ABSTRACT

Title of Dissertation:	AN EXAMINATION OF THE NEEDS OF MOTHERS WITH INFANTS IN THE NEONATAL INTENSIVE CARE UNIT
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This investigation was designed to examine the needs of a diverse group of mothers with infants in an urban hospital's NICU. Forty-six mothers were asked to rate the importance of having various types of needs met while their infants were hospitalized using the NICU Family Needs Inventory. The five need subscales addressed on the inventory are Support (the need for emotional resources needed by the family), Comfort (the need for personal physical comfort), Information (the need to obtain realistic information about the infant), Proximity (the need to remain near the infant), and Assurance (the need to feel confident about the infant's outcome). Overall, while mean differences were relatively small, the participants viewed needs in the area of Assurance as most important and needs in the area of Support as least important to have fulfilled. Various parent and infant characteristic data were also collected and used as predictor variables in a series of multiple regression analyses to determine the degree of their relationships with the needs that mothers viewed as most important to have fulfilled. There was a positive correlation found between mother's annual household income and needs in the area of Support. Infant length of stay was also found to be inversely correlated to mothers' Information needs. In depth discussions about these results are provided, including linkage to Maslow's theory pertaining to the hierarchy of human needs. The findings from this study can be used by providers when interacting with families, as well as during the design and implementation of parent support programs in the NICU. Further investigation of parents' needs with larger samples, including fathers, is needed.

AN EXAMINATION OF THE NEEDS OF MOTHERS WITH INFANTS IN THE NEONATAL INTENSIVE CARE UNIT

by

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Chapter I

Introduction

Neonatal Intensive Care Units (NICUs) around the globe have the enormous responsibility of caring for the most delicate lives that enter this world. “Recent advances in perinatal and neonatal care continue to lead to higher survival rates in newborns” (Cronin, Shapiro, Casiro, & Cheang, 1995, p. 151). A large majority of the progress in improving infant survival has occurred in low birth weight and preterm infants, most likely due to improved technological and procedural developments in obstetrics and neonatology (Alexander, Tompkins, Allen, & Hulsey, 1999). Rais-Bahrami, Short, and Batshaw (2002) define a premature infant as one being born at or before the 37th week of gestation. There are varying degrees of prematurity, with increased risks for complications as gestational age decreases (Horwood, Mogridge, & Darlow, 1998). Infants born too early typically exhibit low birth weights, commonly defined as less than 2,500 grams (Rais-Bahrami et al., 2002; Dammann & Leviton, 1999). Infants are also identified as very low birth weight (less than 1,500 grams), extremely low birth weight (less than 1,000 grams), and micropremie (less than 800 grams). Inclusion in one of these three specific categories carries higher risk for complications as birth weight decreases (Rais-Bahrami et al., 2002). Between 1980 and 2000 in the United States, preterm birth rates increased approximately 12 percent, and in 2003 low birth weight affected about one in every 13 babies born (March of Dimes website, 2006).

While we are now able to save many more of their lives, these fragile infants still face a wide range of possible short and long term complications. Immediate challenges for medical providers in the NICU include regulating body temperature, supplying adequate nutrients, fighting a vast array of infections, battling brain hemorrhages, and providing appropriate ventilation and oxygen. Many of these infants, along with others who have congenital disabilities or intensive medical needs (i.e. exposure to maternal substance abuse), must be treated in a NICU and are immediately considered to be in a "high-risk" category for developmental delays. For instance, a substantial number of researchers warn of the increased risks for cognitive and physical impairments for preterm and low birth weight infants. More specifically, these children have greater chances for developing neurological disorders, such as cerebral palsy, learning disabilities, speech and language impairments, and behavioral problems (Briscoe & Gathercole, 1998; Cherkes-Julkowsi, 1998; Dammann & Leviton, 2000; Horwood et al., 1998; Wolke, 1998; Wood, Marlow, Costeleo, Gibson, & Wilkinson, 2000). Logically, increased survival rates for high-risk infants lead to more children eligible for and entering early intervention programs.

Coping with the fear of immediate, as well as future, complications can be an exhausting task for the parents of these babies. The availability of support is critical as families cope with feelings of shock, grief, and confusion; however, they can be so overwhelmed that they are often unsure of their own needs and do not know how to ask for help from service providers (Lohr, Gontard, & Roth, 2000). Inappropriately responding to a family's needs may lead to yet even more anxiety, fear, and confusion (Ward, 2001). Therefore, understanding each family's unique needs is essential. Since monitoring the development of more and more of these high risk infants is becoming the responsibility of publicly-funded infants and toddlers special education programs governed by Part C, Early Intervention for Infants and Toddlers with Disabilities, of the Individuals with Disabilities Education Improvement Act (Pub. L. No. 108-446), the practice of assessing and incorporating the needs of the child's family in intervention programs is not only best practice, it is mandated.

The rationale for examining the needs of parents with infants in NICU settings stems from four core sources. First, current policies reflect "family-centered practice" in early intervention (IDEA 2004, Pub. L. No. 108-446). Secondly, the concept of neurodevelopmental care in the NICU, an approach that incorporates the idea of family-centeredness, highlights the involvement of parents in an infant's NICU care plan (Als, 1998; Bondurant & Brinkman, 2003; Lester & Tronick, 2004). Third, the theoretical frameworks of child development, on which much of the current legislation regarding family involvement in early intervention programs is based, reinforce the need to examine the child within the context of a family unit (Broderick & Smith, 1979; Bronfenbrenner, 1979, 1995; Hill, 1949; McCubbin & Patterson, 1983). Finally, there has been substantial emphasis in the literature on the role of social support in mediating stress and influencing parenting practices in families of children with special needs, including those hospitalized in the NICU (Able-Boone & Stevens, 1994; Beckman, 1983; Beckman & Pokorni, 1988; Floyd and Gallagher, 1997; Gallagher, Beckman, & Cross, 1983; Holditch-Davis & Miles, 2000; Miles, Wilson, & Docherty, 1999).

It is important to outline the overlapping relationships between, as well as the distinct differences in, the terms "social support" and "family needs". The relationships, interactions, and gestures one person views as supports in a time of need may not necessarily be seen in the same light by another person in the same situation, or even that individual themselves in a different situation or at a different point in time. In addition, a helpful, effective support can quickly turn into an ineffective one under different circumstances, and even into a source of stress itself. For example, a parent may value having a large group of friends available to offer support in a variety of stressful situations, such as caring for a chronically ill child. However, that same large group of friends can also be a source of stress given their potential wide range of opinions on various topics (e.g., childrearing practices).

While we know social support can mediate the effects of stressful life events and can lead to improved family well-being (Beckman, 2002; Beckman, 1996; Beckman, Newcomb, Filer, Brown, & Frank, 1991; Beckman & Pokorni, 1988; Bennett & DeLuca, 1996; Dunst, 2000; Floyd & Gallagher, 1997; Gallagher, Beckman, & Cross, 1983), some confusion exists in the literature. There is a lot of overlap between issues related to supports vs. needs. Neither of these constructs is well defined and each is operationalized in a different way. For example, one of the most widely referenced, traditional usages of the term “social support” is taken from Cobb (1976). Cobb views social support as information exchanged at the interpersonal level that promotes emotional, esteem, and network support. Other authors group their definitions of support into two categories—formal and informal (Beckman, 1983, Dunst, 2000). Informal supports include aid from a spouse, family, and friends, while formal supports come from professionals, community organizations, and other social agencies. Still others have categorized support by types of social interactions, such as spousal, friends and family, parent groups, and professionals (Bennett & DeLuca, 1996; Crnic, Greenberg, & Slough, 1986) and by form (e.g. informational, financial, emotional; Barton, Roman, Fitzgerald, & McKinney, 2002; Brazy, Anderson, Becker, & Becker, 2001). In addition to concentrating on defining and identifying types of support, educators should also focus on examining family needs in an effort to make support services more accurate, effective, and appealing. Unfortunately, literature on the topic of family needs, particularly related to families of children with disabilities and infants in the NICU, is extremely sparse. Therefore, it is an important preliminary step to establish a thorough understanding of the purpose of providing social support in response to family needs, being sure to remember that there is not always a match between what families truly need and the type or amount of support they receive. Needs should drive the support a professional offers. Families should not have to fit into an already existing model of support delivery, for that very model may not match the family's needs or may not logistically fit with the family's life. For example, the meeting time for a parent support group may conflict with a parent's work schedule, children's extracurricular activities, or religious obligations. When working with a family, professionals have the responsibility of matching the family's needs with offered resources. Therefore, it is necessary to take the time to accurately identify those needs and determine how best to provide professional support.

Rationale

In many cases, infants requiring hospitalization in the NICU become part of public early intervention systems. In fact, Maryland's code of regulations for early intervention services views many of the conditions found in infants requiring hospitalization in the NICU to be associated with a "high probability of developmental delay" (Md. Regs. Code tit. 13A § 13.01-2B, 2005). Such conditions include a birth weight of less than 1,200 grams, Grade III and IV intraventricular hemorrhages, severe congenital malformations, inborn errors of metabolism, encephalopathy resulting from trauma to the brain, and withdrawal from exposure to maternal prenatal substance abuse. Infants born with these conditions require immediate care in a NICU setting. Therefore, many of the children cared for in the NICU are often eligible for services provided by local Infants and Toddlers Programs.

Policies Reflecting "Family Centered" Practice

The federal statute that governs services for young children involved in public Infants and Toddlers Programs, known as Part C of the Individuals with Disabilities Education Improvement Act of 2004 (Pub. L. No. 108-446), states that early intervention services should be designed to meet the developmental needs of both the eligible child and his or her family. The law mandates parent-professional collaboration and the development of an Individualized Family Service Plan (IFSP). The IFSP should involve an assessment of family priorities and concerns, and include several specific components that are widely viewed as supportive for families, such as service coordination and interagency collaboration. When evaluating the needs of a family, providers should be cautious to avoid seeming intrusive or judgmental of the family's abilities, and supports should focus directly on the concerns as indicated by the family, how the family views involvement by professionals, and the child's services themselves (Beckman, 1991).

Services for young children with disabilities center around the concept that the child is a part of a family unit (Dunst, 2002). Intervention practices should take into account the family as a whole, as it is expected that services “address the child’s needs in ways that are consistent with the needs of the entire family” (Beckman, 1996, p. 1; Beckman, 2002). Recent legislation governing these services reflects a professional approach known as “family-centered practice”. Family-centered practice is “a combination of beliefs and practices that define particular ways of working with families that are consumer driven and competency enhancing” (Dunst, Johanson, Trivette, & Hamby, 1991, p. 115). The core beliefs of family-centered practice are as follows (Dunst, 2002):

1. Treating families with respect and dignity;
2. Individualized, responsive, and flexible intervention practices;
3. Information shared in a manner that promotes family involvement in the decision-making process;
4. Family choice in regard to practices and interventions;
5. Parent-professional collaboration and partnership as a basis for programming; and
6. Availability and mobilization of supports and resources needed for families to care for their children.

Neurodevelopmental care in the NICU. Similar to family-centered practice in early intervention, the need to address both infant and family psychosocial needs in addition to infant physical needs has also been identified in current medical-based best practices for infants. Recent studies, such as that done by The National Research Council and Institute of Medicine on early brain development and neuroplasticity, which led to the release of their landmark report entitled “From Neurons to Neighborhoods: The Science of Early Childhood Development” (2000), suggest that early newborn experiences, more specifically exposure to stress and the quality of early infant-parent relationships, profoundly affect subsequent brain development. Such findings have pushed for the need to shift care in the NICU from a more reactive to proactive approach (Bondurant & Brinkman, 2003). The approach, known in the medical community as neurodevelopmental care, mirrors the philosophy and standard of family-centered practice in early intervention. It is based on the extensive body of research that places the needs of the infant in the context of the family.

The premise behind neurodevelopmental care is to protect the central nervous system of infants by regulating surrounding auditory, visual, and tactile stimuli in the environment (Aucott, Donohue, Atkins, & Allen, 2002). Other influences, such as features of the baby’s isolette, temperature, nutrition, nursing care, medical interventions, and family involvement can also help support neurological development (Aucott et al., 2002). One of the main goals of neurodevelopmental care is to empower “the family as primary advocates and stakeholders in their baby’s care from the very beginning” (Bondurant & Brinkman, 2003, p. 257). The approach emphasizes the role of the parents as primary caregivers. It advocates for their involvement in decision-making and full participation in daily caregiving activities which have traditionally been performed solely by the NICU’s nursing staff.

Current literature highlights two modern evaluation methods, The Neonatal Individualized Developmental Care and Assessment Program (NIDCAP; Als, 1998) and the NICU Network Neurobehavioral Scale (NNNS; Lester & Tronick, 2004), used to assess the neurodevelopmental needs of infants in the NICU. The techniques are grounded in research regarding the importance of reading infant cues and the involvement of parents in care plans. With the NIDCAP and NNNS, professionals can use direct behavioral observations to formulate developmental plans for parents and caregivers that include “recommendations for ways to support the infant’s physiologic stability, behavioral organization, and developmental progress”, a process that allows the parents and caregivers “to know the baby and learn each baby’s unique responses” (Bondurant & Brinkman, 2003, p. 256). In addition, beyond directly assessing the infant’s needs, the processes require that service providers take into account the participation needs of the parent and his or her level of comfort and competency. Some parents have a strong need to be immediately involved in every aspect of their child’s care, while others prefer to gradually become more involved as they gain more confidence in their ability to care for their baby.

Overall, parent involvement and participation is viewed as an integral part of the neurodevelopmental approach to infant caregiving in the NICU. The philosophy reflects many of the core beliefs of family-centered practice as outlined by Dunst (2002). The conclusions drawn by numerous researchers who have evaluated the efficacy of nuerodevelopmental care indicate significant improvements in developmental outcomes for infants whose providers utilized the assessment and care planning strategies associated with the philosophy (Als et al., 2004; Als, Lawhon, & Brown, 1986; Als, Lawhon, & Duffy, 1994). Therefore, it is gaining considerable attention in both medical and educational communities.

Theoretical Foundations

The movement for family-centeredness in both educational and medical intervention practices stems from a large body of literature associated with various theoretical models related to the influence of family and environment on child development, as well as the role of outside resources, such as social support, on family functioning and adaptation to stress. These theories help to explain the intricate relationships within families and how the experiences of one member can affect all others. They have been used to establish standards for supporting families of all children, including those with or at-risk for disabilities.

Ecological systems perspective. One of the most widely acknowledged frameworks for understanding the needs of families is Bronfenbrenner's (1979) ecological systems theory. Bronfenbrenner initially used this model to explain the relationship between environmental factors and child development. His original model viewed development within the context of nested systems surrounding the child. The microsystem consists of those settings in which the child is a direct participant, such as the family, medical settings, classrooms, and daycare settings. Individuals within this system have direct relationships with the child. Those relationships can be bidirectional, meaning that the individual can influence the child and the child can influence the individual. An example of a bidirectional relationship within the microsystem would be the effect of child temperament on marital or partner relationships, as well as child-parent interactions. A child with a difficult, fussy temperament may cause his or her parents excessive stress and frustration. This can lead to conflicts in a couple's relationship and possibly even harsh or physical disciplining of the child, both of which can influence the child’s well-being.

Interactions between individuals in different settings of the microsystem can also influence the child, and comprise what is referred to as the mesosystem. One important example of such interactions is parent-teacher relationships. For instance, the quality of the relationship between a child’s parent and his or her teacher can influence the parent’s willingness to carry through with educational recommendations at home, which in turn, can influence whether or not the child achieves educational goals. The exosystem involves larger social systems, which do not directly include the child, but can influence the child’s development. For instance, a mother may have a stressful work environment, causing her to come home mentally exhausted or irritable. This may influence how she interacts with her child, ultimately influencing development. Finally, the macrosystem encompasses broader cultural, social and political phenomenon (e.g. federal legislation, cultural values) that have a cascading effect on the other systems in the child’s environment.

More recently, Bronfenbrenner (1995) extended his original model to include a fifth system, which he calls the chronosystem. The chronosystem takes into account the dimension of time, including effects of consistency or change over the course of one’s life. Changes can occur within the developing person (e.g. developmental maturation) or the environment (e.g. parental divorce). The biological changes that occur within a child as he or she moves through various stages of life directly influence development. For example, improved motor coordination from infancy to the toddler years facilitates independent mobility. These changes can be involuntary and follow a natural progression of typical development, or traumatic physical (i.e.

significant illness or injury) and/or environmental (i.e. lack of sensory stimulation due to neglect) events can result in atypical development. The biological influences on child development are particularly relevant when discussing infants born under at-risk conditions, such as prematurity and low birth weight. Numerous researchers have established direct relationships between the physical complications/conditions an infant experiences and his or her subsequent developmental progression (Briscoe & Gathercole, 1998; Cherkes-Julkowsi, 1998; Dammann & Leviton, 2000; Horwood et al., 1998; Wolke, 1998; Wood, et al., 2000). Bronfenbrenner's (1995) recent conceptualization of the model, more commonly referred to as a "bioecological paradigm", also includes the presence of proximal processes, or reciprocal interactions between a parent, child, and other various social influences, such as peers and teachers. These interactions are viewed as essential for establishing healthy psychological functioning; however, if they are to be effective, they must occur regularly and over extended periods of time. In addition, the effectiveness of the proximal processes is also determined by characteristics of both the individual and the environment.

