of the severity of the infant's condition as well as the potential for the baby's death. The second is accepting "her failure" to deliver a normal, full term infant. Symptoms of depression and grief are considered normal at this time as the mother works through these emotions. The third task is begun as the resolution of the first two steps near completion. The mother must now resume the task of accepting the infant and develop a relationship with her baby. At this time, the mother begins to make preparations to assimilate the infant into the family system. Lastly, she must learn the special needs of her premature infant and alter her expectations accordingly.

While for the most part these tasks, identified in the 1960s, are the same today as they were at that time, a few cautions must be discussed. Society's values and attitudes have changed in the past twenty years. Men today are considered a much more integral part of the birthing and parenting process. Consequently, the application of these tasks should be broadened to include the father as well. Another problem seen with Kaplan and Mason's work is related to this same issue of sex role orientation. Their second task referred to the "woman's failure" to deliver a normal infant. This seems to reflect a certain type of value system, which is not as widely accepted as it once was. Guilt and failure are frequently cited emotions experienced by both parents in this situation (Prugh, 1953; Benfield, Lieb, Reuter, 1976; Duhamel, 1977; Otto, 1980). The causes for these emotions varied widely and will be discussed in greater detail later. Perhaps, a broader description of this task, which would account for

this variability, would be more appropriate. Phrasing the task as "acceptance of the premature birth" would allow for more varience in the parental response.

Prugh (1953) made several astute observations concerning parental problems associated with premature birth. The mother, for instance, is forced to delay the assumption of her maternal role and instead must assume a supporting role. She may feel inadequate, in that she is unable to provide the same quality of care to her infant as is being provided by the nursing staff. Resentment of the staff, especially the nurses, may ensue. Prugh suggests that the nurse may even be viewed as a mother figure. This may further increase the resentment, depending on the mother's prior relationship with her own mother. It might be that such feelings of jealousy, resentment, and competition with the nursing staff was more problematic in the 1950s, when parents were rigidly excluded from the nurseries. However, this problem still exists to some degree today as it is cited in several more recent sources (Colen, 1981; Cohen, 1982; Newman, 1980; Hernig, 1983; David, 1983).

Prugh also cited guilt as a common emotional response of both parents, who may fear that the premature birth could have somehow have been prevented. Little is actually known about the causes of most premature births. However, guilt continues to be a problem with many parents as they attempt to rationalize the birth (David, 1983; Duhamel, 1977; Benfield, Leib and Reuter, 1976; Otto, 1980). Due to the greater physiological involvement between the mother and the fetus, Benfield et al. (1976) found a higher incidence of reported guilt feelings in mothers than in fathers.

Benfield, Leib, and Reuter (1976) investigated the grief responses of parents whose infants had been transferred to a regional neonatal intensive care unit. They studied 101 parent dyads and their responses to this crisis. Mothers consistently reported greater grief feelings than did the fathers. Responses,

listed in decreasing order of frequency,experienced by these parents, were sadness, sleep difficulties, preoccupation, loss of appetite, irritability, guilt and anger. The researchers also used a cluster of variables to measure the presence of anticipatory grief in these parents. This was found in the majority of the parents. Anticipatory grief was found to be positively correlated to the degree of pleasure that was reported by the parent over being pregnant ($r=0.02$, $p \leq 0.05$). Anticipatory grief was also reported by Newman (1980), Kaplan and Mason (1960), and Green (1964).

Anxiety, of course, is always prevalent. This was a frequently cited problem for parents in responding to their ill or premature infant (Newman, 1980; Duhamel, Lin, Skelton, and Hantke, 1977; Otto, 1980; Prugh, 1953; David, 1983; Colen, 1981; Benfield et al. 1976; Caplan, 1960; Caplan et al. 1965). This is understandable given the precarious status of the infant's health. Prugh points out that any anxieties which existed during the pregnancy will aggravate anxieties resultant from the baby's problems. Several studies found that there was no association between the severity of the infant's health status and the parent's level of anxiety (Harper et al. 1976; Benfield et al. 1976). Duhamel, Lin, Skelton, and Hantke, (1977) raised the question as to whether this anxiety could have a negative influence on the parent's perceptions of the infant, ultimately disrupting the parent-child relationship. While the existence of anxiety in this situation may appear to be common sense, its effects should not be underestimated.

Newman (1980) found that parents have essentially two styles of coping: coping through commitment and coping through distance ($n=10$). Parents who coped through commitment became actively involved in the care of their child. They spent a great deal of time visiting the unit. They tried to become knowledgeable about the problems their child was experiencing as well as about

the child's care. They also reduced their expectations of the infant. On the other hand, some parents seemed to need emotional distance from the situation. These parents were described by Newman as requiring "a slower acquaintance, relying on expert care, and expressing fear, anxiety, perhaps denial before acceptance of a surviving infant" (p. 189). This group avoided visiting the unit frequently. As one mother expressed it, "We will get to know her when she comes home. Right now, it is too painful." These parents seemed unable to cope with the realities imposed by unit visitations. Newman made no attempt to judge these coping patterns. It was recognized that individual coping patterns must be respected and that parents who "hold back" in response to anticipatory grief should not be pressured into meeting the expectations of the staff. A parent who is attempting to deal with his/her grief may be emotionally unavailable at this time. Allowing parents to determine their own readiness and to pace their involvement accordingly was a conclusion reached by many of the researchers (Otto, 1980; Newman, 1979; Sherman, 1980; Breslin, 1977, Duhamel et al. 1977).

Altered Transactions

The association between hospitalized infants and parenting disorders was noted as far back as the turn of the century by Pierre Budin (Silverman, 1979). Budin, considered by some to be the father of neonatology, stressed the need to encourage parental involvement with these infants. His warnings were largely ignored, and parents were prohibited from interacting with their ill or premature infants until the time of their discharge. This meant that for periods which ranged from days to months, parents and infants were prevented from normal transactions now considered so essential.

Around the mid 1960s, two factors came into play which helped to reverse this trend. The first was the national recognition of the problem of child abuse

and neglect. Research studies were implemented in order to determine thecauses of this tragedy. It was during the course of these studies that the association between hospitalization at birth and abuse was first noted. The second factor was the growth of interest in child development. The importance of these early years had gone largely ignored prior to this time. Initially, the focus was on the toddler and preschooler. As the fields of child development and child psychology further developed, the importance of infancy was eventually recognized. It was this trend, as represented by the works of Kennell and Klaus, which helped to facilitate more flexible and open visiting policies in the nurseries and in the labor and delivery rooms.

Early literature indicated that premature and critically ill infants were disproportionately represented in the statistics on child abuse and neglect. Studies of children with failure to thrive syndrome were also reported to have a high incidence of prematures in their studies. These findings of dysfunctional parenting patterns were attributed to the prolonged separation of these parent-child groups. A closer look at some of these studies raises questions about their validity, as well as about some of their conclusions (Minde, 1981). One pervasive problem in almost all of these studies was that the perpetrator of the abuse was never identified. In order to make an accurate statement about a relationship between poor attachment and abuse, one must clearly be able to isolate a parent as the abuser. This information was not provided in most of these studies.

The Klein and Stern (1971) study used retrospective chart review over a nine year period to determine the proportion of low birth weight infants with a diagnosis of battered child syndrome. They found that out of 51 children meeting their criteria for abuse, 12 were found to have been low birth weight. This represented 23.5 percent of their sample. Of these, nine had significant neonatal problems, including "mental retardation" and microcephaly. Ten of

these children also came from homes described by a social worker as "deprived", with alcoholism, unemployment, poverty, and social disorganization. Also significant to this discussion are the characteristics of the other 39 abused children in this study. Of the 39, 15 (38 percent) had preexisting medical problems such as mental retardation, cystic fibrosis, hypospadias, and cleft lip and palate. The home situations of these children were not discussed. Clearly, there are many confounding variables involved in this study. It seems feasible that a more realistic conclusion of this study would have been to focus on the interaction of the disturbed environments and the special demands imposed by the medical problems of these children.

Another study which is frequently cited relating prematures with child abuse and neglect was done by Elmer and Gregg (1967). This study looked at the charts of 50 children with "unexplained bone injuries". Of these, only 22 could be classified as abused with any certainty. This classification was based on psychological and physical evaluations. "Almost all" of these 22 children were of low socioeconomic status. Housing was defined as substandard. Marital disharmony, isolation, alchoholism, parents with criminal records (including one murderer), and severe psychological problems were reported to be common, but no specific details were provided. A reliance on physical punishment, even for infants, was also reported. Seven of the 22 infants had been "premature". However, this determination was inappropriately made on the basis of the child's weight and not upon a gestational evaluation. This is an important distinction, as these infants could have been small for gestation age (SGA). SGA infants have been reported to have a higher than normal incidence of neurodevelopmental difficulties and early problems with social interaction (Avery, 1981; Als, Lester, Brazelton, 1979). In Elmer and Greggs' study, 12 of the 22 had IQs less than 80. As with most studies dealing with child abuse, it was impossible to determine if

the retardation was the cause or a result of the abuse. Due to the vagueness of the reported data and the existence of so many confounding variables, it appears inappropriate to make any conclusions about a direct relationship between child abuse and prematurity.

Another condition sometimes attributed to a parenting dysfunction, failure to thrive, has also been associated with prematurity. Failure to thrive is a complicated problem with many causes. It is defined as a disproportionate lag in growth in the child. Medically related causes can include dysfunction in almost every organ system: cardiac, central nervous system, gasrointestinal, respiratory, and so on. It also has emotional origins, and in these cases is sometimes traced to parenting disorders. Failure to thrive can be classified in two ways: organic, meaning that a physical cause has been found, and non-organic, meaning that either no physical cause could be found or that an emotional cause was found. Minde (1981) has criticized the methodology of many of the major studies which have tried to link prematurity to failure to thrive. Many of these studies (Ambuel and Harris, 1963; Shaheen, 1968) failed to use the commonly accepted definition of failure to thrive, instead using their own definitions. They also did not differentiate between premature and small for gestational age. As a result, their studies were based on populations which could have been below the third percentile of weight to begin with.

Hunter, Kilstrom, Kraybill, and Loda (1978) conducted a prospective study on 255 infants to evaluate the incidence of child abuse and neglect occurring in the graduates from their NICU. Family evaluations were done prior to the infant's discharge, and determinations for risk of abuse were made at that time. Forty-eight infants were initially identified as being at high risk for abuse. Of these 48, seven were placed in foster care homes before the infants' were discharged. There were no custody changes which occurred in the low risk group.

A 3.9 percent (n=10) incidence of abuse was found out of the total population of 255. Of these, all had been predicted to have been at high risk for abuse based upon their family history and characteristics. These characteristics included social isolation, a family history of abuse, marital problems, personality disorders, and inadequate child spacing. The abused children differed from other neonates in that they were less mature at birth (mean gestation 31.5 weeks versus 35.26 weeks), weighted less at birth (1.477 Kg. versus 2.224 Kg.), were less frequently visited in the unit by the parents, and required longer periods of hospitalization. Congenital defects were present in six out of the ten infants who had been abused, confounding the relationship to prematurity.

This discussion has not been an attempt to negate or deny the higher incidence of child abuse and neglect in NICU graduates. Rather, it has endeavored to put the problem in a more realistic perspective. Based on these studies, as well as those which will follow, it would appear that abuse and neglect arise from situations in which there are problematic transactions between parents and children in a nonsupportive environment.