In general, Bronfenbrenner sees the child as a part of the family, as well as a larger social system, and feels that both direct and indirect relationships between structures in immediate and distant environments have powerful influences on the child's development. He believes that if a family experiences chaos and stress, the creation and maintenance of stable relationships and activities between children and parents that are crucial to child development can be interrupted and weakened. The to impact of stress on family functioning and the availability and use of social resources help cope with stress have been expanded in other reputable theories as well.

Family systems perspective. Rooted in the work of prominent family therapist, Salvador Minuchin, Broderick and Smith (1979) proposed a model, known as the Family Systems Theory. Similar to Minuchin, they view the family as a system with a structure that tends to regulate itself under various changing internal and external conditions (Minuchin, 1974). Families function in response to these changing conditions to meet their own unique sets of needs related to affection, self-esteem, spirituality, economics, recreation, socialization, and education (Turnbull & Turnbull, 2005). The model takes into consideration four components: (1) family structure and member characteristics, (2) the interactional styles of family members, (3) how the family functions or adjusts when faced with challenging situations, and (4) the various life stages through which a family cycles.

A family's general characteristics, such as size and form, cultural background, socioeconomic status, and geographic location, as well as the individual characteristics of its members (i.e. characteristics of exceptionality, health issues, coping styles) all influence how family members interact with one another. Relationships within and among four core subsystems of families (marital, parental, sibling, and extended family) can also influence two primary elements of interaction: cohesion and adaptability. Cohesion "refers to family members' close emotional bonding with each other and to the level of independence they feel within the family system" (Turnbull & Turnbull, 2005, p. 43), and cohesion levels can range from enmeshment to disengagement. It is thought that families with balanced cohesion demonstrate more positive outcomes (Dyson, 1993; Gavidia-Payne & Stoneman, 1997). Adaptability is defined as “the family’s ability to change in response to situational and developmental stress” (Turnbull & Turnbull, 2005, p. 44), and the levels of adaptability can be viewed on a continuum ranging from rigid to chaotic. Similar to cohesion, families typically function more efficiently if they maintain a balance between the two extremes of adaptability.

Transitions between major phases in a child’s life (early childhood, childhood, adolescence, and adulthood) can be particularly stressful and require special attention from providers (Turnbull & Turnbull, 2005). Normative transitions, such as the birth of a new baby or sending a child off to college, should be viewed separately from non-normative transitions, such as the death of a child or premature death of a spouse. Certain factors, such as poverty, substance abuse, geographic location, and family health status, can also pose unique stresses for families (Turnbull & Turnbull, 2005). Overall, Broderick and Smith (1979) believe that the family regulates itself in a systematic fashion, via a series of inputs from the environment, including stress and social support, and outputs, the way the family reacts back to its environment.

Family stress theories. More specifically related to stress and family coping is Hill’s (1949) ABC- X model. His examination of the families of wartime soldiers led to the development of the ABC- X model, which has been used as a foundation for understanding family stress and coping strategies. In his model the "A" stands for the provoking event or stressor. Williams and Williams (2005) describe stressors as normative or non-normative, external (originate outside of the family, such as natural disasters or social prejudices) or internal (originate within the family, such as drug abuse or a parent’s job change), volitional (chosen to create growth or avoid negative consequences, such as going to college or accepting a job promotion) or non-volitional (not chosen or sought after, such as being laid-off from a job), and acute (last for a short period of time, such as a brief illness) or chronic (ongoing in nature and more difficult to resolve, such as cancer or poverty). The "B" in the model stands for the resources, supports or strengths that the person or family brings to the stressful situation. These can include material resources (e.g., money, car), knowledge and information, and social support resources (e.g., extended family and community), as well as the coping skills a family uses in the time of crisis. The model’s "C" represents the family’s perception of the event and the way they interpret its impact. Cultural norms and experiences with past difficulties can influence a family’s perception of the crisis. The “A”, “B”, and “C” factors all interact with each other to create the outcome or the degree of stress or crisis, represented as “X” in the model. Two different families may experience the same stressor, but one may never even enter a state of crisis while the second one may be completely overwhelmed (Williams & Williams, 2005).

Once a crisis comes upon a family, its members may become disorganized for a period of time, the length of which is determined by the level of family functioning and the perceived magnitude of the crisis. Families with a variety of resources and supports available to them tend to feel lesser effects from a crisis and their periods of disorganization are typically shorter, thus allowing them to return to a level of functioning at or higher than the pre-crisis level; however, families who lack sufficient resources and supports are more likely to suffer more frequent crises, experience longer periods of disorganization, and are less likely to return to their former functionality (Williams & Williams, 2005). McCubbin and Patterson (1983) extended Hill's model by proposing the Double ABC-X family stress model, which adds an additional component to each factor. Their model views family experiences, including stressors, as cumulative. As new stressful events occur, the family is faced with the task of now dealing with multiple issues, resources, and perceptions about how to handle them (Williams & Williams, 2005). The model suggests that family life changes are additive, and eventually a family may reach a limit at which it can no longer adjust without experiencing some negative consequences (Patterson & McCubbin, 1983). When this maladaptation occurs, the family is increasingly vulnerable to future stressors and is less able to promote family and individual growth (Williams & Williams, 2005).

Summary. These theories all view social support as a main source of information, advice, and guidance for families. Social support is a key component in many of the features of early intervention and NICU programs, such as service coordination, the development of an Individualized Family Service Plan, and neurodevelopmental care plans (i.e. NIDCAP, NNNS). When working with families, prior to offering support, providers must have a solid understanding of what each family members needs and prioritizes related to the child and overall family well-being. Support that does not accurately meet such individualized needs may not only be unhelpful, but may also deter the parent from asking for or accepting support in the future.

Empirical Literature

The individual needs of a family require them to seek and use social supports.

Not all families require the same type or amount of support, as each has its own unique needs to be met (Broderick & Smith, 1979). A large body of literature documents the positive relationship between the amount of social support available to and utilized by families and improved outcomes for those families and their children (Beckman, 2002; Beckman, 1996; Beckman, Newcomb, Filer, Brown, & Frank, 1991; Beckman & Pokorni, 1988; Bennett & DeLuca, 1996; Dunst, 2000; Floyd & Gallagher, 1997; Gallagher et al., 1983). Members of a family's social network, including informal, community, and formal contacts, can serve as core parenting resources, and such relationships have shown to help support child learning and development (Crnic et al., 1986; Darling & Gallagher, 2004; Dunst, 2000; The Infant Health and Development Program, 1990; Koverola, Papas, Pitts, Murtaugh, Black, & Dubowitz, 2005; Parker, Zahr, Cole, & Brecht, 1992; Ross, 1984). This support can be even more important for families of children with disabilities, as they may experience unique stressors, such has having a child with specialized medical, child-care, and educational needs. Many of these families experience high levels of stress, and feel depressed and isolated from the outside world (Beckman, 1983; Gallagher et al., 1983). Increased parental stress levels can have potentially negative effects on family functioning, including "attitudes, life satisfaction, and interactions with the child" (Beckman & Pokorni, 1988, p. 56). High levels of stress in families of children with disabilities appears to be associated with numerous factors, including the nature of the child's disability, child temperament, socioeconomic status (SES), family structure, personality traits of family members, lack of information, and caregiving demands (Beckman, 1983; Floyd and Gallagher,1997; Gallagher et al., 1983).

Similar to trends seen in some families of children with disabilities, high levels of stress have also been reported in parents of infants hospitalized in the NICU (Able-Boone & Stevens, 1994; Holditch-Davis & Miles, 2000; Kersting et al., 2004; Miles et al., 1999). Many of these parents have described feelings of anxiety, worry, guilt, alienation, and ambivalence after the birth of their infants due to fears about the future and lack of confidence in their caregiving abilities. The NICU can be an extremely overwhelming and frightening place for parents, thus requiring the need for special supports (Ward, 2001). Social support has been found to reduce stress and anxiety for many of these parents (Brazy et al., 2001; Miles, Carlson, & Funk, 1996; Miles et al., 1999).

The Problem

In general, the existing literature related to the effects of social support on family well-being is a bit vague in its global definition of the term "support". It is unclear as to whether or not what constitutes "support" to one family is the same for all others. With so many possible types of support available to families (e.g. emotional, information, financial), persons from the same group may or may not share similar needs, priorities, or sources of support (Darling & Gallagher, 2004). When examining family and child characteristics related to support, that distinction can be even more distorted. While there is some evidence to suggest that family needs differ based on certain characteristics, such as socioeconomic status and geographic location, "caution must be exercised to avoid overgeneralizing based on what is reported by groups" (Darling & Gallagher, 2004, p. 106). Specifically, in investigations conducted with parents of infants in the NICU, there does not appear to be significant evidence to support the ability to make a valid hypothesis regarding a relationship between specific parent and child characteristics and the need for various types of support in families experiencing this potentially traumatic event.

More importantly, while several researchers have studied the psychological effects of the NICU experience on parents, and many others have conducted investigations related to sources and availability of social supports that may help these families cope with negative feelings, few have assessed the actual personal needs as identified by the families themselves. Even less is known about those unique needs while babies are still hospitalized in the NICU. The majority of research has been retrospective, requiring families to reflect on their past feelings rather than identifying them in the moment. In addition, very little research has been conducted involving the use of correlational analyses to examine relationships between parent and infant characteristics and parent needs. With the push for family-centered care in modern hospitals, many NICUs are organizing and providing parent support programs for the families of their infants; however, to effectively develop and implement such programs, target needs must first be identified. Those needs can then be more accurately addressed within a program.

Study Objectives

While there is evidence to support the conclusion that the NICU can be a stressful, overwhelming environment for families, and that providing support to these families can have positive effects on child development, little is known about the actual needs parents have while their infants are hospitalized, and whether or not those needs differ in relation to various parent and infant characteristics. The primary purpose of the present study was to identify the needs that mothers feel are most important to have fulfilled while their infants are in the NICU. I also examined the relationships between maternal needs and certain parent and infant characteristics. The responses obtained from the mothers in this investigation are in no way intended to be used for generalizing family needs; however, the results can offer useful insight for practitioners looking to tailor individualized services for this population. The specific research questions related to the study are:

Research Question 1. What needs do mothers of infants in the NICU view as most important to have fulfilled?

Research Question 2. Is there a significant relationship between maternal age, race, educational level, and annual household income and the types of needs mothers view as most important?

Research Question 3. Is there a significant relationship between infant birth weight, gestational age, length of stay in the NICU, and the presence of certain medical conditions associated with high probability of developmental delay and the types of needs mothers view as most important?

Chapter II

Review of the Literature

The core theories outlined in Chapter I emphasize the important role of family and environment on child development. More specifically, they address the impact of stress, both normative and non-normative, on family well-being and the mediating effect that social support can have on such stress. Families with sufficient and effective resources and coping strategies, such as social networks and balanced intrafamilial relationships, are more likely to work through both normal and abnormal stressors without damage to the family's functioning as a whole (Hill, 1949; McCubbin & Patterson, 1983; Williams & Williams, 2005).

Viewing a child in the context of his or her family was not always standard practice in the field of education. Beginning in the late 1960's, researchers started to realize that it was not enough to just study child development in isolation. Despite the use of excellent educational strategies and techniques in schools, many children were still not succeeding, particularly those coming from impoverished homes (Head Start Bureau website, 2006). There had to be other factors beyond the school walls that were influencing how well children did in school. Because of the extensive research conducted by social scientists like Bronfenbrenner (1979), educators came to understand that one of the most influential of those factors is the child's family. Where it had typically only taken place in the fields of psychology and sociology, family studies quickly became an integral part of educational research as well.

Broderick and Smith's (1979) concept of family needs has greatly influenced modern research on families, particularly family involvement in educational programs. In order for anyone to feel like they are part of a true collaborative team, that person must believe that his or her thoughts, opinions, and priorities are valued and respected. In the past, educators would simply plan programs for children based on what they thought would be best for the child. Even worse, the child's needs would more likely than not be determined by conducting an impersonal, standardized test. What the family wanted and needed for their child was not taken into consideration. We now understand that child and family needs go hand in hand. If a family functions as a unit with balanced cohesion and adaptability, and receives the supports required to effectively fulfill their unit's needs, each member, including the child, will benefit more.

Historically, the influence of stress on family functioning and involvement was grossly misunderstood in the field of education. Families who may have been experiencing high levels of stress, which in turn could have led to subsequent crisis, were viewed as dysfunctional and noncompliant (McCubbin, Cauble, Comeau, Patterson, & Needle, 1980). Family stress was considered to be "a deleterious situation to be contrasted with the smooth operation of the family unit"; however, we now understand that, in fact, adversity may actually "facilitate organization and unity" and promote family solidarity (McCubbin et al., 1980, p. 865). The premises behind Hill (1949) and McCubbin and Patterson's (1983) stress models are evident in current literature focusing on families. A family's ability to locate and mobilize accurate, need-based supports can greatly reduce the negative consequences of a stressful event.

The ecological, family systems, and family stress frameworks combine to form a foundation for much of the current research conducted on families and their influence on the developing child. In particular, when examining the body of research literature that exists related to the importance of assessing needs and providing social support to families of children with disabilities, as well as the importance of family-centered care in the NICU, the theories are even more applicable. Reviewing these studies helps develop a better understanding of the benefits that families can reap from receiving accurate need-based support; however, the studies also reveal what can happen if supports are not available at all or if needs are not taken into consideration when planning support services. In this review, studies that have examined the presence of stress in families of children with disabilities are highlighted. Many of those studies also evaluated the sources and availability of social support that may help families cope with stress. I also looked at the stress and support literature pertaining to research conducted specifically with parents of infants who have been hospitalized in the NICU to facilitate a better understanding of how they are affected by the experience.

Search Methods

To gather information related to stress and support in families of children with disabilities and parents of infants in the NICU, I conducted two core electronic and ancestral searches. The first search was for research published between 1980 and 2005 related to stress and support in families of young children with disabilities. The field was kept broad because much of the foundational work in this area was conducted in the early and mid-1980’s. This was a prominent time in the history of early intervention services, as Congress amended the pioneering legislation, “The

Education for All Handicapped Children Act", with P.L. 99-457, which included a new program for infants and toddlers with disabilities. The development of this program, then referred to as Part H of P.L. 99-457, but now recognized as Part C of IDEA 2004, reflected an "urgent and substantial need" to enhance the development of infants and toddlers with disabilities and encouraged states to create and offer services to support these children and their families (National Early Childhood Teacher Assistance Center website, 2005). The electronic databases utilized for this search were ERIC, Education Abstracts, and Exceptional Child Education Resources. Keywords used in generating references included "family", "support", "stress", "special education", "disabilities", "early intervention", and combinations of them all (i.e. "stress and disabilities" and "support and early intervention"). When used in various combinations, searches yielded approximately 50 matches. I then narrowed the search to include only research directly related to young children with or at risk for disabilities. Final results of the electronic search yielded twelve articles.

Similarly, an electronic search for articles published between 1985 and 2005 related to parent involvement, experiences, and support in the NICU was conducted using the following medical-oriented databases, as this topic of research falls primarily in the nursing domain: CINHAL, Medline (EBSCO), and Health Source: Nursing. The search field started with articles as early as 1985 because Heidelise Als and her colleagues began to publish their pioneering work related to neurodevelopmental care in the NICU around that time, which drew considerable attention to the need for a philosophical switch from an infant to family-centered approach. The keywords used in generating references for this search included "family", "parent(s)", "support", "stress", "NICU", and combinations of them all (i.e. "stress and NICU" and "family and support and NICU"). When used in various combinations, searches yielded roughly 35 matches. I then narrowed the search to include only research directly related to families of infants in the NICU. Final results of the electronic search yielded six articles. In addition, I conducted an ancestral search of two prominent neonatal nursing journals. I examined the index of each volume within a five-year period to locate articles on parent support in the NICU. Periodicals included in this search were *Neonatal Network* and *The Journal of Neonatal Nursing*. Two research articles were found via this search method. In total, I used 20 articles for this review.

Stress and Social Support in Families of Children with Disabilities

The impact of disability on the family may cause a variety of reactions that can be dependent upon individual family characteristics (Turnbull & Turnbull, 2001). One such reaction can be stress. Fortunately, providing families with consistent and reliable social support has been found to help mediate stress (Beckman, 2002; Beckman, 1996; Beckman, Newcomb, Filer, Brown, & Frank, 1991; Beckman & Pokorni, 1988; Bennett & DeLuca, 1996; Dunst, 2000; Floyd & Gallagher, 1997; Gallagher et al., 1983). Studies have been conducted with families of young children with or at risk for disabilities looking at stress levels in isolation, as well as in conjunction with the availability of social support to help mediate stress.

Factors associated with stress. Recognizing that not all families of children with disabilities experience the same amount of stress, Beckman (1983) investigated factors associated with high levels of stress by interviewing the mothers of 31 infants with disabilities participating in an early intervention program. The study yielded results supporting the hypothesis that there would be a direct relationship between child characteristics and family stress. Mothers of infants who had more or unusual care demands, were less socially interactive, had difficult temperaments, and displayed more repetitive behaviors reported more perceived stress. Child age and sex were not associated with stress in this study; however, the author warned that the findings may be a function of the restricted age range of the children in the sample (infants from 6.6 to 36.6 months of age). In addition, the fact that the majority of the participants were white and middle class (96.7%) also limits the generalizability of the findings to other populations.

In a related investigation, Floyd and Gallagher (1997) analyzed the data obtained from three subgroups of families of children ages six through adolescence with either mental retardation (n=112), chronic illness (n=73), or non-specified behavior problems (n=46). The authors correlated a variety of parent and child characteristics to parents' reported stress levels and ratings for utilization of services in four categories: mental health, health, recreation, and other community services. They found significant parent gender differences, with mothers reporting more caregiving demands and higher levels of stress than fathers. While family stress did not differ across child age ranges, similar to Beckman (1983), the type of disability and the presence of child behavior problems were important predictors of parental stress and care demands. Parents of children with mental retardation and parents of children with problematic behaviors reported more stressful worries. In addition, single parent families and families of children with behavior problems more often sought and utilized the support services available to them. Overall, the authors concluded that families of children with disabilities in this study were coping well, indicating the "presence of disability is not necessarily associated with poor family well-being or family dysfunction" (p. 370). This supports the idea that not all families of children with disabilities are overly stressed, and that the child's disability can be a catalyst for intense strength-building and intimacy among family members. The authors noted that the findings of this study may be restricted due to the limited age range of the children involved.

Beckman and Pokorni (1988) conducted a longitudinal study of 44 families of infants born premature and at low birth weights, therefore at-risk for developmental disabilities. They investigated changes in stress and support over time as reported by primary caregivers, which in all cases were the infants' mothers. The authors reported that family stress did indeed change over time, and such changes were directly related to changes in child-related problems, characteristics of the home environment, and the availability of informal social support. Results indicated a direct relationship between decreases in child-related problems from 3 to 12 months of age (more specifically with temperament and physical incapacitation) and family stress. More and unusual child-related caregiving demands, and less organized and responsive home environments were also associated with increased levels of family stress. In addition, while there was no relationship found between the availability of formal support and family stress, there was a direct negative correlation between stress and informal social supports. Specifically, families with more informal social support reported less stress, and "in some instances, more social support at one age was associated with decreased family stress at subsequent ages" (p. 62). Noncaucasian, families of households with lower SES, and parents with more children also consistently reported higher levels of stress; however, these relationships may be limited by the fact that the majority of the participating families were from white, two-parent, and middle class households.

As a whole, families of children with and at-risk for disabilities may or may not experience increased levels of stress when compared to families of children without disabilities. Stress levels can change over time and appear to be associated with numerous factors, including the nature of the child's disability, child temperament, SES, family structure, personality traits of family members, lack of information, and caregiving demands (Beckman, 1983; Beckman, 2002; Beckman & Pokorni, 1988; Floyd and Gallagher, 1997; Gallagher et al., 1983). With an understanding of what factors can be associated with high levels of stress in families of children with disabilities, I will now focus on identifying the sources and availability of social support for these families and its mediating effect on stress.

Social support. Family coping studies highlight interpersonal relationships as a distinct variable associated with the management of stress (McCubbin, 1979). The strength of such relationships has been found to be inversely correlated to family vulnerability and positively correlated to family regenerative power (McCubbin, 1979). This phenomenon has been evidenced in a variety of situations, such as psychiatric and physical illness, death, job termination, pregnancy and childbirth, physical and mental abuse, and poverty. A personal social network, such as family members, friends, self-run parent groups, and support from professionals, has been identified as the “primary coping resource” for families (Bennett & DeLuca, 1996, p. 32). Research conducted with families of children with disabilities highlights the importance of social support as a mediator of stress. Several studies have focused on the social networks available to and used by families and the effect of received support on family well-being.

Dunst et al. (1986) reported “complex relationships between social support and personal, family, and child outcomes” (p. 413) in their investigation involving 137 parents of preschool children with mental retardation, physical impairments, or who were at-risk for other disabilities enrolled in an early intervention program. The families of these young children with developmental delays reported increased levels of stress and child behavior problems when there was a lack of social support. Families who reported higher levels of satisfaction with their available supports also reported less physical and emotional problems, and families with higher incomes were more likely to report positive attitudes about their available supports. Children from families of high SES who reported supportive social networks made more between-measurement gains in cognitive development than children from families of low SES with limited reported supports. In addition, there was a direct positive correlation between the presence of supportive social networks and feelings of integration and acceptance into the community in families of children with more significant developmental delays. In general, the researchers concluded that social support has a powerful mediating effect on stress, personal well-being and parental attitudes toward their children, as well as direct effects on parent-child interactions and child developmental outcomes; however, they cautioned that the analysis of covariance (ANCOVA) method used to assess the effects of social support may have "discerned the unique and nonshared variance accounted for in the dependent measures" (p. 413).

Beckman et al. (1991) used quantitative and qualitative methods to examine the effects of Project Assist, a program designed to support families of young children receiving special education services through a suburban infants and toddlers program. The project included 52 families involved in varying combinations of group, individual, and follow-up support. Group and individual support sessions were conducted for a period of 12 weeks, and included both emotional and informational support. Follow-up support activities after the initial 12-weeks were geared more toward social activities, and membership and attendance was more fluid. Findings from surveys completed by 25 families after participation indicated high levels of satisfaction with the individual and group components and increased feelings of support from professionals. The researchers also subjectively evaluated family stress levels, and while finding no significant decrease, there was considerable variability, which, after informal discussion with families, was later attributed to secondary circumstances (e.g., death of a child). In post-participation interviews, parents described reduced feelings of isolation, a sense of empowerment, increased feeling of support from other parents, and senses of helping, safety, and acceptance. While the majority of the program's participants were African American (51.9%), findings may be limited because most were single mothers (approximately 75%). The effects of such support may not necessarily be the same for married parents and the results may not apply to other ethnic groups.

In a related exploratory study, Bennett and DeLuca (1996) interviewed 12 parents of children with disabilities ages 15 months to 30 years regarding their use of three social networks—friends and family, parent groups, and professionals. Parents in this study described friends and family as strong sources of emotional support, especially when they were feeling troubled or frustrated. Parents were particularly grateful for friends and family who took the time to learn about their child's disability and treated their child like any other. Eight of the 12 parents belonged to some type of parent support group. For these parents, the groups served as safe arenas for expressing frustrations and feelings in the company of other parents who were experiencing the same issues. They also found the groups to be beneficial resources for obtaining current disability-related information. Finally, parents valued professionals for their expertise in educational practices. They especially praised professionals who communicated effectively with them, truly listened to their concerns, and were flexible with their approaches. While the study's findings offer useful information for providers and stress an empowering and proactive approach for building partnerships with families, again, the results are limited by sample homogeneity. Ninety-two percent of the parents were Caucasian, 83% were from middle to upper-middle class households, and 83% were married.

Similarly, Darling and Gallagher (2004) compared the needs and sources of supports for Caucasian and African American mothers of young children with disabilities living in both urban and rural areas of Georgia. The 120 mothers involved in the study were asked to complete standardized self-reported measures. Then, ANOVA and MANOVA statistical procedures were used to compare their responses.

The authors found that mothers differed significantly by race for various types of needs, but not support. They also differed by location for sources of support, but not needs. African American mothers living in urban areas reported higher levels of need for personal and family growth on the *Family Needs Scale* (Dunst, Copper, Weeldreyer, Snyder, & Chase, 1987) and Caucasian mothers in rural areas reported higher levels of spousal/partner support on the *Family Support Scale* (Dunst, Jenskins, & Trivette, 1986) than did all other groups. The analyses also revealed an inverse relationship between family need and family support. Those mothers who reported a lot of needs also reported that they did not receive much support in addressing those needs, while those who reported fewer needs said that they received sufficient support. The authors suggest that "perhaps the receipt of support reduces the need for resources" (Darling & Gallagher, 2004, p. 105). A limitation of this study identified by the authors is the issue of representativeness of the sample. Participants were recruited by early intervention staff members. So, it is cautioned that the staff members may have approached only the caregivers whom they thought would be cooperative and would readily participate.

In general, the availability of social support can have beneficial effects and may mediate the stress associated with parenting a child with disabilities (Beckman et al., 1991; Bennett & DeLuca, 1996; Dunst et al., 1986). Strong social networks, including family, friends, and compassionate professionals, are critical resources for families coping with frustrations and difficult emotions (Bennett & DeLuca, 1996). There is also evidence to support the conclusion that needs and sources of support can both change over time and vary based on family characteristics, such as ethnicity and geographic location (Beckman & Pokorni, 1988; Darling & Gallagher, 2004). By being sensitive, respectful, and taking the time to truly listen to families, professionals can enhance their relationships with families and make positive contributions to social support networks. Providers should constantly monitor and pay close attention to a family's direct and subtle requests for support, as their needs can change frequently and abruptly. Family needs assessments should be on-going and providers should modify supports in response to changes in needs (Beckman & Pokorni, 1988). Because of this, there is no one formula for predicting what supports a family will need; however, it is essential for all individuals involved in a child's life, including parents and providers, to have a thorough conceptual understanding of the importance of social support as it has been found to be associated with child developmental outcomes.

Influence of social support on child development. One of the most important reasons to examine the effects of social support on family well-being is because it has been found to positively affect parenting practices, which in turn influences child development (Dunst et al., 1986). Supporting parents can help define parenting styles and promote instructional practices and opportunities that are most likely to have enhancing effects on development (Dunst, 2000). More specifically, numerous studies focusing on young children at-risk for disabilities, such as those born prematurely and/or at low birth weights (who typically require hospitalization in the NICU) or children living in impoverished homes, have been conducted to examine the effect that providing social support to parents has on child development.

Koverola et al. (2005) examined the influence of social support on child outcomes in their longitudinal investigation of the relationship between a variety of maternal factors and child development in a sample of 203 mother-child dyads from low-income households. Objective (standardized assessments of cognitive and academic functioning) and subjective (parent, teacher, and child self-report measures) data were collected over a four-year period of time, from when the children were 4 to 8 years of age. A series of multivariable regression analyses revealed that increased levels of poverty were associated with more maternal depressive symptoms and lower socialization, academic, and cognitive development in children. Mothers with a history of childhood physical and/or sexual victimization had more depressive symptoms and less social support. The authors attributed this lack of support to the mothers' tendencies to be socially isolated as a result of their depression. This lack of social support was also related to increased externalizing behavior problems and decreased socialization skills in their children, which is understandable since an isolated family environment could also limit the child's opportunities for social experiences necessary to foster healthy interpersonal skills. The authors conclude that there is "a suggestive effect of the role of social support as a mediator between maternal victimization" and the development of behavioral and social problems in children (Koverola et al., 2005, p. 1535). As noted by the authors, while the socioeconomic (70% of the mothers were single and 77% were receiving Aid to Families with Dependent Children) and ethnic (96.1% African American) homogeneity of the study's participant sample may limit the generalizability of these findings, the implications of this study highlight the possibility that some children may be at greater risk for negative outcomes because of their mothers' victimization histories, mental health statuses, and existing social support networks.

Crnic et al. (1986) studied preterm infants and their mothers, assessing various outcomes, including attachment, mother-infant interactions, infant cognitive and language development, home environment, stress, and sources of support. The authors focused on four main categories of social support: intimate (e.g. spouse, family member), friendships, community and professionals, and total combined support. Results revealed that intimate support was the most influential predictor of mother-infant interactions and friendship support was directly related to infant developmental outcomes. In addition, concurrent levels of perceived professional support were positively associated with the quality of the home environment, infant temperament, and maternal parenting satisfaction. More specifically, the authors found that increased levels of maternal stress at 1 month were powerfully correlated to less positive maternal affect, less infant compliance, and less secure infant attachment at 12 months. The authors concluded that "maternal social support during early postnatal crises associated with prematurity has lasting and important influences on infant development, as well as parenting" (p. 31). Homogeneity of the sample and attrition are limitations associated with this study. Ninety percent of the participants were Caucasian and 94% were from two parent households. In addition, the investigation began with 52 participants, and concluded with only 36 at the 12-month measurement period. This altered the original composition of the target group, which can have "significant effects on the results of" a study (Gay & Airasian, 2003, p. 362). In addition, the authors cautioned that the data did not indicate whether the revealed relationships were direct or indirect, and that effects could have also been mediated through other factors, such as maternal attitudes and interactive behaviors, not measured in the study, rather than only by the mother's direct social network.

The Infant Health and Development Program (1990) was designed to evaluate the efficacy of a early intervention program, including an infant directed curriculum and parent support components, in reducing developmental delays and health problems in low birth weight infants. The multi-site, randomized investigation involved 985 infants and their parents. The experimental program, initiated upon discharge from the NICU and continuing through 36 months of age, corrected for prematurity (corrected age = chronological age – weeks of prematurity), included: (1) biweekly home visits providing health and developmental information, the implementation of two specific curricula emphasizing cognitive, linguistic, and social development via games and activities for parents to do with their children, and parent support; (2) child attendance from the age of 12 to 36 months at an early childhood development center five days per week (including transportation); and (3) bimonthly parent group meetings, providing informational and social support. At 36 months corrected age, when compared to infants with similar birth characteristics who did not participate in the program, the infants in the intervention group displayed significantly higher mean intelligence quotient (IQ) scores and fewer maternally reported behavior problems. The investigators noted a variety of potential confounding variables that may have influenced the findings of their study, including reporting bias on maternal-based scales, child exposure to test items or similar materials during the course of the direct instruction, and the fact that 30% of the also control group entered a community daycare program by the age of 3 in which they participated in child development activities.

Similarly, the researchers behind a NICU-based intervention also reported a variety of favorable changes in outcomes within their treatment group. Parker et al. (1992) found increased infant cognitive and motor performance, and improved home environment ratings in a group of 26 preterm infant-mother dyads with low socioeconomic status that completed a program involving weekly sessions until discharge with an infant developmental specialist (an average of 4 sessions total per dyad). The specialist provided each mother with individualized care recommendations based on structured developmental and behavioral assessments of their infants. The authors also reported that mothers in the experimental group rated their infants as less dull and less fussy at the ages of 4 and 8 months, respectively. There were, however, no reported differences in maternal-infant interactions as a result of the intervention. Since the follow-up assessments were limited to 8 months, the authors cautioned that “the duration of beneficial effects is not clear” (p. 784).

After the implementation of a year-long home-based intervention with 40 low-income preterm infants and their mothers, Ross (1984) reported increases in infant cognitive scores and improved home environment ratings, but no differences between the experimental and control groups in infant temperament, maternal attitudes, and neurological qualities. The intervention program required that a nurse and pediatric occupational therapist visit each child’s home twice a month for the first three months after discharge from the NICU, then monthly thereafter until the child reached 12 months adjusted age. Intervention focused on teaching mothers about infant development and caretaking, as well as instructing mothers on how to engage in games and activities with their babies that would encourage cognitive, motor, and social development. However, the author noted that “the emotional support provided by regular and continuous visits throughout the first year of the infant’s life in and of itself may have enhanced maternal behavior and home environment which, in turn, may have improved the infant’s mental development and mother’s perception of her infant’s temperament characteristics” (p. 268).

Summary. An understanding of the relationship between family stress and child outcomes serves as a foundation for individualized intervention program planning. A component of that planning should also include an examination of the family’s needs, and the availability of and satisfaction with social supports (Darling & Gallagher, 2004). Assessing a family’s needs and the presence and strength of their social support network is crucial, as it has been shown to have a positive impact on a variety of parent and child outcomes, including maternal stress levels and child cognitive and behavioral functioning (Beckman & Pokorni, 1988; Dunst et al., 1986; Crnic et al., 1986; The Infant Health and Development Program, 1990; Koverola et al., 2005; Parker et al., 1992; Ross, 1984). Given that families of infants hospitalized in the NICU can be viewed as a unique subgroup within the larger population of families of children with special needs, numerous studies have also been conducted to further examine the potential stress related to the NICU experience and the influence of available sources of support on well-being.

Stress and Social Support in Families of Infants in the NICU

“The initial crisis of admission to the NICU can be overwhelming for families” and “parents usually have the greatest stress from not being able to assume their role in the NICU" (McGrath, 2001, p. 79). The wires and tubes attached to their babies can be great sources of anxiety and uncertainty for parents, and unfortunately, they are still seen by many professionals "as intruders into this highly technical environment, a view that does not foster family growth and support" (McGrath, 2001, p. 75). Mothers and fathers have reported feeling as though they were parenting from a distance (Higgins & Dullow, 2003). In the past, parents were more observers than participators. Traditional care was infant-centered, and focused solely on stabilizing and improving the status of the infant's various physiological systems. Parents were not encouraged or made to feel competent about participating in caregiving activities. Tasks, such as feeding, performing routine medical procedures (e.g., cleaning and changing gastrointestinal feeding tubes, facilitating oxygen treatments), diapering, and bedding and clothing changes, were the sole responsibility of the NICU nurses. Several researchers have investigated the psychological impact of an infant's hospitalization in the NICU on his or her parent(s), as well as the role of social support in helping parents to cope with the experience. Table 1 summarizes the characteristics of the participants and babies associated with the studies presented in this review related to stress and support for parents of infants in the NICU.

Parent stress associated with the NICU experience. Examining the NICU experience in the context of The Preterm Parental Distress Model (Miles, Funk, & Kasper, 1991), a framework that takes into account pre-existing and concurrent factors as attributors to stress levels experienced by families with infants in the NICU, was the premise behind a study conducted by Holditch-Davis and Miles (2000). Mothers of 31 preterm infants were interviewed when their infants were six months

Table 1.