Parent-Infant Transactions

The transactional model is of great importance to the discussion of the premature or critically ill infant as it serves to integrate many of the principles thus far discussed. The problem of child abuse in this population cannot simply be attributed to separation from the parent; there are too many other confounding variables involved. The transactional system approach relates all these variables into a more meaningful, holistic explanation of the problem in question. For instance, the studies presented earlier discuss the high incidence of abuse present in children with preexisting medical problems. These problems occurred in both normal and premature infants. These infants place added stress and demands on their parents in terms of time, emotions, money, and energy.

They may also have disturbances in their ability to communicate with their caretakers. This could be a result of either CNS dysfunction, prematurity, or various other types of problems.

The parent, on the other hand, could also contribute to the dysfunctional interaction. Recall that some of the abusive parents in the studies presented earlier were alchoholic, had marital difficulties, and had moderate to severe psychological problems. These parents may have been unable to function within the realms of normal communication patterns, much less face the demands of their children. While not all abusive parents follow such a disorganized pattern of functioning as was seen in these studies, it is possible that the ability to communicate, interact and/or be emotionally available to the child is impaired in most abusive adults.

The environment is another essential component to the transactions which are occurring. It may either contribute to or enhance the likelihood of an abusive situation occurring. The ecosystem's framework emphasizes that no individual operates within a vacuum. The family system dynamics, together with the social, economic, and cultural environment of which the family is a part, are all impacting to effect change in the family. Any model of human behavior which does not account for these variables is far too simplistic. In the remainder of this discussion, validation for these statements will be provided.

T. Berry Brazelton's work in the field of child development has shown the newborn to be a highly efficient and competent organizer of his environment. He is able to communicate with his caregivers and make his needs known; he is also capable of maintaining the proximity of the caregiver or shutting the caregiver out when this is appropriate. The infant uses his states of consciousness for this purpose. The Brazelton Neonatal Assessment Scale demonstrates the newborn's capacity to habituate to repeated, disturbing stimuli,

and control his state in order to attend to what is significant (Brazelton, 1981). Brazelton feels that these capabilities allow the infant to participate in significant interaction with the parent or the environment. The infant provides rewards to the parents through his/her attention, responsiveness, "babyishness", and cuddliness (Emde, 1981). Later, the social smile and cooing add to the infant's ability to reward the parents for their caregiving behaviors and encourage their continuing proximity. In the ideal transaction, the neonate can organize his state and his responses in order to communicate his needs to the parents. The parents' response, in turn, helps the neonate to expand and further differentiate its capabilities (Als and Brazelton, 1981).

Current studies are attempting to define how prematurity influences the infant's ability to react and respond to its environment. Als and Brazelton (1981) and Als, Lester and Brazelton (1975) proposed a hierarchy for behavioral system organization based upon feedback and interaction between the infant and his environment. They found three parameters useful in assessing the infant's nature of functioning and competence. They were: level of organization, degree of differentiation, and the degree of modulation. The level of organization refers to the degree of integration of which the infant is capable. There are five levels of system organization through which the infant progresses: the physiological system, the motor organizational system, the state organizational system, the interactive and attentional system, and the self-regulation system. The degree of differentiation is the level of sophistication of the infant's behavior. Modulation reflects the ability to implement and sustain a behavior smoothly and easily.

Preterm infants demonstrate a heightened sensitivity to environmental stimuli, responding with physiological decompensation. They require sensitive environmental structuring to facilitate social interaction. This is due to the fact

that their level of organization is within the physiologic system and is not well established (Als and Brazelton, 1981). Divitto and Goldberg (1981) describe this phenomena as "the younger and more physiologically vulnerable the baby, the more the demands of survival consume energy which might otherwise be invested in interactions with the environment" (p. 312). This was also noted in other studies (Gorski, Davidson, Brazelton, 1981; Frodi, 1981).

The altered ability of the premature or critically ill infant to engage in social transactions with the parent has serious implications for the development of the parent-infant relationship. During much of the infant's stay in the NICU, the infant may remain organized at the physiological stage, where social interactions remain fairly limited. As the infant moves through the motor system and becomes more adept at state control, initial attempts are made at "socialization". At this time, the premature infant has a greater tolerance for stimuli and needs to invest less energy in physiological maintenance. This knowledge should not only be incorporated in the NICU staff's care of these infants, but should be taught to the parents as well. This will assist them in developing realistic expectations of the infant's behavior.

Goldberg (1979) reported that evaluation of preterms' behavior at the time of their discharges had several significant differences from the behavior of a term infant. (Statistics not provided.) These prematures spent relatively little time in an alert state, had difficulty maintaining alertness, and were less responsive to their caregivers. They also cried less. Goldberg suggested that, as a rule, premature infants were less likely to give their caregivers clear-cut messages about their needs. They are also less competent in social interactions. Goldberg stated that the normal infant "helps adults" by being readable, predictable, and responsive. The preterm infant, on the other hand, cannot help as a result of poor organization. Parents may end up with feelings of

helplessness and frustration. This was in agreement with the findings of Als and colleagues (1975), Brazelton (1973), and Divitto and Goldberg (1981).

The research of Gorski, Davidson, and Brazelton (1981) has shown that the premature infant must first develop internal stability before social development and organization can occur. Overstimulation can drain the infant's limited resources and cause the infant to further withdraw in order to protect himself. The high levels of negative stimuli to which infants are continually exposed during their stay may be as much a factor in their low levels of social skills as is their immature neorodevelopmental status. Gorski and his colleagues as well as Goldson (1981) both advocated the use of environmental manipulation to improve the recovery rate of infants, based upon this principle.

Frodi and Lamb (1978) added a fascinating twist to the altered communication patterns of the premature infant. They showed videotapes of both normal and preterm infants to a group of 64 parents. The infants were shown both in a quiesent state and a crying state. In half the tapes the soundtracks were switched, so that the preterm infants' had the term infants cry and vice versa. They then gathered physiological data and self-reports from the parents who viewed the tapes. Their data showed that the cry of the premature infant was perceived as the most adversive, and elicited the greatest degree of autonomic arousal. These findings were the most prominent when the preterm infant and the cry were paired. This data suggests that the cry, a major source of communication in the infant, may be perceived as antagonistic by the parent. Rather than accomplishing its purpose of eliciting the proximity of the parent, the parent may instead try to avoid the child. This may eventually decrease the sympathetic responses of the parent and a negative cycle may ensue. It was proposed that the persistence of a negative stimuli, such as a cry, may eventually be the catalyst for an abusive situation. While this research focused

on the altered cry of the premature infant, there are other neonatal conditions which have abnormal, characteristic cries. Application of Lamb and Frodis' model to these children may prove equally informative.

These studies indicate that the premature infant does indeed have an altered response level to the environment. This altered response level may send faulty cues to the parents, such as "leave me alone". Parents will reap few rewards from such interactions unless they are aware of both the neurodevelopmental significance of the behavior and its temporary nature.

While research is beginning to accumulate which substantiates the transactional model as an explanation for dysfunctional parenting patterns (Frodi, 1981), there is little to validate previous suppositions that early parent-infant separation was the major cause in this population. Leifer, Leiderman, Barnett, and Williams (1972) and Crawford (1982) found that any differences which did exist in attachment patterns at the time of discharge from the NICU were not observable by the end of the first year. Rode, Chang, Fisch, and Sroufe (1981) investigated the hypothesis that relationships between parents and infants who had required intensive care as a newborn would demonstrate aberrations as a result of the separation. They were unable to determine a higher incidence of strained attachments in this population. Their data suggests instead that "attachment behaviors are influenced by caregiver-infant interactions over a period of time, and provide evidence for resiliency in the formation of attachment relationships" (p. 190).

Thus far, this review has shown that parents experience deep, emotional responses to the admission of their infant to a neonatal intensive care unit. In addition, many of the normal, reciprocal transactions cannot occur. This is a result of the environmental restrictions, the medical and social limitations of the infant, and the grieving responses of the parents. In order to deal with some of

these problems, NICU staff have tried several types of interventions. This will be discussed in the following section.

Interventions

The first major intervention made by the NICUs was to attempt to upgrade their care and emotional support of the families of the premature or critically ill newborn. This was initially accomplished by liberalizing their visiting policies. The closed door policy was originally instituted to guard the infants from infection. It was found, however, that parents who were allowed to visit with their infants were far more conscientious about scrubbing than was the staff. Soon after, the barriers began to fall (Avery, 1981).

Harper (1976) studied the parental responses to these unlimited visiting policies. While parental anxiety levels remained high and virtually unchanged by the policy, most parents maintained frequent visits. When questioned in retrospect, only 1 percent said that they would have visited less. Rosenfield (1980) analyzed visiting patterns of mothers (n=78). She found that, initially, visiting frequency was low. They were found to gradually increase after the first week. Inclusion of the parents in an infant stimulation program seemed to increase visits even more, presumably because the mothers felt that there was something constructive they could do during the visits. It also may have been that as the infants' conditions improved, their ability to transact served to encourage the mothers to visit more. Minde, Trehub, Corter and their colleagues (1978) found a similar trend in visiting patterns in their study of 18 infants and their parents.

Parent support groups have been a popular and successful source of intervention in the NICUs. Shosenberg (1980) and Minde, Shosenberg, Marton and their colleagues (1980) described their support group which used the idea of

"veteran" or experienced mothers as a part of the support team. The veteran parent is one who has weathered the NICU experience and who can share his/her insights with new NICU parents. A nurse coordinator was also at these meetings to act as a liaison. A comparison between parents who participated in the support groups (n=28) and those who did not (n=29) yielded some differences. Mothers who were a part of the support groups tended to visit more (4.5 times per week, SD=2.5 for those in the group versus 3.1 times per week, SD=1.9; p,0.05). It may be that parents who would not participate were similar to those described by Caplan (1960), who were unable to accept help and, therefore, at a greater risk for a poor crisis resolution. It may also be that some persons, such as those described by Newman (1980) as coping through distance, would require a different, more individual approach. A similar study, controlling for personality characteristics, Caplan's predictors of crisis, and Newman's coping styles, may help to determine if there are certain persons who would derive greater benefit from this type of intervention. This would serve NICU staff in determining the intervention most suited to an individual family's needs.

Other support groups were reported in the literature as well. They differed in the degree of professional involvement. Some groups were made up entirely of parents (Mangurten, Slade and Fitzsimmins, 1979), while others had neonatologists, nurses and social workers (Erdman, 1977; Dammers and Harpin, 1982; Duhamel et al. 1977). They also varied in their purpose. Some parents used these groups as opportunities to share thoughts and feelings, deriving comfort from the knowledge that they were not alone. Other groups were a mix of information sharing, problem solving, and emotional support. In essence, all of the models were an attempt to provide an additional form of support to the parents.

These groups are not meant to substitute for or to delegate away the job of caring for the emotional needs of the parents by the NICU staff. It is thought that the greater emotional support that is provided during a crisis period, the less strain there will be upon the parent-infant relationship (Sherman, 1981; Breslin, 1977; Caplan, 1960). Because of this philosophy, most NICU staff realize that the social, physical, psychological, and emotional impact of their units must be kept to a minimum. Difficulties arise when, in a crisis, staff must concentrate their efforts upon the care of the infant. Often, this situation ties up most of the staff and leaves no one to attend to the care of the worried parents. This same type of situation can occur when units operate without sufficient staff.