Summary of Reviewed Studies Involving Parents of Infants in the NICU

Study	Total N	N mothers/ Mean age	N fathers/ Mean age	% Married	Race of majority	Infant in NICU at time of study?	Reported infant health condition?
Able-Boone & Stevens, 1994	60	30/*NR	30/NR	100	White (100%)	No	No
Barton et al., 2002	31	31/24.6 years	n/a	6.5	African Amer. (100%)	No	No
Brazy et al., 2001	19	15/30 years	4/NR	73	White (92%)	No	No
Holditch-Davis & Miles, 2000	31	31/29.1 years	n/a	80.6	White (62%)	Yes	Yes
Kersting et al., 2004	50	50/NR	n/a	NR	NR	Yes	Yes
Miles et al., 1996	T1-158 T2-89	T1-98/NR T2-51/NR Combined Mean Age = 28	T1- 60/NR T2- 38/NR	86	White (86%)	Yes	Yes
Miles et al., 1999	19	19/28 years	n/a	42	African Amer. (100%)	No	Yes
Ward, 2001	52	14 Combined Mean Age = 28	10	27	White (29%)	Yes	Yes

Note. NR = Not reported; T1 = Time 1; T2 = Time 2.

of age corrected. The authors found one pre-existing factor to be “particularly salient” (p. 15). Mothers who had prior experience related to illness and death in their families seemed to describe more feelings of distress than mothers who had not had such experiences. Factors mothers revealed to be distressing were having to share parental roles, the inability to perform expected caregiving activities (i.e. holding, feeding, bathing), seeing their babies surrounded by medical equipment and tubes in the NICU, and having to deal with the appearance of a small, sick baby. One mother provided a description about the first time she saw her baby in the NICU.

> “When I got there, I felt very queasy. I had to sit down. I had to get my head between my knees. I wasn’t prepared for what I was going to see. And I noticed that the other moms were having the same reaction. One lady hit the floor! She walked in there, and boom, she was down there on the floor. Part of it was that we had just given birth; we’re weak. You walk in there and then this is what you see. I don’t know if you can ever be prepared for what you’re about to see or about to feel” (p. 17-18).

Able-Boone and Stevens (1994) used mixed-methods to examine sources of stress and support for 30 intact families (mothers and fathers) with young children, ages 1 to 3.5 years, who had previously spent time in the NICU. Half of the parents had children who were receiving early intervention services on the basis of a diagnosed disability. Standardized scales were used to assess anxiety and sources of support. High parent stress levels were largely related to being separated from their babies while in the NICU and seeing their babies in pain. In regards to support resources, the parents in this study viewed their NICU nurses and extended family members as core sources of caregiving and domestic support. Families of children with disabilities reported relying on professionals and professional groups for support more often than families of children without disabilities. In-depth interviews revealed that while all families were coping “fairly successfully” (p. 111) with their children’s daily needs and noted positive contributions their children had made to their lives, the parents of children with disabilities shared more negative experiences, primarily related to medical and diagnostic issues. More specifically, they reported feelings of isolation attributed to the massive amount of time and energy required to care for their children’s specialized medical needs, strains on family finances due to rigid requirements for receiving public support, and restrictions on career opportunities (especially for mothers). Overall though, both families of children with and without disabilities reported realizing “a renewed sense of values and belief concerning family and children due to their child’s medical crises and/or disability” (p.111). Unfortunately, homogeneity of the participant sample is also an issue with this study. One hundred percent of the parents were from two parent, Caucasian families.

In a descriptive study conducted by Miles, Wilson, and Docherty (1999), 19 African American mothers with either premature or full-term infants hospitalized at birth for serious health problems shared their opinions about their past NICU experiences via both standardized questionnaires and qualitative interviews (interviews were conducted with 15 of the 19 mothers). Scores taken from standardized self-reported scales measuring stress and anxiety revealed significant worries about when their babies could go home, whether or not their babies would have to be re-hospitalized, and fears about “normal” development (p. 20). In addition, an analysis of the performed interviews revealed four major themes: “(1) responding to the situation, (2) finding hope, (3) establishing a relationship with the infant, and

(4) seeking support" (p. 20). Mothers described feelings of shock upon seeing their babies for the first time, fears about future outcomes, hopefulness that their babies would survive, and fear of difficulty in bonding with their babies. Mothers found the support they received from NICU staff, as well as the positive responses they got from their babies during interactions (i.e. increases in oxygen saturation levels and heart rates, indicating excitement), to positively influence their adjustment to the situation and assist them in developing their maternal roles. The authors noted small sample size and the retrospective nature of the inquiry as limitations of this study; however, it is unique being that it focuses solely on the experiences of African American mothers living in a rural state.

Kersting et al. (2004) also studied maternal stress in 50 mothers after the birth of their VLBW infants who were hospitalized in the NICU. Data were collected at four measuring points: (1) 1-3 days after delivery, (2) 14 days after birth, (3) 6 months after birth, and (4) 14 months after birth. At 14 days, as well as 14 months, after the birth of their children, mothers of VLBW infants reported more trauma-related symptoms (e.g., avoidance, intrusion, hyperarousal) and higher rates of depression and anxiety than did mothers of healthy term infants. The authors suggested that one explanation for these findings "might be that, in contrast to a single traumatic event, the birth of a VLBW infant is a complex, longer lasting traumatic event. Thus, a mother's concerns for her child's health and her fear that her baby's development will be impaired, or at least, delayed, are frequently not confined to the postpartum period but may persist for weeks or months in terms of sustained retraumatisation" (p. 475). A confounding variable discussed by the authors is the fact that mothers of VLBW infants in this sample had more high-risk pregnancies, posing the possibility that preterm maternal disorders and other stressors might have influenced their posttraumatic stress responses. The authors also did not account for the varying number of multiple births in the sample, thus leading to potential "distortion of results" (p. 476) given that mothers with two or more infants may experience more stress than mothers of singleton births.

To summarize, the "birth of a preterm or critically ill infant can be a particularly difficult time for parents in making the transition to parenthood, and support may be even more important" (Miles et al., 1999, p. 45). Research shows that parents of infants hospitalized in the NICU tend to exhibit higher levels of stress, anxiety, and depression than parents of healthy, full term infants (Kersting et al., 2004). Factors that may contribute to parental distress include an unfamiliar and highly technological environment, the appearance of a fragile, sick baby, fear for the baby's survival, fear about future developmental functioning, separation from their baby, and difficulties communicating with NICU staff (Able-Boone & Stevens, 1994; Miles et. al., 1999). Given what we know about the psychological effects of the NICU experience on parents, the importance of providing support to families of infants in the NICU has gained considerable attention from service providers in both educational and medical communities. Therefore, it is also crucial to highlight those studies that have examined the sources and availability of social supports that may help parents during this difficult time.

Supporting families of infants in the NICU. Miles, Carlson, and Funk (1996) surveyed 37 mother-father dyads of critically ill infants about their perceptions of the helpfulness of formal and informal social supports available to them at two different points while their infants were in the NICU (one week after admission and then again one week later). The authors found that opinions changed over time and varied between mothers and fathers. Upon admission to the NICU, both mothers and fathers found each other to be the most important source of support; however, mothers ranked their own parents as the second most important, NICU nurses as third, and NICU doctors as fourth, while fathers found NICU nurses to be the second highest source of support, followed by fathers' parents, then NICU doctors. At the time of the second interview, approximately two weeks after each infant's admission to the NICU, parents continued to view each other as the highest source of support, and also both agreed that the NICU nurses were of second most importance; however, findings suggested that fathers' views of support change over time much differently than those of mothers. Fathers rated overall levels of support much lower during the second week of their babies' hospitalizations, whereas mothers' support scores rose during that time. The authors suggested a possible explanation for this is that "during the early days after admission, when the mother is still recovering from delivery and may even be at a different hospital from the baby, the father may receive more support than the mother does as he plays a major role in communicating with the NICU health care team and the family" (p. 50). Then, when mothers are well enough to become more involved, and fathers may need to become less involved (e.g., have to return to work), mothers may receive more support. Given that specific types of support (i.e. informational, emotional, esteem, tangible assistance) were not identified on the survey used to measure opinions, the authors cautioned that the tool may not have accurately reflected the entire social network available to parents.

Barton et al. (2002) examined the availability and use of support networks and community services in low-income, African American mothers of preterm infants previously hospitalized in the NICU. Participating mothers identified their network members and the level to which they were satisfied with the support received from those members, as well as their knowledge and use of community support services in 14 areas: drug counseling, prenatal care, child medical care, adult medical care, employment, child care, continuing education, abuse, parenting support, assistance with paying bills, appliances and furniture, and emergency housing, food, and money. Similar to other findings from investigations surrounding sources of support for families of children with and without disabilities, such as Bennett and DeLuca (1996) and Dunst et al. (1986), results indicated that core support networks were comprised of informal sources, such as boyfriends/spouses, personal friends, neighbors, and family. Knowledge and use of formal services varied, with most mothers knowing where to go for medical care and material support for themselves and their children, but very few knowing where to go for formal guidance/informational parenting support. In fact, only one mother reported the involvement of such support in her social network. Unfortunately, only half of those who knew where to find parenting support had actually utilized that service at any time in their lives. Overall, the authors found that mothers in this study "were relatively isolated and often did not have either informal or formal community networks to offer broad-based support in response to parenting challenges and concerns" (p. 289). This theme of isolation is consistent with other research on parents of infants in the NICU and children with disabilities (Able-Boone & Stevens, 1994; Floyd & Gallagher, 1997). While this study is beneficial to the body of literature pertaining specifically to parents of infants born prematurely in that it focuses solely on African American mothers, it involves a relatively small sample (n= 31).

In a descriptive, cross-sectional study involving interviews and questionnaires, Brazy et al. (2001) also investigated sources of support and information for parents of preterm infants. The authors found that parents' concerns and needs for informational and emotional support changed over four phases of the child's early life: prenatal, acute stage of illness, convalescence, and post-discharge. Parents reported obtaining formal, informational guidance throughout the first three stages primarily from physicians and nurses; however, the information they received was often too complex for them to understand or they felt they were too overloaded to process the information accurately. In the post-discharge phase, the informational guidance previously obtained from NICU staff was more typically acquired from other non-hospital resources, such as their own mothers, parent support groups, or the baby's primary care pediatrician. Primary sources of emotional support also changed over time. Parents of infants in the prenatal, acute illness, and post-discharge phases most frequently identified spouses, friends, and family as primary sources of support, while nurses were identified as primary sources of support for 71% of parents with babies in the convalescent stage of their NICU experience. Parents in this study felt it was important that providers "acknowledge the severity" of the stress parents of infants in the NICU experience and help them cope with it (p. 47). A substantial limitation to this study is the poor response rate with administered questionnaires.

Only 55% of the parents asked to participate actually completed and returned the 138-item questionnaire regarding kinds of information and support sought.

In a unique effort to expand upon the available knowledge related to sources of social support by examining parent needs, Ward (2001) reported the responses of 52 parents, both mothers and fathers, of infants in the NICU when asked to rank the importance of having various needs met while their infants were hospitalized. Uniquely, the data was collected from parents while their infants were still in the NICU, with a 6.57 day average length of hospitalization at the time of the study. Parents indicated the need for assurance and information as the most important, while interpersonal emotional supports were ranked as least important. The author conducted a one-way ANOVA to determine whether or not significant differences existed between mothers and fathers responses on the survey. While only 10 out of the 52 participants were fathers, she found significant differences in their needs. Fathers rated emotional support, assurance, and informational needs as substantially less important than did mothers. A limitation of the study revealed by the author is that the timing of the data collection (during the first month of hospitalization) could have influenced how the parents rated each particular type of support. The fact that assurance and information needs were seen as being of greatest importance could be because this is often a time when many parents of infants in the NICU “describe feelings of shock, anticipation, and uncertainty concerning the infants’ health outcomes” (p. 6). This particular study highlights the importance of service providers acknowledging and understanding the difference between parental stressors or sources of support and the needs of the family while in the NICU environment.

Summary. For most parents, the birth of an infant requiring hospitalization in the NICU is an extremely emotional and distressing event (Holditch-Davis and Miles, 2000). Families may experience a myriad of emotions, such as anxiety, fear, isolation, alienation, and helplessness (Able-Boone & Stevens, 1994; Barton et al., 2002; Miles et al., 1999). Parents of preterm, low birth weight, and critically ill infants have identified a variety of sources of support both during and after the period of time spent in the NICU, including family, friends, and professionals (Barton et al., 2002; Brazy et al., 2001; Miles et al., 1996). However, it may be difficult for these families to identify their needs for support on their own. "Early on, when their infants are the sickest, parents are in a state of shock and cannot process large amounts of information. Later, they may not know what questions to ask or become too intimidated by the situation to request information from physicians and nurses" (Brazy et al., 2001, p. 41). Providers have the responsibility of actively assessing parent needs and responding accordingly (Ward, 2001).

Conclusions

Theoretical models emphasize viewing the child as a part of a family unit (Bronfenbrenner, 1979, 1995) and help describe how families function to meet specific needs (Broderick & Smith, 1979). The role of social support in meeting those needs, particularly during times of stress, is also reinforced (Hill, 1949; McCubbin & Patterson, 1983). A wide body of literature is available providing evidence to support theoretical assumptions. More specifically, numerous researchers have described factors associated with stress in families of children with disabilities, as well as the mediating role of social support (Beckman & Pokorni, 1988; Beckman et al., 1991;

Bennett & DeLuca, 1996; Dunst et al., 1986; Floyd & Gallagher, 1997; Gallagher et al., 1983). Similar effects have been seen in families of infants hospitalized in the NICU (Able-Boone & Stevens, 1994; Barton et al., 2002; Brazy et al., 2001; Holditch-Davis & Miles, 2000; Kersting et al., 2004; Miles et al., 1996; Miles et al., 1999). In addition, many researchers have also concluded that assessments of family needs related to support must to be on-going as those needs can change over time (Beckman & Pokorni, 1988; Bennett & DeLuca, 1996; Brazy et al., 2001; Darling & Gallagher, 2004).

Regardless of these findings, little is known about the actual needs families themselves view as important to have fulfilled while their infants are in the hospital (Ward, 2001). Moreover, there is a limited amount of available data describing which needs take priority over others during this life experience. As a provider, to simply know that a family is experiencing stress does not mean that you know what they need. When attempting to draw conclusions from the existing literature, part of the problem is the generic use of the term “support”. It becomes critical to understand that appropriate support can vary from person to person and from one time to another in definition and meaning, making it essential to clearly identify individual needs. While ideally, each and every family’s needs should be thoroughly assessed during their infant’s stay in the NICU, this may not be practical given the limited amount of time that some of these families interact with hospital providers and the issue of ever-tightening healthcare budget restrictions that may limit the amount of support staff and services a hospital can provide. By studying this population as a whole and identifying trends that may surface from group data, providers will be able to develop a better understanding of the needs that may be most important to families to have fulfilled. They can then specifically target those needs at the onset of intervention rather than approaching families in a “one-size-fits-all” manner via generic support programs. Simply making supports available is of no use when they are not meeting the needs for which parents seek them in the first place. For instance, if mothers need to be able to talk to someone about the possibility of their babies dying, the availability of a group parent support program that meets weekly to discuss long-range topics, such as infant developmental milestones and services available through infants and toddlers programs, would not be of importance to those mothers as it would not be accurately meeting their needs.

Another gap in the current research is the fact that very few studies have involved the participation of parents of critically ill infants while their babies are still in the NICU. Instead, many have relied on self-report measures or interviews with families related specifically to stress and support post-discharge. While these studies produce meaningful results that are important to acknowledge and incorporate into professional practice to help minimize some of the known stress that parents experience in the NICU, the findings may not be as useful as possible. Asking parents to reflect on the experience retrospectively may not truly depict their opinions at the time in question. The intense emotional journey many parents experience may leave them with skewed impressions of what could have been useful while their babies were hospitalized.

In addition, if NICU providers have more specific information about the needs for a certain subpopulation of parents, such as young parents or parents of children with long periods of hospitalization, they may be better equipped to interact with those families on more individualized levels. Ward (2001) collected data on parent needs and compared the opinions of mothers to those of fathers. She found significant differences in opinions about the importance of specific types of needs based on gender, with fathers ranking support, information, and assurance needs as less important than did mothers. Similarly, Miles et al. (1996) discovered differences in opinions between mothers and fathers regarding the importance and helpfulness of receiving various types of supports in the NICU. These results suggest that needs may vary based on specific parent characteristics; however, correlational data on the needs of parents with infants in the NICU with respect to predictor variables other than parent gender have not been reported in previous investigations.

Finally, as evidenced in Table 1, many of the studies pertaining to the experiences of parents of infants in the NICU have been limited by homogeneous samples or a lack of reported information related to parent and infant characteristics, thus restricting the generalizability of their findings. For example, the participants in most of the studies conducted were primarily Caucasian, middle to upper class, and/or from two-parent households (Able-Boone & Stevens, 1994; Brazy et al., 2001; Miles et al., 1996; Ward, 2001). Extending the current body of research by conducting studies with more diverse populations is warranted, especially since there has been a direct link established between higher instances of prematurity and low birth weight, two conditions that frequently call for hospitalization in the NICU, and parent race and SES. More specifically, mothers of low SES and African American mothers display disproportionably high rates of low birth weight deliveries (Alexander, G., Bader, D., & Allen, M, 2003; Buka, S., Brennan, R., Rich-Edwards, J., Raudenbush, S., & Earls, F., 2003; Rauh, V., Andrews, H., & Garfinkel, R., 2001). In fact, "infants born to African American women are, on average, almost 300 grams lighter and more than twice as likely to be low birth weight than infants of White women" (Buka et al., 2003, p.1). Therefore, while instances of low birth weight are steadily decreasing for all races in the United States, racial disparity continues to exist (Keily, Brett, Yu, & Rowley, 2005).

With the modern neurodevelopmental care philosophy, hospitals are beginning to implement in-house NICU parent support programs; however, in order for professionals to effectively interact with parents and decide to plan such programs, a preliminary examination of what parents say they need is warranted. Therefore, to help provide more accurate need-based professional support, the primary purpose of this study was to identify the needs that mothers feel are most important to have fulfilled while their infants are in the NICU, as well as to determine the presence of relationships between parent and infant characteristics and mothers' opinions regarding those needs. The following research questions served as the foundations for this investigation:

Research Question 1. What needs do mothers of infants in the NICU view as most important to have fulfilled?

Research Question 2. Is there a significant relationship between parent age, race, educational level, and annual household income and the types of needs mothers view as most important?

Research Question 3. Is there a significant relationship between infant birth weight, gestational age, length of stay in the NICU, and the presence of certain medical conditions associated with high probability of developmental delay and the types of needs mothers view as most important?

Chapter III

Research Methodology

The primary purpose of this study was to identify the needs that mothers feel are most important to have fulfilled while their infants are in the NICU. Another goal of the study was to determine the degree of relationship between mothers' opinions and certain parent and infant characteristics. Specifically, this study was designed to answer the following research questions:

1. What needs do mothers view as most important to have fulfilled while their infants are in the NICU?
2. Is there a significant relationship between parent age, race, educational level, and annual household income and the types of needs mothers view as most important?
3. Is there a significant relationship between infant birth weight, gestational age, length of stay in the NICU, and the presence of certain medical conditions associated with high probability of developmental delay and the types of needs mothers view as most important?

A description of the site, participants, recruitment procedures, measures, field procedures, and data analysis is provided.

Site

The NICU of a mid-atlantic, inner-city hospital served as the site for this research study. The 2000 U.S. Census report indicated that the majority (64.3%) of this city's 651,154 residents were African American and 22.9% of those individuals were living below the poverty level (defined as a total family income or unrelated individual income less than the poverty threshold specified for the family's size, age of householder, and number of related children under the age of 18 living in the household for that given year; U.S. Census Bureau website, 2005).

The hospital is a state, regional, and nationally recognized facility for children's health care and research. One of the 23 divisions/specialties within the hospital is the Department of Neonatology, whose staff is responsible for a 40-bed NICU that offers comprehensive evaluation and treatment for critically ill neonates, including preterm and low birth-weight infants, and those with surgical, genetic, and cardiological conditions. The staff members of this division practice a multidisciplinary, neurodevelopmental approach to infant care.

In the past, the nursing and social work staff associated with the NICU organized and implemented a parent support program. Unfortunately, the program ended over two years ago due to a lack of parent participation and there is no data available to help explain why parents did not become involved. While in existence, the program consisted of regularly scheduled group meetings led by hospital professionals. A primary purpose of the group sessions was to share information with parents about infant care and child development topics, such as Kangaroo Care and infant massage. The group facilitators also led open discussions about parents' emotional experiences. At present, there is no formal parent support program for the NICU, but the intent is to use data obtained from this investigation for both staff development purposes and to possibly help design and reinstate a program.

Participants

The participants in this study were mothers of infants who were hospitalized in the NICU. To be recruited, mothers had to meet the following eligibility criteria:

1. The individual must be the biological mother of an infant in the NICU.
2. The infant was at least 48 hours post-admission to the NICU, including those who transferred from another hospital. The time spent in another hospital's NICU did count toward the 48 hours post-admission criteria.
3. The infant was considered to be in stable condition by the NICU attending physician (Note: Medical stability is a subjective classification defined differently by individual attending neonatologists. Physicians use a variety of information about an infant, such as respiratory strength, tolerance to feeds, presence of infection, and response to treatment, to establish their opinion about stability status.)
4. The mother was fluent in English.

Even though infants are admitted to the NICU for a variety of reasons, their mothers are all sharing a common experience. Therefore, to impose specific criteria, such as including only mothers of infants born at or below a particular weight or gestational age, was not appropriate for this study. Parents of multiples (i.e. twins, triplets) were also actively recruited for this same reason.

Sample size. An appropriate sample size to use in the study was determined based on the results of a series of power analyses conducted using a modified version of Cohen's (1988) procedure developed by Howell (2005). Howell's procedure can be used to predict power and effect size with various potential sample sizes in studies involving multiple regression analyses (see Appendix A for a detailed description of Howell's method and preliminary analyses used to determine sample size for this study). It was determined that in a study involving regression analyses with two categories of predictor variables (parent and infant), each containing four variables, in order to assure an approximate power of .80 of detecting a medium effect size with alpha set at .05 (an acceptable, conservative level for social science research; Cohen, 1988), a minimum of 45 participants were needed. A total of 53 mothers were approached to participate in the study. Six mothers simply were not interested in participating, and one mother was too tired at the time of initial recruitment; however, her infant's health status was unstable when she was approached on a different day. Therefore, the final sample for this study included 46 mothers.

While mothers were not eligible for recruitment unless their babies were in stable medical condition, there was still a possibility of recruiting two very different groups of women based on infant health status. For instance, an infant can be considered to be in stable condition, but may still require a substantial amount of rehabilitative time before beginning discharge plans. Another category of infants considered to be medically stable are those who are nearing the end of their course of treatment and plans are being made for them to soon go home with their families. In an effort to represent both categories of stable infants, sampling was stratified. Fifty percent of the participants were mothers of stable infants with discharge plans in effect and 50% were mothers of stable infants with no pending discharge plans.

Measures

To answer the proposed research questions, I collected quantitative data using three instruments. First, the NICU Family Needs Inventory (Ward, 2001) was administered to examine mothers' opinions about the importance of having various types of needs met while their babies are in the hospital. Two additional instruments were used to collect data on the chosen predictor variables. A Demographic Information Form was used to obtain information about the parent, such as age, race, educational level, and annual household income. Finally, an Infant Health Information Form was used to collect data related to each mother's infant, such as birth weight, gestational age, and length of stay in the NICU. A more detailed description of each measure is provided.

NICU Family Needs Inventory. Mothers' opinions regarding how important it is to have certain types of needs met while their infants are hospitalized was measured using Ward's (2001) NICU Family Needs Inventory (see Appendix B). The NICU Family Needs Inventory was adapted from the Critical Care Family Needs Inventory (CCFNI), an instrument that was originally based on the work of Molter (1979), but most recently updated by Leske (1986). Permission was granted from both K. Ward and J. Leske to use the NICU Family Needs Inventory in this study. The CCFNI is aimed at identifying the needs of family members of patients in an adult ICU. While the NICU is considered to be an intensive care setting and understanding the needs of family members of infants is equally important, the statements on the CCFNI do not necessarily reflect the unique experience of having a critically ill baby. Therefore, the need to develop a modified instrument was warranted (Ward, 2001).

The NICU Family Needs Inventory consists of statements designed to measure the importance of various types of needs to a family member. Participants were asked to complete the inventory by reviewing 56 statements related to various needs and rate their opinions on the importance of having those needs met by placing a check mark (√) in the box corresponding to a value presented on a 4-point Likert scale. For this study, one of

Ward's original columns, representing "Not Applicable", was eliminated from the inventory. It was felt that participants could reasonably chose from the four presented options, and that if the "Not Applicable" option was given, participants may decide to rely on it rather than recording a definitive opinion. An example of an item from the NICU Family Needs Inventory is provided in Figure 1. The 56 need statements represent five broad need subscales. The five subscales are: the need for support (S), information (I), comfort (C), assurance (A), and proximity (P). The need subscale to which each statement corresponds is indicated at the end of the sentence (see Figure 1). Leske's (1991) interpretations of the five subscales measured with the inventory are provided in Table 2.

	Not Important (1)	Somewhat Important (2)	Important (3)	Very Important (4)
To be able to visit at any time. (P)	_______	_______	_______	_______

Figure 1. Example of item on the NICU Family Needs Inventory.

Preliminary validity and reliability of the NICU Family Needs Inventory was established in a pilot investigation by Ward (2001). Prior to administering the tool to parents, expert family-centered nurses from diverse geographic areas and parents of infants in the NICU helped the author establish content validity. These individuals examined the statements on the scale and "agreed that the items expressed the essential needs of parents" of infants in the NICU (Ward, 2001, p. 5). After administering the NICU Family Needs Inventory to 54 families, Ward (2001) determined the reliability of the sample using Cronbach's alpha, a measure of internal consistency used to determine

Table 2.

Subscales of the NICU Family Needs Inventory (Leske, 1991)

Subscale	Number of Subscale Statements on Inventory (Total N = 56)	Interpretation of Subscale
Support	18	Resources, systems, and structures needed by family members, such as the need to express emotions, handle financial problems, and obtain spiritual guidance.
Comfort	7	Personal comforts that may be important to family members, such as having a restroom or telephone available close to the NICU.
Information	11	The family's need to obtain realistic information about their infant, including the need to be actively involved in their infant's care and the need for contact with their infant's physician.
Proximity	8	The family's need to remain near the infant, both emotionally and physically, such as visiting frequently and being called at home about condition changes.
Assurance	12	The family's need to feel confident, secure, and hopeful about their infant's outcomes, which stems from their trust in the health care system.

the extent to which the parts of an instrument measure the same thing (Huck, 2001). Analysis revealed a total scale alpha equal to .91, indicating a sufficient measure of internal consistency (Huck, 2001). A rudimentary analysis of the internal reliability of the instrument was also conducted for the population of participants in this study to help support previous findings that the CCFNI measures relatively independent dimensions of family need (Leske, 1991; Ward, 2001). The results of that analysis are presented in Chapter IV.

Because of how relatively new it is, extensive data regarding the technical adequacy of the NICU Family Needs Inventory is not yet available. However, the rigor of the instrument that serves as its framework, the CCFNI, has been thoroughly reported. Leske (1991) examined the internal consistency reliability and construct validity of the CCFNI based on family need data obtained from 667 subjects in 14 different states over a 9-year period. The internal consistency alpha coefficient of the total CCFNI was reported to be 0.92, again considered sufficient (Huck, 2001). Factor correlations were calculated in order to establish construct validity. It was reported that the CCFNI is a "multidimensional tool" that measures five independent dimensions of support "as indicated by the low to moderate correlations" among the factors (Leske, 1991, p. 242). The factor correlations and factor alpha coefficients for the five dimensions, or subscales, obtained by Leske (1991) are shown in Table 3. Overall, the author concluded that "sufficient psychometric properties warrant continuing use of the tool in research and clinical practice" (Leske, 1991, p. 236).

Demographic Information Form. A Demographic Information Form was developed for use in this investigation (see Appendix C). The form was used to gather a variety of information about each participant, such as race, age, educational level, and annual household income. Information related to each participant's visitation with her infant, such as the availability of transportation to and from the hospital and preferred days and times of visiting, as well as the number of adult and child family members in each participant's household, was also collected to help further describe the population.

Table 3.

Factor Correlations and Alpha Coefficients for the CCFNI's Five Dimensions (Leske, 1991)

Factor	Support	Comfort	Info.	Proximity	Assurance	Alpha
Support	1					0.88
Comfort	0.39	1				0.75
Info.	0.39	0.26	1			0.78
Proximity	0.17	0.23	0.17	1		0.71
Assurance	0.08	0.22	0.07	0.16	1	0.61

Infant Health Information Form. An Infant Health Information Form (see Appendix D) was completed for the infant of each mother who participated in the study. The data required to complete the form was obtained through medical record reviews. Since health status data from multiple infants (i.e. twins, triplets) cannot be accurately averaged and analyzed in relation to the needs of an individual parent, in such cases one infant was randomly selected. Infants in sets of multiples were assigned a number that corresponded to their birth order. The number was then used in conjunction with a randomization table (see Appendix E) to select the one infant on which data was collected. This random selection process was thoroughly explained to the applicable participants(s).

The Infant Health Information Form was used to collect data on each infant's birth weight, gestational age, length of stay in the NICU, medical risk of developmental delay, and daily care plan (namely feeding, bedding, and respiratory support). There are numerous available validated risk indices designed to assess medical stability and the probability of future developmental abnormalities, and even mortality, in neonates. Such instruments include the Clinical Risk Index for Babies (CRIBS; The International Neonatal Network, 1993) and the Score for Neonatal Acute Physiology Version II (SNAP-II; Richardson, Gray, McCormick, Workman, & Goldmann, 1993); however, the use of these tools requires prolonged, and often invasive, data collection over an extended period immediately after birth. In addition, they are intended to be used specifically with low birth weight and preterm infants. Therefore, is was not feasible to use such instruments in the current investigation since the babies of eligible participants were admitted to the NICU at varying times and may or may not be have been born premature or at low birth weights. For this reason, a developmental delay medical risk indexing method was specifically designed for the study.

The method involved assessing the presence of the conditions associated with high probability of developmental delay as outlined in the Maryland State Code of Regulations for Infants and Toddlers Programs (Md. Regs. Code tit. 13A § 13.01-2B, 2005). In compliance with Part C of IDEA 2004, the three ways in which a child can be found eligible for Infant and Toddler services in the state of Maryland are: (1) by demonstrating a 25% or more delay in one or more of the five major developmental domains (cognitive, communication, social-emotional, adaptive, motor development), (2) by demonstrating "atypical" development in one or more of the five major developmental domains, or (3) by being diagnosed with one or more conditions associated with a high probability of developmental delay (Md. Regs. Code tit. 13A § 13.01-2B, 2005; Maryland IFSP, Part II, Section E, 2003). Table 4 provides a list of the specific conditions included under the state's eligibility guidelines.

Table 4.

Conditions with High Probability of Developmental Delay, Maryland Infants and Toddlers Programs

Chromosomal disorders
Intraventricular hemorrhage (IVH)-Grade III or IV
Periventricular Leukomalacia (PVL)
Congenital infection
Effects of maternal drug abuse
Prematurity with LBW (< 1,200 grams)
Severe congenital malformations (i.e. hydrocephalus)
Inborn errors of metabolism
Neurodegenerative disorders
Seizures
Severe encephalopathy
Sensory impairments (i.e. Retinopathy of Prematurity)
Acquired Immune Deficiency Syndrome (AIDS)
Lead poisoning
Surgical necrotizing enterocolitis (NEC)
Bronchopulmonary dysplasia (BPD)

Each of the conditions indicated under Maryland's guidelines have been found to be associated with greater instances of developmental delay. For example, numerous researchers have concluded that school-aged children who were born preterm with very low birth weights demonstrate higher rates of a variety of educational difficulties, such as central processing deficits, visual-motor functioning, logical reasoning weaknesses, difficulties with short term memory, receptive and expressive language delays, and poor attention skills, than their same-age peers who were born full term (Briscoe & Gathercole, 1998; Cherkes-Julkowski, 1998; Wolke, 1998). In addition, many of the conditions that place children at risk for delays are closely related. For example, low birth weight increases an infant's risk for various forms of respiratory dysfunction, including respiratory distress syndrome (RDS) and bronchopulmonary dysplasia (BPD). These conditions result in higher instances of hypoxic-ischemic episodes, defined as low oxygen content in the blood and decreased rate of circulation (Rais-Bahrami et al., 2002). When this occurs, the infant experiences fluctuations in cerebral blood pressure which may ultimately cause an intraventricular hemorrhage (IVH). A severe intraventricular hemorrhage can lead to permanent white brain matter damage, known as periventricular leukomalacia (PVL). Mental retardation and/or cerebral palsy are seen in 30% of infants with Grade III IVH and 75% of infants with Grade IV IVH (Vohr, Wright, & Dusick, 2000).

The Infant Health Information Form contained a checklist of all but one of the conditions listed in Table 4. Lead poisoning was excluded from the checklist since newborn infant lead levels are not taken as part of standard care practices in the NICU. The checklist was used in conjunction with a dichotomous coding system to calculate a medical risk of developmental delay index score. Medical records were reviewed to see if the infant had been diagnosed with any of the conditions on the list on the day the infant's mother completed the NICU Family Needs Inventory. One point was assigned for each diagnosed condition on the list, for a maximum medical risk of developmental delay index score of 15. While it may be true for some combinations of conditions, it is not statistically appropriate to conclude that an infant with a higher index score is necessarily at risk for more severe delays (i.e. a child with both Down syndrome, surgical NEC, and BPD may experience the same level of delay as he would if he only had Down syndrome). Therefore, the index score was used only to indicate how many of the risk conditions the child experienced at the time of data collection. The index score was not used as a probability index for developmental delay. Data were also collected on the infant’s history of ventilation and current method of respiration (room air, oxygen hood, or nasal canula), bedding (open crib, radiant warmer, or isolette), and method of feeding (Total Parenteral Nutrition-TPN, tube feed, and/or nipple feed) on the day his or her mother completed the survey to help better describe the baby’s health status.

Procedure

Prior to initiating data collection, Institutional Review Board (IRB) approval was obtained from both the University of Maryland at College Park and the hospital that served as the site for the investigation. I took part in a NICU orientation conducted by a member of the hospital’s Neonatology team prior to beginning recruitment. The orientation included familiarization with policies, procedures, and routines of the NICU, an introduction to the NICU care staff (i.e. nurses, physicians, social workers), and instructions for accessing information from infant medical records. In addition to the NICU orientation, I completed all hospital-required trainings related to the use of human subjects in research and the Health Insurance Portability and Accountability Act (HIPAA) to ensure compliance with hospital research regulations.

Recruitment. Eligible participants were identified during weekly NICU meetings known as “multidisciplinary rounds”. Rounds involve a variety of NICU staff, including, but not limited to, attending physicians, nurses, social workers, developmental specialists, hospital case managers, and rehabilitative service providers (i.e. Occupational Therapists, Physical Therapists). One of the NICU’s standard procedures is to convene this group of providers weekly to discuss the individual status of each baby. I participated in these rounds and maintained a confidential enrollment log to record eligible participants. Once a participant was identified and her infant was determined to be in stable condition by the

NICU attending physician, I contacted her either in writing via a bedside note or I spoke with her in person while she was visiting the baby in the hospital.