To bridge the gaps at these times, units have tried various methods to fill in the void. Primary care nursing is one such approach. This is a system of care where one or two nurses on each shift will be routinely assigned certain infants. This system of care provides more consistent and thorough care of both infant and parent. The families become familiar with "their" particular nurse and do not need to reestablish a new relationship with someone different each time they visit. In turn, the nurse is aware of the needs of the parents, as well as their individual coping patterns (Sugar, 1978). This idea of having a consistent person to communicate with parents was emphasized in several sources (Green, 1979; Sherman, 1980; Klaus and Kennell, 1982).

Neonatal nurse specialists or clinicians, social workers, and child psychiatrists have also been made available on a twenty-four hour basis in some units. Their purpose is, again, to meet the parents' needs when staff pressures preclude staff involvement. Use of such professionally trained personnel eliminates the possibility that time conflicts could prevent meeting parental

needs. Such a person can give the parents the personal attention that is so needed during this critical time (Sherman, 1982; Schmidt, 1977; Steward, 1982).

Regionalization of perinatal care has greatly improved morbidity and mortality figures by making specialized care more available. It does this by organized planning and even distribution of expensive and scarce resources. While the concept of regionalization has accomplished its goal of improving care provided to mothers and infants, it has exacerbated the problem of the separation of the family, sometimes by hundreds of miles. While the expense of providing high risk perinatal care precludes expansion of these services, there are ways to help offset some of the negative impacts of the transport situation. Whenever possible, high risk mothers should be transported to the perinatal center prior to delivery. This minimizes complications of both mother and infant. It is a well known fact that morbidity and mortality figures for outborn infants are significantly worse than those for inborn infants (Avery, 1981). A transport in this manner also ensures that the mother and infant will be in the same hospital. Sometimes it is not always possible to predict situations which will require transport. In addition, the mother's condition may contraindicate being moved at that time. In these cases, transport of the mother should follow that of her infant, whenever her condition warrents (Kennell and Klaus, 1982). As the infant's condition stabilizes, he should be returned to the referring hospital in order to be closer to home (Kennell and Klaus, 1982).

Extended Family Concerns

There has been little discussion thus far about the other members of the child's family aside from the parents. This is due mainly to a paucity of research done in this area. Grandparents are occasionally allowed visitation in some units if space and the physicians allow. The major concern in a NICU is that as the

number of visitors increase, so will the risk of infection. Initial studies have not substantiated this fear, however. Umphenour (1980) studied the effect of sibling visitation in an obstetrical unit. There were 215 control infants and 182 experimental infants in this study. Bacterial colonization prior to the sibling visitation program was 70 percent. The colonization with the experimental infants was 67 percent. The conclusions of this study was that sibling visitation did not pose a risk in a normal newborn nursery.

While sibling visitations have become a more accepted practice in some obstetrical and term nurseries, it is less common in the NICU. Schwab, Tolbert, Bagnato, and Maisels (1983) evaluated the effects of a sibling visitation program in their NICU. They measured behavior patterns through interviews with the children and their parents, as well as by direct observation. The children were a mean age of 5.2. The results were promising. There were no negative behavior changes in the children, either before or after their visits. They did not exhibit fear of the unit, whereas this was seen in the control population. The increased fear was attributed to the controls having greater fantasies about what was happening as a result of being excluded. The routine of the unit was not at all disrupted by the visits and there was no increased incidence of infection noted during their trial period. The sample size of this study was small (n=16), so results must be interpreted with caution. However, this approach seems to have merit as a way which the NICU staff may enhance family cohesiveness and to also increase their support to the family system.

While this study was one of the few which actually documented the effects of sibling visitation, it was advocated in several sources (Breslin, 1977; Goldson, 1981). Small children normally experience a certain amount of trauma with the birth of a new baby in the family. This may become accentuated with the birth of an ill newborn, as it entails the parents spending an even greater amount of

time away from the home. In addition, the grief responses that the parents are experiencing may cause them to be less emotionally available to the siblings at home. If the situation is not explained to them sufficiently, they may fantasize about what is occurring (Goldson, 1981).

The Discharge

After parents have weathered the initial crisis of having a critically ill newborn, they are faced with what some parents perceive as yet another crisis, the discharge (Lund and LeFrak, 1982). Even when parents have participated in their infant's care throughout the course of the hospitalization, the discharge leaves the parents without the support of the monitors and staff. In order to alleviate these difficulties, several strategies have been suggested.

Discharge teaching is not new to nursing. It has been a vital part of newborn and intensive care nursery care for as long as these units have existed. To supplement its effectiveness, several changes have been suggested. Discharge education should ideally begin at the time of admission. Promotion of the parents' comfort with the care and handling of the infant is integral to relieving some of the anxiety surrounding the discharge (Cagen and Meier, 1979). Creating a supportive environment where parents feel comfortable enough to ask questions and to practice the various skills required of them by their infants, is an important role of the nurse. Involving the parents early on in the infant's care eliminates the need for a "crash course" just before discharge. A crash course leaves everyone, including the nurse, feeling rushed and anxious. Changes or elimination of important information regarding a medication or some other element of care increase in this type of situation. Use of the primary care nurse is also beneficial at this time. It provides continuity in the teaching. In addition, the pre-existing relationship may help the parents to feel more relaxed, which will, in turn, enhance their learning (Bresodola, 1977; Sugar, 1978).

The use of "rooming-in", common to most term nurseries, has become increasingly popular in recent years. It provides the parents with a "transition period", allowing them the opportunity to provide complete care for the infant, while at the same time providing backup for questions, problems, or reassurance. Varner, Ossenkop, and Lyon (1980) found this to be useful with their parents. They also mentioned the unexpected benefits found in the infants. They noted one infant whose apneic episodes decreased when removed from the critical care environment. Breastfeeding in this infant also progressed gradually over a period of a few days. This coincided with similar reports by Gorski et al., (1981).

A more formalized extension of the rooming-in concept was in a report by Goldson (1981) of the Family Care Center developed at Children's Hospital in Denver. This is an eight bed step down unit available to parents who wish to take advantage of it. The goal is to remove the infant from the physiological stresses of the intensive care unit environment to allow him to develop his level of organization to the highest possible degree. It has the added benefits provided by rooming-in for the parents and allow sibling visitation.

Thus, these various authors have shown that a greater degree of humaneness and creativity are possible in the intensive care setting. The NICUs have come a long way since their rigis, antiseptic days of less than 10 years ago. It is hoped that the trend will continue to evolve towards complete involvement of the family in this setting.

CHAPTER III

THE QUESTIONNAIRE

Purpose

The purpose of the questionnaire was twofold. First, it was intended to provide preliminary validation for conclusions which were modeled from the literature review. Also, the questionnaire was presented to elicit parents' personal comments and suggestions. This was accomplished through a combination of open-ended, scaled response, and short essay questions.

Sampling

The questionnaires were mailed to the sixteen active members of a local neonatal intensive care unit support group. Of these sixteen, eleven fathers and mothers responded. All of the parents involved in this study had had an infant in the NICU within the past five years. There were parents of both inborn and transported infants in this sampling. No other characteristics of the infants were known.

Due to the small numbers belonging to this group, it was decided not to ask descriptive or demographic data from the parents. To do so could have betrayed their confidentiality. In future studies with larger samplings, such information would enable determinations to be made concerning the special needs of specific subpopulations.

Procedure

Based upon a thorough review of the literature, the questionnaire was created. Topics covered in the questionnaire included initial parental reactions, their coping mechanisms, their responses to the NICU environment and staff, and their evaluations of the interventions provided to meet their emotional needs. (See Appendix B).

The questionnaire was mailed to the parents with two cover letters. One was an introductory letter from the group's president, the other was a cover letter for the study from this student. In these letters, the purpose of the questionnaire and its anticipated benefits were explained. Parents were told that their participation in the study was voluntary. They were also assured that their answers would be kept confidential and that they would remain anonymous.

In order to assure their confidentiality, parents were specifically asked not to include their names or addresses anywhere on the form. In addition, the questionnaires were addressed and mailed by a person unaffiliated with either this student or the study. Lastly, as mentioned earlier, demographic information was purposely not requested.

Results

To determine the initial responses experienced, parents were asked to choose from a list of eighteen emotions. The emotions found on this list were based upon those commonly reported in the review of the literature (Benfield et al. 1976; Sherman, 1982; Otto, 1980; Prugh, 1953; Caplan, 1960; Caplan et al. 1965; Duhamel et al. 1977). The parents were asked to choose the response which they felt most closely represented how they felt at that time. An additional space entitled "Other" provided parents with the opportunity to write in emotions not mentioned.

The most commonly reported reaction to this situation was "Guilt", chosen by seven parents. This was followed by "Love" and "Cheated", each having been chosen by six parents. (See Table 1.) The rest of the responses were chosen by less than half of the parents in this sampling. "Resentment", "Hopelessness", and "Grief" were not selected at all. It is interesting to note, however, that while the "Grief" response was not chosen, many of the responses that were are symptomatic of grief (Benfield et al. 1976; Linderman, 1965). Two parents also voluntarily wrote in "Numbness" as a response.

Such variation in the responses is to be expected. The usefulness of this type of data is not to be able to determine what responses are normal or common. Rather, it is important for health professionals who work with these families to be aware of the wide range of responses which are possible in this situation. It was interesting to note that while "Guilt" was the most commonly chosen response, "Failure" was chosen by only three parents. This would seem to indicate that the guilt experienced by this group of parents is not a result of the failure to produce a healthy, term infant as was suggested by Caplan, Mason, and Kaplan (1965). Rather, parents may have been concerned that they had done something to cause the infant's problems. Further investigation into this area is necessary, as this could be an area where the unit's staff could provide immediate and effective intervention. By clarifying for parents that little is actually known about the causes of prematurity and other neonatal problems, it is possible that in some of the cases the guilt feelings of the parents could be lessened or alleviated. It might also serve as an opening into a discussion concerning these feelings that the parents might have.

The second question was also related to parental reactions, but were somatic responses as opposed to emotional. Every parent but one reported that

Table 1. Parental Response Frequencies to Question 1.

Please circle those responses which you feel most closely represent how you felt at the time your child was admitted to the NICU.

Guilt	7
Love	6
Cheated	6
Empty	4
Depression	4
Fear of Unknown	4
Anxiety	3
Concern	3
Failure	3
"Left Out"	3
Anger	2
Fear of Loss	2
Apprehension	2
Hope	2
Low Self Esteem	1
Resentment	0
Hopelessness	0
Grief	0
Numb	2

N=11

he/she cried easily. (See Table 2.) Fatigue, inability to sleep, and altered relationships with friends and family were also frequently cited. Aside from these four somatic responses, there was much variability seen. This, again, reflects individual coping patterns.

Parents were asked how they contended with this crisis situation in their lives on a behavioral level as well. Their responses could be grouped into three types of patterns. Many turned to religion for support and guidance. As one mother described this, "We relied on our Faith in God the most and I knew our little guy would be alright." Others turned to the support of friends and relatives for their help and emotional support. Several of the parents expressed the feeling that the experience had strengthened their marital relationship. Lastly, parents stated that they tried to cope with involvement. Visiting frequently, coming to the unit for all the feedings, and performing caretaking activities when possible, were actions that helped some of these parents to cope. This was also reflected later in question ten. These responses will be discussed shortly.