Procedure for informed consent. During initial contacts, I discussed the purpose and procedures of the study, including procedures for informed consent. I provided each participant with a detailed description of the nature of the study and the requirements for participation. The right of the participant to refuse or withdraw consent at any time during the investigation without repercussions was explained. I also explained that there was no monetary cost or reimbursement for participating; however, the parent would be offered a small token of appreciation, such as a baby toy, for participating. If interest in participating was expressed, I reviewed and asked for the parent's signature on the consent form (see Appendix F). The parent was then asked to sign a HIPAA Authorization Form (see Appendix G) giving me consent to review her baby's medical record to collect data needed to complete the Infant Health Information Form. Additionally, names and contact information for the personnel involved in the investigation were also provided in the event that the participant had any additional and/or future questions about the study.

Participation requirements. It took approximately 20 minutes for each participant to take part in the study. After informed consent was obtained, the participant was asked to complete the Demographic Information Form and NICU Family Needs Inventory. I told the participant that both documents could either be read aloud to them or filled out independently. Two mothers asked that I read the survey and demographic form to them and record their answers. If any questions arose, I was available to assist each participant.

The Infant Health Information Form was completed after a participant finished the NICU Family Needs Inventory and Demographic Form. Participants were not present while the Infant Health Information Forms were completed. I reviewed the infant's medical record to obtain the information required to complete the form. In an effort to ensure confidentiality, all parent and infant data were coded. The codes corresponded to participant names recorded in a confidential enrollment log. Prior to initiating the study, interrater reliability on the Infant Health Information Form was established. The Division of Neonatology's Developmental Specialist and myself reached an agreement of 1.0 using Cohen's Kappa with data for 5 randomly selected babies currently hospitalized in the NICU (roughly 10% of the required sample size). The agreement between the evaluators was based upon the accurate recording of all data included on the Infant Health Information Form (birth weight, gestational age, birth type, birth order-if applicable, length of stay in the NICU, hospital of birth, history of ventilator and/or oscillator use, type of respiration, bedding, and feeding, and medical risk of developmental delay index score). These reliability checks continued at random instances during the data collection period for the infants of five participants (again, approximately 10% of the required sample size), and an overall agreement of 1.0 was again determined.

Data Analysis

An investigation of the needs of mothers with infants in the NICU was conducted by analyzing participant responses to the items on the NICU Family Needs Inventory. Demographic and infant data were also analyzed to identify potential predictors of the perceived importance of those needs. The primary research question was: What needs do mothers view as most important to have fulfilled while their infants are in the NICU? The secondary research questions were: Is there a relationship between maternal age, race, educational level, and annual household income and the types of needs mothers view as most important? Is there a significant relationship between infant birth weight, gestational age, length of stay in the NICU, and the presence of certain medical conditions associated with high probability of developmental delay and the types of needs mothers view as most important? These questions were answered using three different quantitative procedures and the SPSS statistical program to analyze the data. First, I analyzed and reported descriptive data. Next, to determine the presence of relationships among predictor variables, I calculated simple paired correlation coefficients. Finally, I used multiple regression methods to obtain data related to the degree of relationship between selected parent and infant characteristics and mothers' opinions about the importance of having certain needs met while their infants were hospitalized. A detailed description of each data analysis method is provided in the following chapter.

Chapter IV

Results

The study was designed to examine the needs of mothers with infants in the NICU, as well as to determine whether or not certain parent and infant characteristics are significant predictors of mothers' needs. The specific research questions were:

1. What needs do mothers of infants in the NICU view as most important to have fulfilled?
2. Is there a significant relationship between parent age, race, educational level, and annual household income and the types of needs mothers view as most important?
3. Is there a significant relationship between infant birth weight, gestational age, length of stay in the NICU, and the presence of certain medical conditions associated with high probability of developmental delay and the types of needs mothers view as most important?

An inventory of parent needs was administered to 46 mothers of infants in a NICU. In addition, family demographic and infant health data were collected. The study was conducted at an urban hospital an average of five days per week for approximately two months (12/20/05-2/14/06). While general characteristics of the residents of the city in which the hospital is located were provided in Chapter III, it is also useful to include data related to the characteristics of the total population of infants in the NICU during the time frame in which the study was conducted, as well as available information about their mothers. This data can be used to compare the characteristics of the study's sample to the total population. Therefore, a query was run of the hospital's database to obtain the information presented in Table 5.

Table 5

Infant and Mother Characteristics, Total Population In NICU During Time of the Study (N= 74)

Infant Gender	
Male	43.2% (n= 32)
Female	56.8% (n= 42)
Infant/Mother Race	
Black	64.9% (n= 48)
White	28.3% (n= 21)
Hispanic	4.1% (n= 3)
Asian	2.7% (n= 2)
Infant Birth Weight (grams)	
Range	545-4250
Mean	2436.07 (SD= 975.50)
Infant Length of Stay in the NICU (days)	
Range	1-82
Mean	18.14 (SD= 14.46)
Mother's Age (years)	
Range	15-42
Mean	26.18 (SD= 6.70)

Note. Infant length of stay data was calculated for only 73 infants because one infant has yet to be discharged, and data for mother's age was calculated for only 68 infants because age was not reported in the hospital's database for 6 mothers.

Descriptive Statistics

Parent and infant data obtained using the Demographic Information Form and Infant Health Information Form were analyzed and reported using descriptive statistics. Parent data included: age, race, educational level, annual household income, and visitation preferences and conditions. Infant data included: birth weight, gestational age, length of stay in the NICU at the time of the parent's participation in the study, medical risk of developmental delay, and daily care plan components (i.e. bedding, feeding, respiratory support). Data obtained from the Demographic Information Forms and Infant Health Information Forms were also analyzed to help provide detailed descriptions of the population. Means, percentages, frequencies, and ranges were used where appropriate. Descriptive statistical procedures were also used to calculate mean scores per need subscale for each participant based on responses from the NICU Family Needs Inventory. Those individual scores were then combined to calculate mean subscale scores for the entire sample. Higher mean domain scores indicated more perceived importance. In addition, mean scores for individual need statements were calculated and used to rank them from most to least important.

Parent characteristics. The Demographic Information Form was used to collect information about the participating mothers, their households, and hospital visitation routines and preferences. Mothers were asked to complete the form prior to completing the NICU Family Needs Inventory. The following parent characteristics were noted. Mothers ranged in age from 15 to 42 years, with a mean of 28.22 and a standard deviation of 7.57. The sample was heterogeneous with respect to race (see Table 6). Specifically, 60.9% were ethnic minorities. Sixty-three percent of the mothers were married or in a live-in relationship and 37% were single, divorced, or widowed. The maximum educational level for most participants (47.8%) was a high school diploma or General Educational Development (GED) completion. Information regarding each mother's routines and preferences when visiting her infant was also recorded. Most (69.6%) mothers reported that they visited their infants on a daily basis, while another

Table 6.

Parent Characteristics (N = 46)

Category	N	Percent of Sample
Race		
White	18	39.1
Black	21	45.7
Hispanic	4	8.7
Asian	2	4.3
Middle Eastern	1	2.2
Marital Status		
Married or in other live-in relationship	29	63.0
Single, divorced, separated, or widowed	17	37.0
Education		
Less than high school diploma	8	17.4
High school diploma or GED	22	47.8
College degree (AA or higher)	16	34.8
Employment status		
Employed	24	52.2
Unemployed	22	47.8
Annual Household Income		
Less than $10,000	9	19.6
Between $10,000 and $30,000	11	23.9
Between $30,000 and $70,000	14	30.4
Greater than $70,000	12	26.1
Number of Family Members in Household		
2	9	19.6
3	8	17.4
4	15	32.6
Greater than 5	14	30.4
Number of Children <18 Years of Age in Household (including hospitalized infants)		
1	19	41.3
2	18	39.1
3	3	6.5
4	4	8.7
5	2	4.4

23.9% visited between 3 and 5 days per week, and 6.5% visited 2 or less days per week. Mothers' travel times from home to the hospital ranged from 10 to 180 minutes, with a mean of 48.70 and a standard deviation of 36.64. Fifty-four percent drove their own car when they came to visit their babies, 26.1% got a ride from a family member or friend, and 19.6% relied on public transportation. The following time-of-day visitation preference were reported: early morning-before 9:00 a.m. (2.2%), morning-between 9:00 a.m. and noon (19.6%), afternoon-between noon and 5:00 p.m. (45.7%), evening-between 5:00 p.m. and 9:00 p.m. (19.6%), late night-after 9:00 p.m. (8.7%), and weekends (4.3%).

Infant Characteristics. The Infant Health Information Form was completed during medical record reviews and used to collect data related to past and current health status for the infants of the 46 participants. Twenty-nine (63%) were male babies and 17 (37%) were female. The group of infants had a mean birth weight of 1990.87 grams and a standard deviation of 931.24. Gestational ages ranged from 26 weeks to 40 weeks with a mean gestational age of 33 weeks and a standard deviation of 4.13. Thirty-nine (84.8%) of the infants were from singleton births, six infants (13%) were twins, and 1 infant (2.2) was a triplet. Fifty percent of the infants had private medical insurance and 50% were receiving publicly-funded Medical Assistance. Geographically, these infants represented births from all five of Maryland's regions: 82.6% were born in the Greater Baltimore area (consisting of urban, suburban, and rural areas), 6.5 % in Southern Maryland (a rural area), 6.5% in Western Maryland (suburban and rural areas), 2.2% in the National Capital region (a suburban area), and 2.2% were born in hospitals on the Eastern Shore (a rural area). The majority (60.9%) of the babies were born in Baltimore City at the hospital serving as the site for the study. Infant length of stay in the NICU ranged from 2 to 78

Table 7.

Infant Health Characteristics (N = 46)

Category	N	Percent of Total Sample
Diagnosed Conditions Associated with D.D.		
Birth weight less than 1,200 grams	14	30.4
Chromosomal disorder	4	8.7
Bronchopulmonary dysplasia	4	8.7
Surgical necrotizing enterocolitis	3	6.5
Severe congenital malformation	2	4.3
Seizures	1	2.2
Grade IV intraventricular hemorrhage	1	2.2
Periventricular leukomalacia	1	2.2
History of Ventilation		
Yes	23	50.0
No	23	50.0
History of Oscillator		
Yes	3	6.5
No	43	93.5
Current Means of Respiration		
Elective Ventilation	1	2.2
Oxygen Hood	1	2.2
Nasal Canula	3	6.5
Room Air	41	89.1
Current Type of Bedding		
Isolette	15	32.6
Radiant Warmer	14	30.4
Open Crib	17	37.0
Current Method of Feeding		
TPN	10	21.8
Tube (continuous or gavage)	14	30.4
Tube and nipple	4	8.7
Nipple (breast or bottle)	18	39.1

Note. TPN = Total Parenteral Nutrition, nutrition administered via intravenous infusion only.

days with a mean of 14.15 and a standard deviation of 17.21 at the time of their mothers' participation in the study. Past and current medical diagnoses and daily care plan characteristics varied (see Table 7). As previously discussed, a data collection index was created for the study to record the presence of diagnosed medical conditions associated with high probability of developmental delay for each infant (see Chapter III for specific details about the index). It is important to restate that a higher risk index score is not necessarily associated with higher probability of developmental delay. The index score simply equates to the number of diagnosed conditions that have been found to be associated with higher instances of developmental delay. At the time of data collection, 27 infants (58.7%) had not been diagnosed with any of the 15 medical conditions associated with high probability of developmental delay (refer to Table 4 for a list of the specific conditions). Twelve (26.1%) were given a developmental delay risk index score of 1 and seven (15.2%) were given a score of 2 or higher. Specific conditions diagnosed in this population of infants are also summarized in Table 7.

Parent needs. The first research question was aimed at identifying what needs mothers found most important to have fulfilled while their infants were in the NICU. To answer that question, the NICU Family Needs Inventory was administered to each participant. A rudimentary analysis of the scores obtained from the instrument was then performed to determine the level of internal consistency. The factor alpha correlations for each subscale and the total scale are shown in Table 8. Given each of the values is greater than .50, the findings suggest that scores obtained using the NICU Family Needs Inventory are internally consistent for this population (Huck, 2001). This supports Leske's (1991) findings from more previous reliability analyses. To reiterate, the Support

Table 8.

Reliability Analysis for Sample's Scores on the NICU Family Needs Inventory

Subscale	Cronbach's Alpha
Support	.869
Comfort	.747
Information	.782
Proximity	.613
Assurance	.630
Total Scale	.928

subscale refers to the resources, systems, and structures needed by family members to meet their emotional needs (i.e. the need to express themselves openly, the need to obtain spiritual guidance). The Comfort subscale addresses personal, physical comforts that may be important to family members while their baby is hospitalized, such as having a restroom or telephone available close to the NICU. The family's need to obtain realistic information about their infant, including the need to be actively involved in involved in their infant's care plan and the need for contact with their infant's physician, is measured by statements in the Information subscale. The Proximity subscale refers to the family's need to remain near the infant, both emotionally and physically, such as visiting frequently and being called at home when their baby's condition changes. Finally, the family's need to feel confident, secure, and hopeful about their infant's outcome is addressed by statements in the Assurance subscale.

Next, descriptive statistics, namely means and standard deviations, were calculated to rank the importance of having various needs met as perceived by mothers. The Likert scale used on the inventory was as follows: 1= Not important, 2= Somewhat important, 3= Important, 4= Very important. Ratings of the 56 statements on the NICU Family Needs Inventory were averaged and ranked to determine what needs this sample of mothers found most and least important to have fulfilled while their babies were in the NICU. The need to have questions about their infants answered honestly was found to be most important. On the contrary, mothers found it least important to talk to the same nurse all of the time. Tables 9 and 10 show the ten most and least important need statements for the sample.

In addition, mean scores per need subscale were also calculated for each participant based on responses from the NICU Family Needs Inventory and then combined to calculate mean total subscale scores for the entire sample. Subscale scores were also averaged and ranked in order of most to least importance (see Table 11). Although differences in means were relatively small, the findings indicate that participants viewed needs in the Assurance area (M= 3.85, SD= .192) as most important, followed by Information (M= 3.73, SD = .307), Proximity (M= 3.71, SD= .285), Comfort (M= 3.33, SD= .507), and, finally, needs in the Support area (M= 3.26, SD= .513) as least important to have fulfilled while their infants were in the NICU. While the range of scores for each subscale consisted of a maximum score of 4.00, minimum scores varied (Assurance= 3.25, Information= 2.55, Proximity= 3.00, Comfort= 2.00, Support= 2.18).

Bivariate Correlations

Post-hoc Pearson Product Moment correlational analyses and *t* tests of significance were conducted to examine the level of relationship between mothers'

Table 9.

Ten Most Important Need Statements

Statement	Subscale	Mean	Standard Deviation
To have questions about my infant answered honestly.	Assurance	4.00	.00
To know how my infant is being treated medically.	Information	3.98	.16
To see my infant frequently.	Proximity	3.96	.21
To be assured that the best care possible is being given to my infant.	Assurance	3.96	.30
To be able to visit at any time.	Proximity	3.96	.21
To know the expected outcome for my infant.	Assurance	3.96	.21
To see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using blankets to support my infant's body, and talking softly to my infant.	Comfort	3.96	.21
To know that my infant is being handled gently by healthcare providers.	Assurance	3.96	.21
To be called at home about important changes in my infant's condition.	Proximity	3.94	.25
To know why things are done for my infant.	Information	3.94	.33

Table 10.

Ten Least Important Need Statements

Statement	Subscale	Mean	Standard Deviation
To talk to the same nurse most of the time.	Proximity	3.11	.92
To have a telephone near the waiting room.	Comfort	3.11	.90
To have a bathroom near the waiting room.	Comfort	3.07	1.02
To have a place to be alone while in the hospital.	Support	3.07	1.08
To have someone to help with transportation.	Support	3.04	1.07
To be able to talk to other parents whose infants are in the NICU or who have been in similar situations.	Support	2.98	1.04
To receive help in responding to the reactions of my infant's sibling(s).	Support	2.93	1.14
To have comfortable furniture in the waiting room.	Comfort	2.89	.97
To have a support group of other families available.	Support	2.74	1.04
To have a pastor, clergy, or other person from my church visit.	Support	2.65	1.06

Table 11.

Mean Subscale Scores

Subscale	Range	Mean	S.D.
Assurance	3.25-4.00	3.85	.192
Information	2.55-4.00	3.73	.307
Proximity	3.00-4.00	3.71	.285
Comfort	2.00-4.00	3.33	.507
Support	2.18-4.00	3.26	.513

visitation frequency, conditions for visitation (i.e. transportation), and mean need subscale scores. This analysis provided an additional layer of valuable information about each participant's needs, as there was a lot of variation in how frequently mothers came to visit their babies and the conditions under which those visits occurred. As illustrated in Table 12, there are strong positive correlations between the frequency of visits, travel time, and transportation, and negatively associated relationships between frequency of visits and Assurance and Proximity needs. Therefore, after reviewing the nominal values used to record visitation frequency and transportation on the Demographic Information Form, it can be concluded that less frequent visits (2 or less days per week) are significantly related to a mother's need to rely on public transportation, longer travel times from home to the hospital, and lower opinions about the importance of having Assurance and Proximity needs met while their infants are hospitalized. The analysis also revealed that all five need subscales were significantly positively correlated, meaning that higher mean scores in one subscale are associated with higher mean scores in all other subscales.

Table 12.

Correlations Among Visitation Frequency/Conditions and Mothers' Needs

	Visitation Freq.	Travel Time	Transportation	A	P	I	C	S
Visitation Freq.	1.00	.35*	.32*	-.45*	-.32*	-.27	-.18	.07
Travel Time		1.00	-.21	-.04	-.04	-.04	-.03	.11
Transportation			1.00	.03	-.05	-.06	.02	.19
A				1.00	.77**	.63**	.59**	.58**
P					1.00	.65**	.70**	.55**
I						1.00	.60**	.68**
C							1.00	.65**
S								1.00

Note. A= Assurance needs, P= Proximity needs, I= Information needs, C= Comfort needs, S= Support needs.

**p* < .05 (2-tailed). ***p* < .01 (2-tailed).

Additional pair-wise correlations were calculated prior to conducting regression analyses to determine the magnitude and direction of relationships between the selected parent (age, race, education level, and annual household income) and infant (birth weight, gestational age, length of stay in the NICU, and medical risk of developmental delay index score) predictor variables. The results of the correlational analysis were also used to help determine whether or not each variable should be included in the regression models. Pearson Product Moment correlations were computed between all possible combinations within and across the two predictor variable categories (see Table 13).

Table 13.

Correlations Among Potential Predictor Variables

	Age	Race	Education	Annual Income	Birth Weight	Gestational Age	Length of Stay	DD Risk
Age (P)	1.00	-.22	.69 **	.52**	-.06	.01	-.03	.03
Race (P)		1.00	-.39**	-.32*	.07	.17	-.18	-.05
Education (P)			1.00	.72**	-.08	-.04	.10	0
Annual Income (P)				1.00	0	-.05	.03	-.07
Birth Weight (I)					1.00	.87**	-.47**	-.50**
Gestational Age (I)						1.00	-.60**	-.44**
Length of Stay (I)							1.00	.51**
DD Risk (I)								1.00

Note. P = Parent domain, I = Infant domain.

*p < *.05 (2-tailed).* **p < *.01 (2-tailed).*

As expected, results of the analysis confirmed significant relationships between numerous variables within categories; however, there were no significant relationships found between variables across categories. In the parent characteristic category, educational level, annual household income, and age were all positively correlated with one another. Race was also found to be significantly associated with education and household income. Within the category of infant characteristics, findings revealed positive correlations between birth weight and gestational age, and length of stay in the NICU and medical risk of developmental delay index score. Negative correlations were found between birth weight and length of stay in the NICU, gestational age and length of stay in the NICU, birth weight and medical risk of developmental delay index scores, and gestational age and medical risk of developmental delay index scores.

The covariance that given independent variables share with other independent variables in a regression model can interfere with the calculation of unique covariance values shared with the dependent variable (Pedhazur, 1982). Therefore, based on this rule, two independent variables were removed from the models. The final regression analyses were conducted with the following variables in the parent characteristic category: annual household income, age, and race. Educational level was eliminated because it was highly correlated with annual household income ($r= .722$, $p<.05$). Gestational age was removed from the group of infant variables because of its high correlation with birth weight ($r= .874$, $p<.05$), leaving birth weight, length of stay in the NICU, and medical risk of developmental delay index score as the three variables in the infant category.

Regression Analyses

To examine the unique contribution of parent and infant characteristics to the prediction of mothers' needs while their babies are hospitalized in the NICU, a series of hierarchical multiple regression analyses were performed. "Multiple regression is a method of analyzing the collective and separate contributions of two or more independent variables" to the variation of a dependent variable (Kerlinger, 1973, p.

3). To obtain a better understanding of the data set, a visual inspection of plots, namely stem and leaf and box and whisker plots, was first conducted. The plots were inspected for linearity and extreme residuals, or outliers. The results of the plot inspection revealed a notable outlier in the data set for the Information subscale, as well as two extreme outliers in the data set pertaining to infant length of stay in the NICU. For the regression analyses, the three outlier cases were removed, as they may have possibly seriously distorted the results (Pedhazur, 1982).

Next, given that regression assumes interval data (Pedhazur, 1982), sets of dichotomous dummy variables were created for maternal race and annual household income, and infant developmental delay risk index scores, as they were originally coded using nominal and ordinal values. This allowed them to then be used in combination with the other continuous independent variables during the analyses, and also, in addition to dropping highly correlated variables, helped to prevent multicollinearity (Kerlinger, 1973). Table 14 displays the binary values assigned to the characteristics in each set of dummy variables.

Table 14.

Dummy Variable Coding for Nominal and Ordinal Data Used in Regression Analyses

Independent Variable	Coding System	N
Race	1 = Caucasian	18
	0 = Non-white	28
Annual Household Income	1 = less than $30,000	20
	0 = greater than $30,000	26
Developmental Delay	1 = a score of 1 or higher	27
Index Score	0 = a score of 0	19

Analyses were conducted in three different stages. Stage 1 involved an analysis of parent characteristic variables as predictors of mothers' needs in each of the five subscale areas. Then, infant characteristic variables were analyzed as predictors in Stage 2. Lastly, after each subsequent stage, nonsignificant predictors were dropped until a final stage (Stage 3) included only significant predictors in either category, parent or infant. The decided order of entry of each independent variable into the Stage 1 and 2 regression models was based on the findings of Beckman (1983), Beckman and Pokorni (1988), and Floyd and Gallagher (1997) which reveal that parents of households with low SES and parents of children with severe disabilities and intensive caregiving demands tend to exhibit higher levels of stress, and may require more or different social supports. Therefore, annual household income was entered first into the Stage 1 regression analysis using characteristics in the parent category, followed by age, and finally race. Developmental delay risk index scores was entered first during the Stage 2 analysis involving infant characteristics, then birth weight, and lastly length of stay in the NICU. The variables entered first into both analyses were selected because they were predicted to correlate the most with parent opinions regarding the importance of the various types of needs measured with the NICU Family Needs Inventory. The data analysis procedures produced three sets of findings: (1) the prediction of mothers' needs from parent characteristics, (2) the prediction of mothers' needs from infant characteristics, and, (3) the prediction of mothers' needs from significant parent and infant characteristics combined. Results will be presented separately.

Parent characteristics as predictors. Results for the prediction of mothers' needs from parent characteristic variables (Stage 1) are presented in Table 15. Findings indicate that maternal age and race are nonsignificant in predicting mothers' needs in any area; however, annual income is a significant predictor of mothers' Support needs. The contribution of annual income to the prediction of mothers' Support needs is 21.3% of the variance. When age is added to the model, the variance contribution does not change, and finally, when race is added, the variance in mothers' Support needs accounted for jointly by all three independent variables only increases to 21.9% (an R^2 change of only .006). The direction of the contribution of annual income to the prediction of mothers' Support needs is positive ($\beta = .462$), meaning that for every one standard deviation annual income increases, mothers' Support needs increase by almost half of a standard deviation.

Infant characteristics as predictors. Table 16 shows the pattern of results for the prediction of mothers' needs from infant characteristic variables (Stage 2). Similar to the results from the analysis involving parent characteristics, two of the three independent variables are nonsignificant. Neither infant developmental delay index scores nor birth weight significantly predict mothers' needs in any of the five subscale areas. Infant length of stay in the NICU was the sole significant predictor of mothers' needs, but only in the areas of Support and Information. When entered alone and jointly with infant birth weight in two of the three models used to predict mothers Support needs, developmental delay index scores contribute to only .60% of the variance in mothers' needs (R^2 change from Model 1 to Model 2 = 0); however, when length of stay is added in Model 3, the contribution increases to11.1 %. In addition, while the R^2 for the entire model involving all three predictor variables yields an

Table 15.

Models for Regression Analysis Predicting Mothers' Needs (Stage 1-Parent Category)

Predictor	Model 1				Model 2				Model 3			
Variables	R^2	F	ß	t	R^2	F	ß	t	R^2	F	ß	t
					Assurance							
Income	**.003**	**.142**	.057	.377			.097	.580			.099	.574
Age			---	---	**.011**	**.234**	.096	.573			.094	.554
Race			---	---			---	---	**.011**	**.154**	.009	.058
					Proximity							
Income	**.006**	**.280**	.080	.529			.092	.553			.081	.472
Age			---	---	**.007**	**.154**	.031	.185			.039	.229
Race			---	---			---	---	**.010**	**.144**	-.058	-.360
					Comfort							
Income	**.035**	**1.579**	.186	1.257			.200	1.213			.192	1.131
Age			---	---	**.036**	**.793**	.033	.201			.039	.232
Race			---	---			---	---	**.037**	**.541**	-.042	-.266

Note. **(---)** The variable was not entered in that model. R^2 and F values were calculated once for each model. See Appendix H for correlation and model summary tables.

**p* < .05. ***p* < .01.

Table 15 (cont.).

Models for Regression Analysis Predicting Mothers' Needs (Stage 1-Parent Category)

Predictor Variables	Model 1				Model 2				Model 3			
	R^2	F	ß	t	R^2	F	ß	t	R^2	F	ß	t
					Support							
Income	**.213**	**11.944****	.462	3.456**			.455	3.056**			.440	2.885**
									2.885**			
Age			---	---	**.213**	**5.845****	-.017	-.115			-.007	-.046
Race			---	---			---	---	**.219**	**3.920***	-.074	-.518
					Information							
Income	**.030**	**1.336**	-.174	-1.156			-.185	-1.190			-.153	-.950
Age			---	---	**.033**	**.712**	.053	.339			.071	453
Race			---	---			---	---	**.048**	**.693**	.131	.816

Note. **(---)** The variable was not entered in that model. R^2 and F values were calculated once for each model. See Appendix H for correlation and model summary tables.

**p* < .05. ***p* < .01

Table 16.

Models for Regression Analysis Predicting Mothers' Needs (Stage 2-Infant Category)

Predictor Variables	Model 1				Model 2				Model 3			
	R^2	F	ß	t	R^2	F	ß	t	R^2	F	ß	t
					Assurance							
DD Index	**.014**	**.594**	.118	.771			.070	.410			.095	.554
Birth Weight			---	---	**.025**	**.525**	-.116	-.681			-.193	-1.030
Length of Stay			---	---			---	---	**.048**	**.667**	-.176	-.975
					Proximity							
DD Index	**.003**	**.125**	.055	.354			.047	.273			.071	.405
Birth Weight			---	---	**.003**	**.067**	-.018	-.106			-.090	-.475
Length of Stay			---	---			---	---	**.023**	**.309**	-.163	-.891
					Comfort							
DD Index	**.028**	**1.192**	.166	1.092			.206	1.220			.245	1.457
Birth Weight			---	---	**.035**	**.746**	.095	.565			-.023	-.127
Length of Stay			---	---			---	---	**.088**	**1.286**	-.269	-1.523

Note. (---) The variable was not entered in that model. R^2 and F values were calculated once for each model. See Appendix H for correlation and model summary tables.

**p* < .05. ***p* < .01.

Table 16 (cont.).

Models for Regression Analysis Predicting Mothers' Needs (Stage 2- Infant Category)

Predictor Variables	Model 1				Model 2				Model 3			
	R^2	F	ß	t	R^2	F	ß	t	R^2	F	ß	t
					Support							
DD Index	**.006**	**.260**	.078	.510			.075	.440			.130	.785
Birth Weight			---	---	**.006**	**.128**	- .007	-.041			-.174	-.960
Length of Stay			---	---			---	---	**.111**	**1.659**	-.378	-2.167*
					Information							
DD Index	**.001**	**.044**	.033	.209			.061	.358			.125	.763
Birth Weight			---	---	**.006**	**.177**	.074	.437			-.108	-.603
Length of Stay			---	---			---	---	**.131**	**1.960**	-.414	-2.370*

Note. (---) The variable was not entered in that model. R^2 and F values were calculated once for each model. See Appendix H for correlation and model summary tables.

*$p < .05$. **$p < .01$.

insignificant F value (p= .191), the result of the F-test conducted on R^2 change after the addition of the length of stay variable is statistically significant ($p < .05$). This suggests that length of stay is a significant predictor of mothers' Support needs.

Similarly, there is a significant change in R^2 after the addition of length of stay in the third model (involving all three independent variables) used to predict mothers' Information needs. The contribution of developmental delay index scores alone and when combined with birth weight is only .1% and .6% of the variance respectively, but when length of stay is added in the last model, joint variance contribution increases to 13.1%. Again, while the F test indicates nonsignificance of Model 3 as a whole, it does yield a significant F change value ($p < .05$). Therefore, it can be concluded that infant length of stay significantly predicts mothers' needs in the area of Information as well. Unlike in the relationship found between mother's household annual income and Support needs (the significant correlation found in the parent category analysis), the direction of the contribution of infant length of stay to the prediction of mothers' Support and Information needs is negative. Thus, for every one standard deviation infant length of stay increases, mothers' Support needs decrease by 37.8% of a standard deviation and Information needs decrease by 41.4% of a standard deviation.

Significant predictors across categories. Results from a final analysis of the prediction of mothers' Support needs from significant predictors found in the parent (annual income) and infant (length of stay) characteristic categories are presented in Table 17. Given that maternal annual household income was the sole significant predictor of mothers' Support needs in the parent category and length of stay was the only significant predictor in the infant category, Support was the only subscale for which an across-domain regression analysis was possible. Since a higher beta weight was calculated for annual income during its category-specific analysis than was for infant length of stay in the NICU, annual income was entered into the final regression (Stage 3) first. In these two models, annual income remains a significant predictor of mothers' needs in the area of Support, contributing to 21.3% of the variance in scores; however, infant length of stay is no longer a significant predictor of Support needs. With a small R^2 change of .026, length of stay does not contribute significantly to the variance in mothers' Support need scores once added into the model with annual income.

Table 17.

Final Regression Analysis Predicting Mothers' Support Needs (Stage 3-Significant Predictors from Within Category Analyses)

Predictor Variables	Model 1				Model 2			
	R^2	F	ß	t	R^2	F	ß	t
Income (Parent Category)	**.213**	**11.401****	.462	3.376**			.430	3.090**
Length of Stay (Infant Category)			---	---	**.239**	**6.426****	-.162	-1.164

Note. (---) The variable was not entered in that model. R^2 and F values were calculated once for each model. See Appendix H for correlation and model summary tables.

**p < .01.

Summary. This series of regression analyses conducted using parent characteristic data (annual household income, age, and race), infant characteristic data (developmental delay index score, birth weight, and length of stay in the NICU), and data from the five need subscales (Assurance, Proximity, Comfort, Support, and Comfort, Support, and Information) reveals two significant relationships. First, infant length of stay in the NICU was found to be inversely correlated to mothers' Information needs, meaning that lengthier stays are predictive of less maternal needs in the area of Information. Findings also reveal a positive correlational relationship between mothers' annual household income and needs in the area of Support. As household annual income increases, mothers' Support needs increase.

Chapter V

Discussion

The intent of this study was to examine the needs of mothers with infants in the NICU and to determine the degree of relationship between parent and infant characteristics and mothers' needs. To address these issues, the following three research questions were asked:

1. What needs do mothers view as most important to have fulfilled while their infants are in the NICU?
2. Is there a significant relationship between parent age, race, educational level, and annual household income and the types of needs mothers view as most important?
3. Is there a significant relationship between infant birth weight, gestational age, length of stay in the NICU, and the presence of certain medical conditions associated with high probability of developmental delay and the types of needs mothers view as most important?

To explore the first question, the NICU Family Needs Inventory was administered to a sample of 46 mothers with infants hospitalized in the NICU. In general, mothers viewed needs in the Assurance area as most important and needs in the Support area as least important to have fulfilled while their babies are in the NICU. In addition, regression analyses revealed a significant predictive relationship between maternal annual household income and Support needs, and infant length of stay in the NICU and Information needs. A discussion of these results is presented in this chapter.

Current legislative requirements and empirical literature emphasize the importance of accurately assessing and responding to the needs of families involved in early intervention programs. These best practices are even more evident when reviewing the recommendations of researchers who work with parents of infants in the NICU, as there is a substantial body of literature that examines the unique psychosocial experiences of these families. Yet little is known about the needs parents have during their infants' hospitalizations, or if parent and infant characteristics influence those needs. More specifically, since we know the NICU can be a stressful and overwhelming environment for parents of the babies who are cared for there, hospitals continue to search for ways in which they can provide effective assistance during this time. Parent support programs are becoming increasingly more common in hospitals with NICUs; however, simply designing and offering a program is not enough. If it does not meet the needs of the population for which it was developed, it is simply a waste of effort, time, and money. Practitioners who misinterpret needs and subsequently provide inappropriate supports and resources can often discourage families from seeking the assistance that may truly help them (Ward, 2001). While taking caution not to assume that all families need the same thing, a group analysis of parent needs during this experience, such as the one conducted in this investigation, is useful, as it provides a foundation on which providers can begin to organize accurate need-based support.

In this study, and similar to the results obtained from a previous study using the NICU Family Needs Inventory (Ward, 2001), the majority of the 10 statements mothers ranked as most important fell in the category of Assurance needs. This finding supports the conclusion drawn by other researchers that parents of infants in the NICU have a tremendous amount of anxiety and fear about their babies' outcomes; understandably, they have reported fears about their infants dying and the possibility of chronic health problems and/or disability (Holditch-Davis & Miles, 2000; Kersting et al., 2004; McIntosh, Stern, & Ferguson, 2004; Miles et al., 1999). Therefore, the need to be reassured that they and their babies will and can make it through this experience is a top priority. In addition, as in Ward's (2001) study, Support needs were ranked as least important. This may also be due to the same explanation Ward provides. The NICU in which this study was conducted did not offer a parent support program, and two of the statements in the Support subscale pertained to participating in a support group. Subsequently, both of those items were ranked among the five least important need statements for this study's population. Not having the opportunity to experience the potential benefits of participating in a parent group can logically affect the level of importance one places on its existence.