Parents were also asked several questions regarding their perceptions of the impact of the NICU environment upon their anxiety levels. For the most part, variability in responses was again the rule. There were, however, certain environmental factors which had a definite affect on the parents in this study. (See Tables 3, 4 and 5.) The other babies in the unit, the alarms, and the tubes and equipment on their own infant all had high mean response values (4.3, 4.2, and 4.5, respectively). These three factors seemed to impact upon the families at a more personal level than did the others. For instance, the alarms, tubes, and equipment attached to their infants were continual reminders of the precarious health status of their infant. The condition of the other infants in the unit may have served to reinforce their own vulnerability as they watched these children regress and suffer setbacks in their conditions.

Table 2. Parental Response Frequencies to Question 2.

At this time, did you experience any of the following?

		YES	NO
a.	Loss of appetite	3	8
b.	Increased appetite	2	9
c.	Inability to sleep	8	3
d.	Increaded irritability	7	4
e.	Cried easily	10	1
f.	Mood swings	7	4
g.	Physical Complaints (Headaches, Stomach Complaints, etc.)	5	6
h.	Fatigue	9	2
i.	Alterations in relationships with family and friends	8	3
j.	Other responses given:		
	"My wife and I grew closer"		
	"Nervous"		

N=11

Table 3. Explanation of Scales Used.

There were several questions which asked for a response based on a continuum. A five point scale was used. Parents were requested to circle the appropriate number, from 1 to 5, which best described their response.

1. DIDN'T AFFECT ME
   DIDN'T CAUSE CONCERN
   NOT AT ALL HELPFUL

2. RARELY AFFECTED ME
   RARELY CAUSED CONCERN
   RARELY WAS HELPFUL

3. NEUTRAL

4. OFTEN AFFECTED ME
   OFTEN CAUSED CONCERN
   OFTEN WAS HELPFUL

5. VERY MUCH AFFECTED ME
   CAUSED MUCH CONCERN
   WAS VERY HELPFUL

Table 4. Mean Parental Responses to Question 4.*

The NICU environment can be a stressful place in itself. Do you feel that any of the factors listed below affected your anxiety levels? Please circle the appropriate response.

	MEAN PARENTAL RESPONSE	RANGE
a. SIGHTS		
i. The equipment in the unit	3.2	(1-5)
ii. The other babies in the unit	4.3	(3-5)
iii. The activity in the unit	2.7	(1-5)
b. SOUNDS		
i. General noise levels in the unit	2.3	(1-5)
ii. The alarms	4.2	(2-5)
iii. Conversations of the staff	2.1	(1-4)
iv. The radios in the rooms	2.0	(1-3)
v. Babies crying	2.5	(2-5)
c. SPATIAL CHARACTERISTICS		
i. Crowded conditions	3.0	(1-5)
ii. Lack of privacy	3.5	(1-5)
iii. Number of persons in the rooms	2.5	(1-4)
d. OTHER COMMENTS		

"Being in the unit was reassuring and lessened anxiety by experiencing the love, concern, and professional competency of the entire staff." "Drawn curtains-always a sign of trouble." "Banging the isollete doors, (which) made the baby jump was irritating."

*See page 64 for an explanation of the scales used.

Table 5. Mean Parental Responses to Question 6.*

What about your baby's appearance caused you the most concern initially?

		MEAN PARENTAL RESPONSES	RANGE
a.	The baby's size	2.5	(1-5)
b.	The tubes and equipment on the baby	4.5	(4-5)
c.	The baby's activity level	3.0	(1-5)
d.	Other		

"That terrible grey color"
"Bruises from the needles"
"The baby's color"

N=11

*See page 64 for an explanation of the scales used.

Other environmental stimuli did not appear to disturb the parents much at all. One parent even commented that such things as the staff's conversations, radios, and crying babies were reassuring to her, creating a sense of normalcy. One mother was able to describe the unit's wallpaper and rocking chairs. It seemed that many of the parents had a heightened sensitivity to certain characteristics of the environment while not noticing others which may have been cited as noxious and disruptive in the literature (Miller et al. 1974; Kellman, 1982; Woods and Falk, 1974; Gowen, 1979).

The parents were also asked to evaluate the staff's ability to provide emotional support. The parents in this survey rated the nurses quite highly (mean response 4.9). (See Table 6.) The effectiveness of the nursing staff in their ability to provide emotional support and reassurance to these parents was also reflected in parental responses to question five. This question asked parents to describe if there was anything about the NICU that the parents found reassuring or comforting. Every parent cited the staff, more specifically the nurses, in response to this question. The "genuine love and concern for their little patients", "their professional attitude" and "willingness to empathize with our pain" were reasons given for this response.

All the parents in this study reported having consistent nurses caring for their infants. This was found to have been very helpful. One father even felt that his son appreciated this. Knowing the nurses that were caring for their infants was described as reassuring. Many felt that primary nursing facilitated "a closer, more honest relationship". Others stated that it helped them to feel more comfortable in expressing their concerns.

The neonatologists were reported to be moderately helpful (mean response 3.4) in promoting the emotional comfort of the parents. This is probably a result

Table 6. Mean Parental Responses to Question 7.*

In general, how would you describe the staff's ability to help decrease your anxiety and make you feel more comfortable?

	MEAN PARENTAL RESPONSES	RANGE
a. The neonatologists	3.4	(1-5)
b. The nurses	4.9	(4-5)
c. The social workers	3.5	(2-5)
d. The residents	3.7	(2-5)

N=11

*See page 64 for an explanation of the scales used.

of the fact that the neonatologists must divide their time between all of their small patients, and consequently do not have the time to provide as much individual attention to each family. Several parents commented that they would have appreciated more involvement with these doctors, but that they were not available at the times when parents visited. The inconsistent philosophies of the different neonatologists was also cited as problematic and, oftentimes, stressful.

Activities which were reported as the most reassuring were those which involved the parent's direct participation. (See Table 7.) Seeing and touching the infant and holding the baby, both had scores of 5.0. Having a picture of the infant, actual caretaking of the baby and talking with the staff were also highly rated, having mean scores of 4.8, 4.7, and 4.5, respectively. The rooming-in option was generally not responded to, presumably because it was not an option offered to any of these parents. Discounting rooming-in, the mean response to all of the measures listed in this section was 4.4. This indicates that, in general, these measures provided a fairly high degree of reassurance to these parents.

It would seem that greater involvement was most helpful for this group of parents. Involvement was achieved either through developing a cognitive grasp on the situation or participation in nurturant and caretaking activities. These parents indicated that opportunities to become further involved would have been welcomed. (See Table 8.) Many of the parents stated that having a veteran parent would have been valuable (mean response 4.5). Attending support meetings and having more written and media information available were also rated positively (4.3 and 4.2 mean responses).

These parents had many valuable suggestions which might serve to ease this situation for future parents. Some of the parents thought that prenatal classes should, at least briefly, discuss the possibility of needing the NICU.

Table 7. Mean Parental Responses to Question 10.*

What measures did you find reassuring?

		MEAN PARENTAL RESPONSE	RANGE
a.	Seeing and touching your baby	5.0	(5)
b.	Having a picture of your baby	4.8	(3-5)
c.	Seeing your baby in clothes	3.8	(2-5)
d.	Holding your baby	5.0	(5)
e.	Bringing in toys, clothes, pictures	3.8	(2-5)
f.	Talking with the staff	4.5	(3-5)
g.	Talking with other parents who had or previously had, an infant in the NICU	4.2	(3-5)
h.	Actually caring for your infant	4.7	(4-5)
i.	Rooming in (Item eliminated)		
j.	The discharge teaching	3.9	(3-5)

N=11

*See page 64 for an explanation of the scales used.

Table 8. Mean Parental Responses to Question 11.*

Do you feel that any of the following would have been helpful?

	MEAN PARENTAL RESPONSE	RANGE
a. Having "veteran parents visit to share their experiences	4.5	(3-5)
b. Having weekly support meetings on the unit	4.3	(4-5)
c. Having slides, videotapes and better written materials explaining the problems of the newborn	4.2	(1-5)
d. Being more involved in the baby's care	4.1	(2-5)

N=11

*See page 64 for an explanation of the scales used.

These parents thought that perhaps if parents were at least aware of this as a possibility, it would come as less of a shock.

It was also thought that the staff should prepare the parents for the infant's appearance before seeing the infant for the first time (n=3). One mother suggested showing the parents a picture first.

Some of these suggestions were directed specifically to the parents. One mother stated that couples with infants in the NICU should "draw together as a couple". Others felt that the parents should keep abreast of their child's condition at all times.

Several of the mothers described how difficult it was to have to remain in the maternity unit. It was suggested (n=4) that not only should these mothers not be placed in a maternity unit but that attempts should be made to put mothers of infants in NICU in the same rooms. They felt that this would provide them extra support at this very difficult time.

Mothers of transported infants seemed especially left out at this time. Often, rigid hospital policies at the mother's hospital prevented the mother's use of the phone to make long distance phone calls to the NICU. These mothers were not offered the opportunity to be transferred with their infants but would have appreciated this option. One mother stated that she was never contacted by any of the physicians. Her husband would travel back and forth between the two hospitals, became very tired and often would not remember information about the baby. Clearly, this is an area which requires the attention of the NICU staff.

Lastly, a majority of the parents felt that active parent to parent support should be reinstituted in this hospital. Most stated that they had not had the benefit of talking with a veteran parent but thought that this would have been helpful. As one father put it, "Many parents in the past have greatly appreciated

and benefitted from these visits in a way that no staff member could understand or duplicate." It was also suggested that the parent support group might also be useful to parents after the infant's discharge from the unit, as this was another time of stress and uncertainty.

Limitations

The results of this questionnaire must be used cautiously. There are several reasons for this. The most obvious is the small number of parents in the sample. Further studies with a larger sample size would be necessary in order to be able to generalize these results. The variability between the NICUs and their staff is also a factor to be considered in relation to this questionnaire. The philosophy and focus of care may vary greatly between units. Without further study including several units, the responses of these parents from one NICU cannot be assumed to be typical. Lastly, the fact that these parents were members of a volunteer support group may reflect certain personality characteristics. These characteristics may reflect a certain type of coping pattern, such as Newman's "coping through commitment" discussed earlier (1980). A future study of this type could partially control for these variables by offering the questionnaire to all parents near the time of the discharge. A study should ideally include several units to improve the generalizability of the results.

While this initial study was small and limited in scope, some valuable data was obtained. The responses of these parents provided many insights into the parental perspective into this situation. Based upon this information, interventions can be designed and evaluated which will better meet the needs of families with infants in an NICU.

Discussion

There appeared to be several themes which occured throughout this questionnaire. One of these related to the care of parents of an infant which required transport to the NICU. These parents had a unique set of needs which were not being met. A few of these parents mentioned that they would have liked to have been offered the option of being transported along with their infant. Having mother and infant in two separate hospitals placed added pressure upon the father. He had to divide his time between the two hospitals as well as attending to the care of any siblings. It was much more difficult and expensive for these parents to maintain any degree of contact with the staff or even their infant.

It was also expressed by these parents that the visits of veteran parents was a very worthwhile program. Currently, the program at this hospital is not functioning as actively as it once did. Many of these parents did not have access to the group at a time when it would have done the most good. Many of the parents stated that it would have helped to have been able to share their experiences with someone who could truly empathize with what they were feeling at that time. This would appear to be a worthwhile program for the NICU staff to implement for parents.

Many of the parents indicated that they would have appreciated more knowledge about premature and critically ill infants. One mother said, "The unknown and not knowing what to fear is worse than knowing the truth." Having a comfortable knowledge base helps some parents gain a sense of control over the situation. There are others who do not respond in this fashion. Another mother states, "Sometimes ignorance is bliss." This is a point well taken. Staff should determine the degree and amount of information that parents wish to have. Their needs should be respected.

Aside from a few of the environmental characteristics which were more personally related to their infants, parents did not express major problems with this area. One mother stated that she was just tuned into her infant when she was in the unit and hadn't really taken note of what was going on around her. Some of the stimuli helped to provide a sense of reality and normalcy to the environment. One father felt that, "the environment on a whole was calm and not like (one would have) imagined for an ICU." Perhaps this reflects that the parents are not exposed to the stimulation of the unit for prolonged periods as are the staff and infants. It is possible that they are consequently not subject to its detrimental effects. They may also be preoccupied with their own infant and consequently may "shut out" the excess stimulation in order to focus their attention on the resolution of their own personal crisis. While the health hazards described earlier cannot be ignored, it is reassuring that many parents do derive comfort from the environment. Sensitivity on the part of the staff in terms of controlling unnecessary environmental inputs may provide further reassurance.

The use of primary care nursing was a unanimous success in the eyes of these parents. It was reported as having been helpful by all of the parents who had participated in this study. Parents reported feeling that these nurses genuinely cared for their child, and themselves as well. They also felt at ease expressing their concerns and asking questions. It would seem that the parents of infants who had been transported would derive extra benefit from primary care nursing if such care is available. A primary care nurse could provide the extra attention and reassurance that these families appear to need.

In summary, parents reported a wide variety of emotional, somatic, and behavioral responses when faced with a critically ill newborn. The contributions of the environment to the parents levels of comfort and anxiety were discussed. Lastly, measures which helped parents to alleviate fears were presented. In the

following chapter, this information will be integrated with that derived from the literature review. Implications for practice will be presented along with suggestions for future research.

CHAPTER IV

CONCLUSIONS

Implications For Practice

The crisis that parents experience when their infant must be admitted to an intensive care nursery is, indeed, difficult and stressful. This crisis is disruptive to the family system at many levels. It interrupts the normal transactions which occur between parent and infant. It also depletes the family's physical, financial, and emotional resources. As discussed in chapters one and two, there are interventions which can be provided by the NICU staff which can ease this situation for these parents. In the remainder of this thesis, the implications of the literature review and the questionnaire results will be discussed concomitantly. Based upon this final review, possible interventions and research questions will be identified for future study.

The Environment

The NICU environment has rarely been described in a positive fashion in the literature (Gowen, 1979; Falk and Woods, 1973; Miller et al., 1974; Long et al., 1980; Agnostakis et al., 1980; Bess et al., 1979; Kellman, 1982). The noise, the sights, and the hectic pace all contribute to a high stimulation environment. To those who are continually exposed to this environment, as are the patients and staff, definite health hazards exist. In the questionnaire, there were a wide variety of responses to the questions concerning various inputs from the environment. It was interesting to find that several of the parents found the environment reassuring. This reassurance was derived from the fact that these

parents were able to physically see that their infant was receiving "intensive care". Thus, they knew that everything possible was being done for their child. It must be recognized, however, that the parents were retrospectively reporting their responses. This time lapse may have altered these parents' memories and interpretations of these events.

Parents also reported that a sense of normalcy was derived from the "social air" of the unit. Staff and parents routinely chat across the room or over the isolettes. The conversations are, as often as not, unrelated to patient care. This may be a key element in providing the normalcy which many of the parents expressed as comforting. The fact that the staff could be discussing such mundane and everyday topics may have helped the parents to feel that things were not as bad as they thought. On the other hand, such conversations may appear to be callous to parents who are experiencing grief responses.

One final explanation for the discrepancy between the parental responses to, and the literature's descriptions of, the NICU environment is found in Lindemann's discussion of grief responses. Lindemann (1965) describes these grieving persons as being preoccupied and having selective attention. In order to most efficiently deal with the crisis these parents may have unconsciously tuned out the extraneous inputs of the environment.

Kellman (1982) described several adaptations which could provide a safer environment for the patients and staff. At the same time, those characteristics from which parents were able to derive comfort could also be preserved. Some of the major contributors to the excess noise in these units were variables which could be easily controlled by the staff. Included are the volume of conversations and radios, the slamming of doors and diaper pails, and so on (Kellman, 1982; Miller et al., 1974; Woods and Falk, 197 ; Bess et al., 1979; Long et al., 1980). Inservices for the staff as to the problems which result from the excess noise as

well as how noise levels can be controlled is the first step. Bess et al., (1979) reported that this step alone reduced the noise to healthier levels. The American Academy of Pediatrics Committee on Environmental Hazards suggests the periodic measurement of ambient noise with a sound level recorder will serve both to increase staff awareness and help to identify trouble areas (Miller et al., 1974). Kellman (1982) further suggests the use of architectural planning in the design of new units which would incorporate special materials and spatial arrangement to absorb sound waves. Equipment rearrangement was also suggested. An example of this would be moving loud equipment, such as the centrifuge, out of the immediate patient care areas.

Environmental controls must also extend to the visual field as well. Recall that parents responding to the questionnaire perceived certain sights, such as the tubes and equipment on their and other infants, as highly anxiety provoking. One mother responding to the questionnaire still recalled the disturbing sight of all the bruises which resulted from the attempts to insert IVs. (See Table 5.)

There were only a few mentions of the problem of disturbing visual inputs mentioned in the literature. Jacobson (1978) and Astbury and Yu (1982) cited the impact of certain sensory inputs, which included the visual, as a stressor to the nursing staff. Harper, Conception, Sokal, and Sokal (1976) mentioned that the parents involved in their study reported increased anxiety as a result of the sight of other sick babies in the NICU. These parents felt that this increased their concern for their own child.

These studies for the most part mention the effects of sensory impact upon the staff or parents only as a result of research in other areas. What is needed is a thorough study which would assess directly the effects of the sounds and sights of the NICU. Such a study would provide the documentation which is necessary to bring about environmental restructuring to meet the emotional and physical

needs of patients, family, and staff. Pending the results of such research, the NICU staff should use discretion and common sense to alleviate the impact of negative sights in the unit. Invasive or traumatic procedures, such as intubations, exchange transfusions, and codes, should not be done in the presence of parents. Aesthetic measures, such as removing or covering stained linen or clothes, take little time. Some parents reported that seeing their infant dressed helped to relieve some of their anxiety (see Table 7) and made their infant look more like a baby should.

The NICU Staff

The problem of staff burnout in the NICU has been well documented (Astbury and Yu, 1982; Jacobson, 1978; Gribbons and Marshall, 1982; Marshall and Kasman, 1980; Schmidt, 1977; Walker, 1982). In all of these studies, the effects of burnout on the effectiveness of the staff was enumerated. A nurse or physician who is suffering from this "job depression" is apt to lose his/her "creative involvement" with his/her career, and eventually will leave (Marshall and Kasman, 1980). The staff must be responsible for the problem of burnout. In order to ensure that the staff is capable of responding to the emotional needs of the families, routine measures should be instituted to deal with unit problems. Just what these measures should be is another question. Despite the ample documentation of the existence of burnout, there is a paucity of research regarding its treatment and prevention. The measures which will be discussed, therefore, are only suggestions which have been made by several sources. Research will need to accompany these measures to determine their effectiveness. Effectiveness should be made at two levels: on an individual basis and on an administrative level.

A. Unit Orientation

The nursing orientation can be used as the initial point of intervention for staff burnout. Nurses who are new to the NICU have a different set of stressors than do the more experienced nurses. The new nurse is more concerned about skills, knowledge, and competence in this environment (Walker, 1982; Jacobson, 1978; Gribbons and Marshall, 1982). The nurse may also feel uncomfortable in providing comfort and support to the parents at this time due to her inexperience and anxiety (Gribbons and Marshall, 1982). The orientation period can be used to assist the nurse orientee to cope with these problems. In addition to teaching them the skills and knowledge which will be needed in the unit, therapeutic communication skills could also be taught at this time (Sherman, 1982; Gribbons and Marshall, 1982; Schmidt, 1977). Offering crisis theory as part of orientation would provide the orientee with a framework for understanding and empathizing with the parents (Caplan, 1960).

In addition, it is important to help these new nurses anticipate the stresses which they will encounter and to help them develop effective techniques for stress reduction. These methods for personal stress reduction should then be incorporated into a daily routine. Examples of these methods would be meditation, biofeedback, jogging, music, and so on. Such a routine is necessary to help nurses maintain an awareness of their stress levels as well as to actively seek its reduction.

Effective communication skills will play an important role in coping with stress encountered at all levels of the NICU. Teaching communication skills during the orientation period will lay the groundwork for the future by aiding the nurse's ability to confront conflicts as they arise (Gribbons and Marshall, 1982).

The nurse orientee should never be placed in a situation of having to cope with an emergency or new admission on his/her own. This is neither safe for the patient nor the nurse. Utilization of a preceptor is an effective way of developing the orientee's skills to the point where he/she is both capable and comfortable in accepting the full responsibility for a patient's care (Walker, 1982; Schmidt, 1977).

B. Unit Support Groups

Regular, interdisciplinary staff support groups were identified as a potential avenue for dealing with problems leading to burnout (Gribbons and Marshall, 1982; Marshall and Kasman, 1982; Schmidt, 1977; Sherman, 1982). These meetings can be used to discuss specific issues or general topics. Gribbons and Marshall (1982) reported that their group initially was not effectual. Some of the nurses felt that while much was said in these meetings, little was ever actually accomplished. This problem could potentially be overcome by providing structure to these meetings. Having a person who has been trained in group communication skills to lead the discussions may be helpful in providing such structure. A specific agenda which includes problem discussion, problem solving, and the delienation of specific interventions might also help to alleviate frustration resulting from ambiguous solutions.

C. Inservice

As the field of neonatology is changing rapidly, nursing must keep pace to maintain a high quality level of care. Insecurity as a result of the pressure to remain informed was also a frequently cited source of stress for the nurse (Astbury and Yu, 1982; Schmidt, 1977; Jacobson, 1978; Marshall and Kasman, 1982; Gribbons and Marshall, 1982; Frader, 1979). Providing regular inservice

training accessible by all shifts, was suggested by all sources as a means to alleviate such concerns. Inservice training should include new theories, techniques, and technology. Inservices could also be utilized to practice communication skills through role playing and exercises. Stress reduction techniques could also be presented at such sessions (Schmidt, 1977).

D. Staff Liaison Person

There are times when group support mechanisms will not suffice. It was suggested that nurses new to these units as well as nurses with special problems will not derive benefit from group meetings (Gribbons and Marshall, 1982; Cape, 1982). For these circumstances, a special liaison person was suggested as a useful alternative. This person would be an individual with special training in counseling and communication, such as a social worker (Schmidt, 1977), psychiatrist (Sherman, 1982), or a clinical nurse specialist (Cape, 1982). This individual would assist the individual or the group to learn how to effectively cope with the tension of their job and provide support as this task is accomplished.

E. Primary Care Nursing

It has been suggested that a major cause of burnout is an imbalance between the rewards and the negative drains of this system (Schmidt, 1977; Gribbons and Marshall, 1982). Primary care nursing has been cited as a method of nursing care which enhances job satisfaction as well as improves patient and family care (Bresadola, 1977). Recall from the questionnaire results that parents derived a sense of comfort and trust from this mode of care (see page 67). Bresadola suggested that this parent-nurse interaction serves to improve the nurse's morale (1977). The institution of primary care nursing could help to

decrease the problems of burnout in the NICU by allowing for greater autonomy and responsibility. It must be recognized that the primary care situation may become detrimental if the nurse becomes excessively involved or if the family situation becomes too demanding. In these cases, relief from the situation should be sought by the nurse through involvement of a social worker and additional nursing support.

F. Positive Reinforcement

Rewards should be added to the NICU system to provide the staff with recognition for their hard work and dedication. Schmidt (1977) suggested regular rotation of the nurses through the developmental follow-up clinic. This was thought to provide some gratification to the staff by allowing them to see the fruits of their labors. As most infants in the NICU do develop normally, this experience may reaffirm an individual's belief in what is being accomplished. Schmidt (1977) and Gribbons and Marshall (1982) also suggested some form of "ranking", or promotional system, which would recognize the physical, educational, and emotional investment made by the staff nurses. It would also provide a means of identifying the various levels of expertise, which in turn would prevent disparity in expectations from creating problems and stress. Walker (1982) suggested increased financial incentives although, given the current economic crisis of the health care system, this is a less feasible alternative.

Individual staff members also play an important role in the prevention of burnout. Nurse to nurse as well as nurse to physician conflicts are mentioned frequently as stressors to the NICU staff (Jacobson, 1978; Astbury and Yu, 1982; Gribbons and Marshall, 1982; Marshall and Kasman, 1982; Schmidt, 1977). Schmidt describes this phenomena, stating "People tend to scapegoat, to blame

others for what goes wrong, and to engage in backbiting" (1977, p. 39). The staff of the hospital involved with this study devised a "Regular Incident Report", designed in a format similar to the accident reports used in all hospitals. Its purpose was to recognize the staff members for all the positive work that is done by them. These forms are filled out by individuals to thank or compliment other staff members for their work. This measure was designed to accentuate the positive and encourage better staff relations.

G. Supportive Management

The smooth functioning of an NICU is dependent on effective management. It is the function of both nursing and medical management to facilitate the delivery of health care to the infants and their families by ensuring that an optimal physical, psychological, and emotional climate exists to enhance this goal. Gribbons and Marshall (1982) point out that most nurses and physicians do not have training in management skills, but suggest that such training is vital to the smooth functioning of the unit.

H. The Physician

The neonatologist has problems unique to his/her profession. While many of the interventions discussed thus far would also be helpful to these physicians, other initiatives are also necessary. For instance, the competing demands of their personal lives versus the demands of their work was the most frequent source of stress to the neonatologists in the study by Astbury and Yu (1982). These physicians carry the ultimate responsibility for the welfare of the infants in these units twenty-four hours a day. The suggestion of this study for these physicians was to concern "themselves with less urgent pediatrics and ,delegate. to other doctors—for example, to senior registars ,residents." (p. 111). The

difficulty with this suggestion is that, first, it encourages the neonatologist to leave the field, something they may not desire to do. This would serve only to put additional strain on those remaining in the field. It also encourages the shifting of responsibility onto the shoulders of the residents, physicians who are still in training. This is neither safe nor is it in the best interest of the resident physician. Hayden (1982) suggests other measures for these physicians. First, he suggests that priority setting is essential. He states, "A list or, at the very least, a mental ordering of priorities decided upon in times of peace and quiet and forged in the fires of past experience will be of immense benefit when, not if, conflicts arise among needs, wants, and desires" (p. 78).

He also encourages the use of work related resources such as colleagues and nurses. He feels that having confidence in those you work with allows your free time to be unencumbered with concerns for the patients. Lastly, Hayden considered time away from the unit critical to maintaining peace of mind. Goal setting, special hobbies and activities, and time with family and friends were thought by Hayden to be therapeutic . In summary, it was stated, "If he is going to survive for any reasonable period of time and know some job satisfaction, he must know himself and his resources and be willing to use them in a creative fashion." (Hayden, 1982, p. 81).

The above are all reasonable, feasible, and economical interventions for the reduction and prevention of burnout in the NICU staff. A combination of these interventions would, of course, be necessary due to the diverse causes of this problem. Continuing research in this area is essential in order to prevent any compromise in the care of these infants and their families.

Parental Reactions

As seen in both the review of literature and the questionnaire results, parental responses to the crisis of a premature birth or a critically ill newborn

vary greatly (Otto, 1980; Duhamel et al. 1977; Benfield et al. 1978; Prugh, 1953; Caplan, 1960; Caplan et al. 1965). (See Table 1.) The importance of this is not so much to be able to identify what a parent is feeling, but, more importantly, why. It is important to identify the circumstances surrounding the crisis in order to be able to support the parents effectively (Hill, 1965; Rapoport, 1965; Otto, 1980; Caplan, 1960).

Two emotions, or responses, to this crisis should be discussed independently. Guilt was found to be common, both in the literature and in the questionnaire (Duahmel et al. 1977; Caplan et al. 1965; Otto, 1980; Benfield et al. 1978; Prugh, 1953). (See Table 1.) The reported causes of this guilt were quite variable and individual. Due to the frequency with which guilt was found, this is an area which should be explored with each parent. The opportunity to express and work through any feelings of guilt is essential for its resolution (Caplan, 1960; Kennell and Klaus,1982; Sherman, 1982). Anticipatory grief is the other emotion frequently cited which warrants discussion. While the "Grief" response was not chosen by the parents involved with this study, it was interesting to note that many of the responses which were chosen were symptoms of grief reactions (loss of appetite, inability to sleep, preoccupation, guilt and sadness), (Benfield et al. 1978; Lindermann, 1965). It is necessary for those who work with these families to recognize the presence of anticipatory grief. It can be observed that, at times, a parent's response to his/her infant's condition seems disproportional to the severity of the situation. In these situations, the parent is most likely experiencing anticipatory grief. Consequently, they will require a greater degree of intervention than was initially indicated by the status of the infant (Benfield et al. 1978, Harper et al. 1976).

Parent-Infant Transactions

The literature review demonstrated that the preterm infant and the infant who is critically ill will not have the same capacity to transact with their parents as would a healthy, term newborn (Emde, 1981; Als and Brazelton, 1981; Als, Lester, and Brazelton, 1975; Gorski, Davidson, and Brazelton, 1981; Divitto and Goldberg, 1981; Frodi, 1981; Frodi and Lamb, 1978; Goldberg, 1979). This literature has several implications for this study. First, it is critical that parents be aware of the alterations in the infant's behavior. The lack of activity and responsiveness in these infants may cause the parents undue alarm if they are not alerted to its cause and protective functions. Aside from relieving the parental anxiety, such knowledge will also assist the parents in altering their expectations of the infant. In their attempts to elicit social responses from their preterm infant, parents could cause the infant to further withdraw (Field, 1977; Als and Brazelton, 1981; Gorski et al. 1981). This in turn could further frustrate the parent. Education of these parents as to the altered patterns of behavior may help to create more realistic expectations and thus decrease their frustrations. This education should also include how and when stimulation to the infant could be provided to achieve maximum benefit for both parent and child. The Assessment of the Preterm Infants Behavior (APIB), an adaption of the Brazelton Newborn Assessment Scale, might be an excellent tool for such teaching (Als and Brazelton, 1981).

As these infants do not appear to communicate their needs with the same degree of effectiveness as does the term infant, this information should be provided to parents as well (Goldberg, 1979; Frodi and Lamb, 1978; Als et al. 1981; Brazelton, 1973; Divitto and Goldberg, 1981). Such knowledge may also help to offset a certain degree of frustration which may be experienced in their early interactions with the infant.

It was also suggested that the NICU alter the care provided to these infants as well as the environment in which this care is provided. The object of this would be to minimize the stresses to which these infants are exposed (Goldberg, 1978; Goldson, 1981; Gorski et al. 1981; Brazelton, 1981). By decreasing the unnecessary stimulation that the infant must contend with, the infant's condition may improve at a greater rate. The neonate may also have more energy available for social interactions (Brazelton, 1981; Gorski et al. 1981).

Research needs to be continued in this area to further document the altered neuro-organization of the premature infant. The implications of these studies are great, both in terms of parent-infant attachment and neonatal care in general (Brazelton, 1981; Frodi, 1981; Goldberg, 1978, Gorski et al. 1981; Goldberg, 1979). Research also needs to be applied to the effects of educational programs, such as those discussed above.

Extended Family Concerns

Siblings and other significant members of the premature or critically ill newborn's family are also impacted upon by this situation. If family centered care is the goal of neonatal intensive care units, then the needs of the extended family must be addressed as well.

Initially, it was a major concern that the incidence of infection would increase if parents were allowed to have contact with their infants. This was a fear which was not substantiated, however, and parental visitation has become a vital part of the system (Avery, 1981). The same process is now beginning with the extended family. Early research in this area, such as that done by Umphenour (1980), has thus far not documented contraindications to sibling visitations in term nurseries on the basis of bacterial colonization. In order to

change current hospital policies, further research which documents that safety and the desirability of sibling visitation must be completed.

Schwab, Tolbert, Bagnata, and Maisels (1983) took sibling visitation one step further and evaluated its impact in the NICU. While the sample was small, the results indicated that visitation was beneficial to these families and not detrimental to either the infant's or the unit's functioning. Breslin (1977) and Goldson (1981) both advocated the inclusion of the siblings. The Family Care Unit described by Goldson did allow such visitation. No problems were reported as a result.

Data on other extended family visitations was not found. However, it is a more common practice to allow adult visitation than children. This is most certainly an area to be explored further in terms of research and documentation.

Interventions

There were a wide variety of programs discussed in the literature directed toward the emotional and psychological support of the parents . Many of the parents who responded to the questionnaire of this study also had suggestions as to potential interventions. Some suggested interventions were quite simple in nature, while others were more complex. These suggestions will be discussed along with their implications and need for further research and documentation.

A. Attention to Comfort

Green (1979) criticized the care provided in the NICU as being oriented to technology, while ignoring the personal aspects of care. He encouraged attention to the simple things, such as asking a mother how she is recovering, or inquiring if the parents are sleeping and eating well. Often, these mothers have undergone difficult, even dangerous, pregnancies and labors. Green stresses that

they need to ventilate their experiences. Even more importantly, the mothers need to feel that the staff is concerned about them as individuals.

This attention to the parents' comfort and to their needs goes a long way. Recall from the questionnaire responses how parents did indeed focus on "the little things", both positive and negative. How an isolette door was closed, a cheery resident who took the time to talk with them each day, even the wallpaper are examples of how important the attention to details can be to these parents. These "extras" which take little effort can make a significant difference in a parent's comfort level.

B. Communication With Parents

Communication with parents is another basic form of intervention provided by the staff. While it is basic to the care of the parent, it is by no means a simple task.

Effective communication with parents was stressed by Otto (1980), Kennell and Klaus (1982), Breslin (1977), Green (1979), Sherman (1982), and Taylor and Hall (1981), among others. Realistic optimism, explanations at a level the parents can comprehend, and consistency in the information which is provided were cited as essential components of communication with these parents. The establishment of a supportive relationship was considered critical to healthy crisis resolution by the family (Breslin, 1977).

It was also stressed that such communication should be paced to the needs of the parents. Parents may not be ready to assume a total understanding of the problems at hand. Due to the stress that they are experiencing at this time, they may be unable to comprehend such information. Several repetitions may consequently be required (Breslin, 1977; Otto, 1980; Green, 1979; Sherman, 1980; Kennell and Klaus, 1982). This point was also reflected in some of the

questionnaire responses. Recall the response of the one mother who perceived ignorance to be bliss at this time. Green (1979) felt that such denial was a healthy response and should only be considered a problem if it was prolonged.

Ten out of the eleven parents who responded to the questionnaire felt that the information regarding their child was presented in a way that they could understand. One parent felt that it had been too pessimistic and one felt that it had been presented inconsistently by the various staff members. This problem of inconsistent presentation of information might be partially alleviated by the use of a liaison person, as was suggested by Breslin (1977), Otto, (1980), Sherman (1980) and Cape (1982). This person could be a social worker, nurse clinician, or psychiatrist. The role would be one of a consistent contact person whom parents could utilize for both information and its interpretation, and also for support in crisis resolution. This person would in turn communicate to the staff the individual needs of each parent. The liaison person would also be available to take up the slack when staff pressures preclude their direct attention to the family. Psychosocial rounds performed on a regular basis would be an effective avenue for interstaff communications regarding the status of the family.

Parents who responded to the questionnaire in this study indicated that they would have benefited from more supplemental information. (See Table 8.) Films, videotapes, slide presentations as well as better written material were all ideas which parents thought would have been helpful. Weekly meetings are used by some units to provide information and opportunities to ask questions. This was also thought to be a valuable idea by the parents in this study.

C. Primary Care Nursing

The use of primary care nursing in the NICU is an intervention which serves many functions. As has already been discussed, primary care nursing

provides rewards to the nursing staff and improves their morale. It also improves the care of the infant by providing greater consistency. The primary care nurse has a more thorough knowledge of the patient's history (Sugar, 1978; Bresadola, 1977). The parents also derive benefits from the primary care nursing system. This system decreases the number of staff that the parents are exposed to and, as a result, decreases the conflicting information and interpretations they may receive. It also allows them to develop a trust and rapport with one or two of the nurses which provides a greater potential for a helping relationship (Sugar, 1976; Otto, 1980; Bresadola, 1977; Harmon, Glicken, and Good, 1982).

According to the results of the parents polled in this study, primary care nursing was an effective mechanism for decreasing their anxiety. (See page 67.) This was found to be reassuring to them, perhaps allowing them a greater sense of control over the situation. Parents also felt that they were more comfortable in expressing their concerns.

Based upon the various merits of this system of care for patients, family, and staff alike, this would seem to be an effective intervention which could be implemented. Research should accompany the implementation of primary care nursing in order to document its effects and to identify any unforeseen complications.

D. Prenatal Classes

Two of the parents indicated that the introduction of the neonatal intensive care unit during prenatal classes might ameliorate some of the immediate shock of the situation. They felt that if parents were aware of the possibility of complications and of the facilities to handle such complications, they might be better prepared should the situation occur. Breslin (1977) agreed with this viewpoint, stating that this would provide intervention at the earliest

possible point. Harmon, Glicken, and Good (1982) also identified this benefit. They also felt that the prenatal classes could play an important role in "dispelling unrealistic notions about the attachment process" (p. 30). They felt that this might help to alleviate guilt feelings which may arise when the delivery process does not go as anticipated. Hubner (1983) and Dunn (1982) also supported the introduction of regionalized neonatal care during childbirth classes to try to dissipate the shock of such a situation on the parents.

E. Parent Support Groups

Parent support groups were widely reported in the literature (Duhamel et al. 1977; Breslin, 1977; Dammers and Harpin, 1982; Erdman, 1977; Kennell and Klaus, 1982; Mangurten, Slade, and Fitzsimmons, 1979; Minde, Shosenberg, Marton et al. 1980; Otto, 1980). Minde et al., (1980) found that mothers involved in their support group visited more than did the control mothers. Dammers and Harpin (1982) found that such meetings provided the staff with greater insight and sensitivity to the problems of their parents. Minde (1981) describes how the parents of infants in the NICU have difficulty in conceptualizing their own caretaking roles as a result of the altered environment and the altered transactional processes between themselves and their infants. Minde perceived that the use of veteran parent visits was helpful in assisting the new parents define their roles within the context of the NICU.

Questionnaire responses indicated that these parents perceived this to be a valuable intervention. One father stated that the veteran parents could provide the insight, advice, and empathy that could not be equaled by any staff member. It was also indicated that the support of these parents would have been worthwhile not only during the hospitalization, but also at the time surrounding the discharge. (See Tables 7 and 8.)

The benefits of such a program are clear. The veteran parent truly is a valuable resource. However, the development of this type of program must be carefully planned and executed. Issues such as patient confidentiality must be addressed. Problems with parents who are still working through grief and anger surrounding this crisis have been reported (Mangurten et al. 1979). It must also be recognized that this program does not meet the needs of all parents. Some parents may be in need of professional assistance while others may not be ready to face the realities that such meetings would entail (Shosenberg, 1980; Mangurten et al. 1979, Minde et al. 1980; Duhamel et al. 1977).

Such problems are not insurmountable. A referral system or the utilization of parental requests for this service are two possible ways to deal with the confidentiality issues. The veteran parents should be interviewed and screened as suggested by Otto (1980). This will help to identify parents with unresolved issues related to their NICU experience. Special training could be provided to the parent who will be participating in the visitation program. Such a model was used in a similar parent visitation program for first time parents (Boger, 1983). The parent volunteers were given thorough training to prepare them for their supportive and informational roles. The adaptation of Boger's Perinatal Positive Parenting model to the NICU would serve the needs of these parents well. At the same time, its structure and design would prevent the occurence of such problems as described earlier.

F. Room Assignments

The room situation of an NICU mother was cited as problematic by three of the mothers in this study. One mother said that it made her feel guilty being in the room with a mother with a healthy infant. She felt that this also increased her discouragement when she could not hold her infant while the other

mothers on the postpartum unit were holding theirs. Another stated that this situation was very depressing, and at times, unbearable. These mothers suggested being placed in a different unit. They also felt that attempts should be made to assign these women to the same room. They felt this would have allowed them to talk with someone who was in the same situation.

Benfield and his colleagues (1976) recognized the necessity for such flexibility in room assignments. They found that not all mothers desired separate rooms. Some of the mothers in their study found reassurance in being in rooms with healthy babies. They encouraged giving an option to the mother as to which situation would best meet her needs.

G. The Transport

A transported infant is an added stress to the parent. These parents are limited in their ability to see and interact with their infant and the unit staff. Taylor and Hall (1981) found in interviews with parents whose infants had been transported that "their fantasies about the infant's appearance, suffering, and general condition were almost always far worse than reality" (p. 330-331). They also found that these mothers experienced a certain amount of guilt as a result of not being at their child's side during its critical period.

The most obvious answer to this problem is the antenatal referral of both mother and fetus to the perinatal center. This has both physiological and psychological benefits. Antenatal referral decreases the incidence of perinatal morbidity and mortality (Avery, 1981; Taylor and Hall, 1981). It also facilitates communication between the parents and the staff. Parents have greater access to their child. The high risk centers are also more attuned to the special problems, concerns, and needs of the parents and have programs and staff which are geared toward these needs (Taylor and Hall, 1981). The smaller community

hospitals, on the other hand, often are less aware of the needs of these families. Communication between the mother and father and between the parents and the NICU may be impaired as a result of rigid visitation policies (Benfield et al. 1976; Hubner, 1983).

Several of the parents who were affected by transports indicated that there were indeed such problems with the outlying hospitals. One mother reported that she was not allowed to make any long distance calls to the NICU to determine the status of her infant, nor did she ever receive any calls from the baby's physician. Her husband, trying to maintain visits at both hospitals, quickly tired and was unable to remember information to relate to her. Other problems which were described by these parents were financial stresses and an inability to communicate routinely with the NICU staff.

There are many alterations which could be made in this system to alleviate many of these problems. These begin at the time of transport. The transport team should talk with parents and discuss why the transport is necessary and what the immediate plans and prognoses are. Eager (1977) reports the use of a short filmstrip which is shown to the parents while the team is stabilizing the infant. The film shows the parents the NICU, the equipment, and the staff. This was reported to have been successful in allaying some of the fears and anxieties of these parents. Booklets with explanations of unit policies, brief descriptions of the unit, and other pertinent information are also given at this time. Many transport teams have begun to carry a Polaroid camera with them, so that pictures of the infant can be left with these parents. Parents are encouraged to see, touch, and if possible, hold their infant prior to the infant's departure. Positive aspects of the infant's appearance and condition should be identified at this time to provide hope to the parents (Hubner, 1983; Eager, 1977).

If maternal transfer is not a feasible option, other measures have been suggested to improve the communication between the mother and the NICU staff. A nurse or physician should initiate a call to the mother at the referring hospital after the infant is stabilized and then at least daily thereafter. This ensures a stable communication and signals to the parents that the staff is concerned (Hubner, 1983; Taylor and Hall, 1981). Other units have sought to improve communication through the installation of toll-free lines (Benfield et al. 1979) or videophone systems (Hubner, 1983). The benefit of the videophone system is that parents can actually see their infants while they talk with staff.

A primary care nurse should be assigned to all transported infants and their families. This nurse would then become familiar with the special needs of these families. In turn, the individual attention provided by the primary care nurse may increase the families' sense of control over the situation (Harmon, Glicken and Good, 1982).

One transported mother suggested that a veteran parent would have been especially helpful to her. This would not be a difficult task, once a program at the regional center was established. Again, the Perinatal Positive Parenting model would be a useful program for this purpose (Boger, 1983).

Continuing outreach programs to the smaller community hospitals can also do much to improve the care of the parent whose infant requires transfer to the NICU. In addition to providing inservices on the stabilization and care of the sick infant, awareness of the problems encountered by these parents could be stimulated. Flexible visitation policies should be encouraged so that these mothers are not cut off from their support systems, which they so deeply need at this time (Breslin, 1977; Hubner, 1983; Taylor and Hall, 1981).

The return transport of the infant to the community hospital is recommended for both economic and emotional reasons (Jung and Bose, 1983;

Kennell and Klaus, 1982; Hubner, 1983). This eliminates costly travel and long distance phone calls. It also opens up beds in the NICU to be available for the more critical patients (Jung and Bose, 1983). The transition back to the community hospital is not always welcomed by parents, however. Once they have become adjusted to the NICU and its staff, it is difficult to readjust to a new environment. This situation may renew feelings of disequilibrium. It may also cause parents to feel a loss of control and security (Hubner, 1983). For these reasons, parents should be given ample preparation. They should be encouraged to visit the new hospital and become acquainted with the staff (Hubner, 1983). This concept of return transport is relatively new. While it has many positive elements, there are indications that this is not an easy transition for some parents. Their equilibrium is still in the recovery phase from the initial crisis, and their ability to adapt at this time may be impaired. For these reasons, further research is needed in this area. The positive and negative aspects of return transports need to be determined, especially from the perspective of the parents.

H. The Discharge

Some parents view the discharge as yet another crisis that must be faced (Lund and Lefrak, 1982; Cagen and Meier, 1979). In order to lessen the impact of this period, parents should be encouraged to begin participating in the care of their infant early on. This allows them to practice their skills and develop confidence in them. Parents should be allowed to determine their own readiness and pace. Again, the primary care nurse can play an important role. The rapport established with the parents may serve to facilitate their comfort in trying new skills.

The information given to parents in preparation for the discharge should ideally encompass more than just formula preparation and bath demonstration. Premature infants have additional needs unique from those of the term infant. As discussed, they also have altered responses to the environment and to social situations. Awareness of these needs may prevent unnecessary frustration and anxiety on the part of the parents. Just as the Brazelton Newborn Assessment Scale has been utilized to increase parent's awareness of the capabilities of the term infant, so could the Assessment of the Preterm Infant's Behavior Scale be used with the premature and his parents (Brazelton, 1981; Als et al. 1981).

In addition, the parents of a preterm infant need to be informed that their infant will be developing according to the gestational age and not according to the chronological age. This may help to decrease the expectations of these parents and alleviate concerns about delayed development.

Discharge education has been a standard practice in all areas of nursing care. However, it would be helpful to evaluate the inclusion of this additional information in the discharge planning of the NICU staff. It would be important to know if such teaching did, in fact, facilitate the parents' understanding and consequent expectations for their infant.

I. The Family Care Center

The family care center discussed by Goldson (1981) would seem to be an excellent model of care for the entire family. This type of unit is based upon the needs of the infant and the family system and not upon a traditional medical model of care. Most infants do not require intensive care for the entirety of their NICU stay. Many are convalescing and growing during much of their hospitalization. It would seem that, for these infants at least, much benefit could be derived from their removal from an intensive care environment. This

may serve to enhance their recovery and improve their ability to interact with their parents (Brazelton, 1981; Als and Brazelton, 1981; Gorski et al. 1981). It would also allow the family to assume a greater proportion of their infant's care and develop confidence in their caretaking skills. This would help to relieve some of the pressure experienced at the time of discharge. The extended family involvement would provide the parents with their natural support systems. It would decrease the fragmentation of the nuclear family at this time. Siblings would not be isolated from involvement, as they are under current systems (Goldson, 1981).

While not every hospital would have the room or the facilities to develop such a unit, it would seem possible that many of the unique features of Goldson's unit could easily be adapted to almost any NICU. The flexible family visiting policies, the greater involvement of the parents in the caretaking and decision making, and most important, the "normalization" of the environment to enhance the infant's recovery are measures which could be incorporated into current policies. Granted, more research is needed to document the safety and advantages of these steps. Such research is necessary to prevent NICU policies from becoming stagnant and outdated. If neonatal intensive care units are to provide true family centered care, then interventions such as these must be sought for, researched and documented.

SUMMARY

It was the intention of this study to determine the unique needs and concerns of parents who have their newborn admitted to a neonatal intensive care unit. This study was also directed toward determining how the NICU could best meet these needs. Parents arrive at this crisis with widely varied backgrounds, circumstances, resources, and perceptions of the situation. Their individual coping patterns are also variable. The NICU staff must be able to

respond to the uniqueness of each family system with flexibility and sensitivity. The care provided must be adapted to each family's unique needs.

APPENDICES

APPENDIX A

THE COVER LETTERS

Dear NICUF Member,

I hope you are enjoying your summer. It is hard to believe that it is almost half over already!

I was recently approached by Muri Robertson, one of the NICU nurses who is currently working on her master's degree at Michigan State. As explained in her cover letter, she is working on a study which is attempting to explore ways to help parents with premature and ill newborns in the NICU. Enclosed is a questionnaire which is a part of her study. She has asked if we could help by providing feedback by answering these questions. This is strictly voluntary on your part. Your answers will remain confidential. Should you decide to participate, please fill out the questionnaire and return it to Muri in the envelope provided. Due to time constrictions, please try to have it completed and mailed by **July 22. Again, please do not feel obligated. If you have any questions contact Muri at 372-2288. She would be happy to answer any questions you might have.

I hope to see you at the July Meeting!

Sincerely,

**If you receive the questionnaire in time and wish to participate, I will have an envelope addressed and stamped at our July 18th meeting for your convenience in mailing back to Muri.

Mary E. Robertson (Muri)
1327 Edward Street
Lansing, Michigan 48910
(517) 372-2288

Dear NICUF Member:

As I am sure you will agree, having an infant admitted to the Neonatal Intensive Care Unit (NICU) is a stressful and traumatic experience for most parents. While there are some aspects which cannot be changed and made easier for the parent, there are some parts which can. Currently, I am a student at Michigan State University finishing up work on my master's degree. I am involved in a study looking at those components of the NICU experience which can be altered to help decrease the negative impact upon the parent. The results of this study will be used to help find ways to provide parents with extra support during this most important time for themselves and their baby. They will also be used to help plan programs which would try to eliminate some of the unnecessary stresses of the NICU situation.

Your response to this questionnaire will help in this process. It will provide some feedback on some of the ideas that are being looked at. It is important to know how parents like yourself perceived the experience as well as what you felt made the situation better or worse. As everyone responds to this situation differently, it is important to obtain as many opinions as possible. If you have any additional comments or suggestions, these would be most welcome.

While I do hope you will share your responses with us, answering and returning this questionnaire is voluntary on your part. Should you decide to participate, your answers will be kept strictly confidential and anonymous. If you are willing to participate, please fill out the form completely, adding any

comments you might have. Then, simply return it in the enclosed self-addressed envelope. Please do not put your name on the questionnaire.

I believe that this study will help the NICU staff to better meet the needs of parents. Having a newborn in need of NICU care is a scary experience. With greater consciousness and awareness of the needs of parents at this time, perhaps the staff could provide better, more insightful care.

The results of this study will be provided to NICUF upon its completion, hopefully in late August. In the meantime, if you have any questions or suggestions, please feel free to contact me. I would be most willing to try and answer any questions that you might have.

Sincerely,

Muri Robertson, R.N.

APPENDIX B

THE QUESTIONNAIRE

A HEURISTIC STUDY
OF THE IMPACT OF THE CRITICALLY ILL NEONATE
UPON THE PARENT

1. Parents have expressed a variety of emotions in response to having an infant admitted to a Neonatal Intensive Care Unit (NICU). Below are listed some of these responses. Please circle those you feel most closely represent how you felt at the time your child was admitted to the NICU. Feel free to add those not listed.

Anxiety	Fear of Loss	Love
Concern	Apprehension	Hope
Guilt	Depression	Fear of Unknown
Empty	Resentment	Hopelessness
Anger	Failure	"Left Out"
Low Self Esteem	Cheated	Grief
		Other (Please Specify)

2. At this time, did you experience any of the following?

a.	Loss of appetite	Yes No
b.	Increased appetite	Yes No
c.	Inability to sleep	Yes No
d.	Increased irritability	Yes No
e.	Cried easily	Yes No
f.	Mood swings	Yes No
g.	Physical complaints (Headaches, Stomach complaints, etc.)	Yes No
h.	Fatigue	Yes No
i.	Alterations in relationships with family and friends	Yes No
j.	Other (Please Specify)	

3. Please describe briefly how you attempted to cope with the admission of your infant to the NICU. For example, did you try to avoid or deny the situation, talk it over with friends and family or pray?

There are several questions which ask you to give a response based on a continuum. A five point scale is used. Please circle the appropriate number, from 1 to 5, which best describes your response.

1. DIDN'T AFFECT ME
   DIDN'T CAUSE CONCERN
   NOT AT ALL HELPFUL

2. RARELY AFFECTED ME
   RARELY CAUSED CONCERN
   RARELY WAS HELPFUL

3. NEUTRAL

4. OFTEN AFFECTED ME
   OFTEN CAUSED CONCERN
   OFTEN WAS HELPFUL

5. VERY MUCH AFFTECTED ME
   CAUSED MUCH CONCERN
   WAS VERY HELPFUL

4. The NICU environment can be a stressful place in itself. Do you feel that any of the factors listed below affected your anxiety levels? Please circle the appropriate response.

	DIDN'T AFFECT ME		NEUTRAL		VERY MUCH AFFECTED ME
a. SIGHTS					
i. The equipment in the unit.	1	2	3	4	5
ii. Other babies in the unit.	1	2	3	4	5
iii. The activity in the unit.	1	2	3	4	5
iv. Other (Please Specify)	1	2	3	4	5
b. SOUNDS					
i. General noise levels in the rooms	1	2	3	4	5
ii. The alarms	1	2	3	4	5
iii. Conversations of the staff	1	2	3	4	5
iv. The radios in the rooms	1	2	3	4	5
v. Babies crying	1	2	3	4	5
vi. Other (Please Specify)					
c. SPATIAL CHARACTERISTICS					
i. Crowded conditions	1	2	3	4	5
ii. Lack of Privacy	1	2	3	4	5
iii. Number of persons in the rooms	1	2	3	4	5
iv. Other (Please Specify)					

d. Please add in here if there was anything else about the NICU environment that you felt added to your anxiety level. Use the back of this paper, if necessary.

5. Was there anything in the NICU environment that you found comforting or reassuring?

6. What about your baby's appearance caused you the most concern initially? Please circle the appropriate response.

	DIDN'T CAUSE CONCERN		NEUTRAL		CAUSED MUCH CONCERN
a. The baby's size	1	2	3	4	5
b. The tubes and equipment on the baby	1	2	3	4	5
c. The baby's activity level (Too much or too little)	1	2	3	4	5
d. Other (Please Specify)					

7. In general, how would you describe the staff's ability to help decrease your anxiety and make you feel more comfortable?

	NOT AT ALL HELPFUL		NEUTRAL		VERY HELPFUL
a. The neonatologists	1	2	3	4	5
b. The nurses	1	2	3	4	5
c. The social workers	1	2	3	4	5
d. The residents	1	2	3	4	5

8. Regarding the information that you received about your infant's condition, please circle the number by the statement(s) below that you feel apply.
   a. It was presented in a way that I could understand.
   b. It was not presented in a way that I could understand.
   c. It was too pessimistic.
   d. It was too optimistic.
   e. It was often inconsistant due to different interpretations by the various staff members.

9. Did your infant have nurses that routinely cared for him or her? YES NO

a. If yes, did you find this helpful? YES NO

b. Please comment on your answer.

10. Lastly, I would like to ask you a few questions regarding measures that you may have found reassuring. These are somewhat listed in the order which you might have experienced them. Please circle the appropriate response.

	NOT AT ALL HELPFUL		NEUTRAL		VERY HELPFUL
a. Seeing and touching your baby.	1	2	3	4	5
b. Having a picture of your baby.	1	2	3	4	5
c. Seeing your baby in clothes.	1	2	3	4	5
d. Holding your baby.	1	2	3	4	5
e. Bringing in clothes, toys, pictures, for the isolette, etc.	1	2	3	4	5
f. Talking with the staff.	1	2	3	4	5
g. Talking with other parents who had or previously had an infant in the NICU	1	2	3	4	5
h. Actually caring for your infant (feeding, changing, etc.)	1	2	3	4	5
i. Rooming in.	1	2	3	4	5
j. The discharge teaching.	1	2	3	4	5

11. Do you feel that any of the following would have been helpful? (Use the same scale as above).

a. Having "veteran" parents visit you to share their experiences.	1	2	3	4	5
b. Having weekly support meetings on the unit.	1	2	3	4	5

	NOT AT ALL HELPFUL		NEUTRAL		VERY HELPFUL
c. Having slides, video tapes, and better written material explaining the problems of the ill newborn and his family.	1	2	3	4	5
d. Being more involved in the baby's care.	1	2	3	4	5

12. What suggestions could you make that might help to make the situation easier for other parents?

13. Do you have any further comments or suggestions?

Once again, thank you very much for your time and help in this project!

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