While several similar conclusions can be drawn from the data obtained during this investigation and that collected by Ward (2001), substantial differences can also be highlighted. First, Ward found that 95% of the statements on the NICU Family Needs Inventory received a minimum rating of "Important" or "Very Important", three were regarded as "Somewhat Important" by at least one parent, and none of the statements were ever ranked as "Not Important". However, for this study, only 25% (n= 14) of the statements received a minimum rating of "Important", 21% (n= 12) were viewed as "Somewhat Important" by at least one mother, and 54% (n= 30) of the statements received a minimum rating of "Not Important". It should be noted that a rating of "Not Important" for some of the statements in the current investigation might have been given because the inventory did not include a “Not Applicable” option, as it did in Ward’s study. For instance, where a mother may have ranked the need to have someone help them explain her baby’s condition to siblings as “Not Applicable” on Ward’s inventory, she may have ranked that same need as “Not Important” on the version used for this study. In fact, three of the 30 statements that received a minimum rating of “Not Important” in the current study were related to the following topics: breastfeeding, siblings, and visitors from church. Each of these topics could have been viewed as “Not Applicable” if the inventory provided that option.

As previously discussed, it is easy to misinterpret family needs, partially due to confusion and overgeneralization regarding the various types and roles of social support in meeting needs. The relatively marginal differences in mothers’ opinions of the importance of the five areas of need found in this study is further evidence of that confusion and potential misinterpretation of what a family may prioritize. For instance, there was only a difference of .59 between the combined mean rating in the most important area of need, Assurance, and the least important area of need, Support. There were also high standard deviations associated with some of the mean subscale scores, namely Comfort (SD = .507) and Support (SD = .513). In addition, the small standard deviations calculated for the Assurance, Information, and Proximity subscales are indicative of an attenuated range issue. These findings suggest the argument that needs may frequently overlap and parents themselves may have a hard time distinguishing between the needs they want providers to address and what could be supportive. It therefore becomes a delicate, and often difficult, task for interventionists to decide what type and amount of support to provide. In fact, the findings solidly back the conclusion that social support in response to family needs "is a multidimensional construct" that includes a variety of assistance in numerous categories, such as emotional, informational, and physical (Dunst et al., 1986, p. 403). Combinations of these supports are intricately intertwined, making it essential to take the time to conduct in-depth, individualized inquiry into each family's circumstances.

The results from this study also suggest two significant relationships between parent and infant characteristics and mothers' needs. These findings reinforce a component in Broderick and Smith's (1979) Family Systems Theory which explains the important influence of characteristics of both the entire family and individual members on family reaction and adjustment to stress. First, analyses revealed that higher levels of annual household income predict increased Support needs. The prediction of income on Support needs may be due in part to the fact that higher income households in this sample were significantly related to higher levels of maternal education. Other authors have suggested that maternal education is associated with the quality of mother-infant interactions and a greater knowledge of infant development (Crnic et al., 1986; Hess, Teti, & Hussey-Gardner, 2004). Therefore, these mothers may actively seek more information and explanation regarding their infants' courses of care in the NICU as they may have a better understanding of the potential ramifications of neonatal illness. Consequently though, this same increased understanding may also lead to higher levels of anxiety, which could account for the need for more emotional support. This positive correlational relationship between income and support can also be viewed in the context of

McCubbin and Patterson’s (1983) Double ABC-X model. The model discusses family resources, and suggests the more resources a family has (with income being considered a resource), the more factors they bring to bear on a problem or crisis. Families with an abundance of resources, in this case possibly an enormous wealth of information and knowledge regarding the potential risks associated with neonatal complications, may actually feel more overwhelmed than relieved. They, in turn, may seek more emotional support to help them deal with the stressful situation. It can, in some ways, be associated with the saying, “What you don’t know can’t hurt you.”

Another possible explanation for the correlation found between income and support is related to the findings from other investigations that families of households with low SES have been found to be strongly associated with poorer quality of home environment (Crnic et al., 1986; Thompson, Catlett, Oehler, Gustafson, & Goldstein, 1998). This phenomena is also supported by Bronfenbrenner’s (1979) ecological paradigm that highlights the influence of large social structures or elements, such as poverty, in the exosystem of a child’s environment on microsystem elements (i.e. the home) that directly interact with the child. A mother living in poverty may feel a sense of confidence that her infant is safe and receiving competent care in the NICU, and could also possibly be relieved that she does not yet have to take on the challenge of caring for her baby under less than desirable home conditions. She may be expending a tremendous amount of energy on trying to take actions to help improve her home situation for when her infant is ready for discharge, such as obtaining stable medical benefits, locating better housing, escaping an abusive partner relationship, or finding employment. In such a case, the mother may not be placing an emphasis on having her own personal emotional needs met, as she is truly just trying to keep her head above water.

When discussing the significant relationship between mothers from households with low income and the lower Support needs identified in this study, reference to a prominent theory related to human motivation is warranted. In his original presentation and subsequent adaptations, Maslow (1954, 1970, 1998) proposes a hierarchy of human needs (see Figure 2) based on two categories: deficiency needs and growth needs. Maslow describes deficiency needs as those basic needs that one must satisfy before they can act unselfishly, whereas growth needs are those that surface after all basic, deficiency needs are met. Growth needs are satisfied on one's journey to becoming everything he or she is capable of being, with the ultimate goal of reaching a transcendent plane.

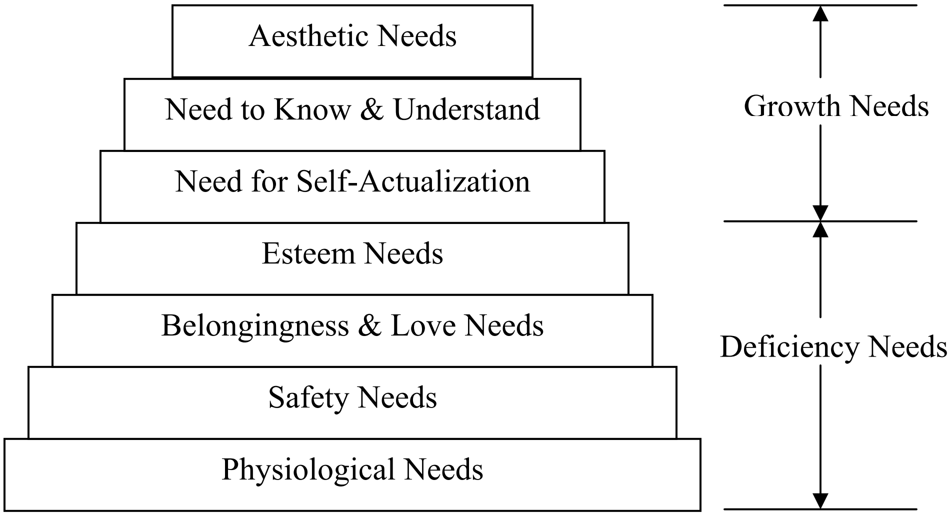

Figure 2. Maslow's Hierarchy of Needs.

Within the deficiency needs category of the hierarchy model (physiological, safety/security, belongingness/love, esteem) lies an explanation for the correlation found between income and Support needs. Maslow believes that an individual must have each lower need met prior to being able to move up to the next highest level toward actualization. Maslow also believes that physiological needs tend to have the highest strength until they are satisfied. As a result of the predominance of these physiological needs, an individual will deprioritize all other needs and desires if their physiological needs are not being met. Therefore, mothers with low income may be focusing on fulfilling their families' physiological (i.e. nourishment, sleep) and safety/security (i.e. employment, income, physical safety) needs. In such cases, they are not ready to enter the more social levels, belongingness/love and esteem, where the involvement of emotionally-based relationships comes into play. Without the need for this intra- and interpersonal emotional growth, the need for emotional support is moot. Maslow's theory has been commonly used, particularly in the fields of psychology and family studies, in investigations examining individual's involvement in support programs designed to address a variety of issues, such as mental illness, residential placements for individuals with developmental delays, and assistance to families living in poverty (Annison, 2000; Mottaghipour & Bickerton, 2005; Ramirez, 2005).

A significant inversely correlated relationship between infant length of stay and mothers' Information needs was also revealed in this study. This finding suggests that the longer infants remain hospitalized in the NICU, the less emphasis their mothers place on the need for information, and that mothers of newly admitted babies feel the need to receive more information about their babies' conditions. This is consistent with the conclusions drawn by many researchers that intensity and types of needs can change over time (Beckman & Pokorni, 1988; Bennett & DeLuca, 1996; Brazy et al., 2001; Darling & Gallagher, 2004). Families of newly admitted infants may understandably have different comfort levels related to the comprehension of medical information, their involvement in daily care routines, and their own personal confidence in being able to parent their infants than do families of infants that have been in the NICU for longer periods of time. For many babies, medical stability levels fluctuate the most during those first several days and weeks they are in the unit. With such constant and often rapid changes in health status comes the logical need to be continuously updated about infant prognosis. As babies progress into more stable statuses after being treated for longer periods of time, they are, in many cases, remaining hospitalized just to feed and grow. The mothers of these “veteran” NICU patients may feel as though they have a thorough understanding of their infants’ conditions and care plans. Therefore, they may no longer feel the intense need to receive frequent updates from providers.

Post-hoc analysis. Descriptive analysis of the additional data (that not used during regression analyses) obtained using the Demographic Information Form revealed substantial variability in mothers’ visitation frequencies and the conditions associated with their visiting routines. This initiated the desire to conduct a supplementary post-hoc correlational analysis (see Table 11). Findings from this analysis suggest several strong relationships. More specifically, mothers who visited their babies less frequently reported significantly lower Assurance and Proximity needs. When interpreting this finding, one must take into consideration potential factors that are often related to lower visitation frequencies, namely travel time and transportation. Mothers who did not have their own cars to use to travel to and from the hospital tended to report less frequent visits, and visitation also significantly decreased as the travel time from home to the hospital increased. Given that correlation does not imply causality, it is inappropriate to assume that mothers place less emphasis on having Assurance and Proximity needs met because of these visitation habits and conditions or vice versa. However, the relationship is an interesting one and worth mentioning, if not simply to add another layer of complexity and individualized circumstances through which providers must penetrate in order to accurately address family needs. Assessing family needs and the type of supports that may be useful in addressing those needs cannot be viewed as a simple task.

Implications for Research

The accurate identification of the needs of the diverse group of families for whom early interventionists design and provide service programs is only possible if we conduct on-going population-specific inquiries, such as the one that took place in this study. By examining the priorities and needs of families experiencing similar situations, like parents of infants hospitalized in the NICU, providers gain a more thorough understanding of what we can do to address and support them. Moreover, such studies supply interventionists with the data needed to help either defend or dismiss the effectiveness of various types of support models (i.e. group, parent-to-parent, individual) for certain families. The availability and success of professional support can have a profound positive impact on child development, the ultimate goal of any early intervention program (Beckman & Pokorni, 1988; Bronfenbrenner, 1979, 1995; Dunst et al., 1986; Crnic et al., 1986; The Infant Health and Development Program, 1990; Koverola, et al., 2005; Parker et al., 1992; Ross, 1984).

In addition to applying quantitative methods to assess parent needs, such as the ones used in this study, it is also important to continue to conduct qualitative investigations. Such studies offer additional, elaborative insight otherwise not accessible within the confines of a quantitatively designed protocol involving standardized measures. Providing parents with opportunities to tell their own stories and share their personal needs may uncover other ways in which providers can support them in particular situations, such as the birth and hospitalization of an infant requiring specialized care in the NICU. For instance, it would be useful to ask parents to discuss their need priorities and what they see as the hospital staff's role in helping to meet those needs. Do they have concerns or suggestions about specific topics related to the various types of needs assessed in this investigation, such as the frequency of sharing information about infant status, parameters regarding physical access to the infant, or the NICU staff's facilitation of supportive relationships among families (either current or families of children previously hospitalized in the NICU)?

The many relationships revealed in this study substantiate the theoretical models of Hill (1949), McCubbin and Patterson (1983), and Broderick and Smith (1979) in relation to the influence of family characteristics on functioning and adaptation during stressful or challenging life situations. The results from the post-hoc analysis conducted with mothers' visitation frequency/conditions and needs also suggest that there may be larger social issues related to needs, a finding consistent with Bronfenbrenner's ecological systems approach. Further analyses of correlations between other parent characteristics, such as marital status, at-risk behaviors (e.g. substance abuse), number of other children, and geographic location, and parent needs while their infants are hospitalized in the NICU using larger samples would add to the existing body of research that examines the numerous factors that affect family well-being. Such investigations would help provide an even more sophisticated understanding of these characteristics, and may yield results that can be used to help establish intervention programs targeting certain populations or communities (i.e. rural vs. urban). In general, the findings from this study make it quite apparent that research aimed at helping to provide practitioners with insight and understanding of family reactions to various situations should continue.

Implications for Practice

The importance of accurately assessing family needs and priorities in early intervention is reflected in policies from Part C of the Individuals with Disabilities Education Improvement Act of 2004, as well as empirical literature conducted with families themselves. More specifically, when working with families of infants in the NICU, current best practices, such as neurodevelopmental care, also emphasize the importance of actively involving parents in care plans and addressing their needs in conjunction with the needs of their infants. The results of this study provide interventionists working in the NICU environment, including early childhood educators, nurses, and physicians, with a better understanding of the needs parents feel are most important to have fulfilled while their infants are hospitalized. While it may be unrealistic to expect NICU staff to deal with all aspects of families' needs, investigation such as this may help them to coordinate and prioritize interventions to help meet specific needs (Leske, 1991). This information, in combination with the findings from the analyses of the relationships between parent and infant characteristic and mothers' needs, can be useful when offering individualized support to families.

While a hospital may not necessarily have the funds, staff, or desire to design and implement a formal parent support program, NICU staff members can still use the information from this study in their everyday interactions with parents. For instance, knowing that mothers have placed an emphasis on Assurance needs, practitioners can concentrate on establishing honest, open, and trusting relationships with families. Without this foundation, doubts about the quality of care their infants are receiving and feelings of uncertainty about their babies' outcomes may linger in the minds of parents. This can lead to feelings of anxiety, stress, and discomfort, on top of what parents may already be experiencing to begin with. In addition, if a trusting relationship fails to develop, families may go home with their babies feeling as if they did not have the confidence or faith in hospital providers necessary to obtain needed information or learn how to best care for their infants after they are discharged. While the fundamental goal of providers working in the NICU is to make their infant patients healthy, they must also strive to ensure that these babies will be going home with safe, competent, and nurturing parents who have been taught the necessary skills to provide proper care.

The complex, overlapping relationships among various types of needs revealed in this study raises speculation about whether or not a group parent support program for families of infants in the NICU could be effective. If parents are experiencing a myriad of needs, and data suggests that those needs change over time, then how can providers possibly accurately address those needs with a solitary, generic group program? An individualized, either professional-to-parent or parent-to-parent, support program would lend itself better to the complex need constructs identified in this and many other investigations. Of course, such a program would require more support providers, each of which would need to be properly trained on how to assess and offer need-based support. For hospitals, this additional staff and training would equate to the need for additional funds, unless individuals participated in the program as volunteers. Essentially, but unfortunately, the decision to implement such a program may not lie in the hands of those who work directly with the families who would reap the benefits.

Limitations

There are several limitations associated with this study. First, it involved the use of a relatively small sample of only mothers. The study should be replicated with larger samples, inclusive of both mothers and fathers, and even extended family members, such as grandparents. This would align more closely with the belief that the purpose of early intervention programs is to assist the entire family unit, not just the child and only one of his or her caregivers. In addition, incorporating additional predictor variables into regression analyses involved in future investigations aimed at examining the influence of parent characteristics on needs while infants are hospitalized in the NICU, would automatically substantiate the inclusion of additional subjects to obtain adequate power and effect.

Second, while a stratified recruitment plan helped to ensure the sample was somewhat representative of the NICU's population, mothers of infants who were in critical, unstable conditions were not allowed to be recruited, as it interfered with the participating hospital's ethical regulations regarding the use of human subjects in research studies. It was felt as though recruiting mothers of infants who were in immediate danger of severe medical complications or death would cause undue stress and only add to the many overwhelming feelings that may already possess. Given this, a very important group of mothers, many of whom may understandably have intense needs, was excluded from the sample.

Another limitation of the study is that the NICU Family Needs Inventory was adapted to exclude the choice of "Not Applicable" for each statement. Therefore, it would be important to conduct validity and reliability analyses on the inventory with that modification. In addition, while the sample was more ethnically diverse than the samples used in many other investigations (Able-Boone & Stevens, 1994; Brazy et al., 2001; Miles et al., 1996; Ward, 2001), it was still comprised of significantly small numbers of races other than Caucasian and African American, such as Hispanic, Asian, and Middle Eastern. It would be important to include larger numbers of these other races in future studies, so that findings may be more representative of the United States' ever-changing demographics.

The fact that confidentiality guidelines mandated by the Health Insurance Portability and Accountability Act (HIPAA) did not allow for data to be collected on mothers who refused to participate in this study (e.g. race, age, income) may also be seen as a limitation. Examining these characteristics may have provided useful insight and sparked the need for additional inquiry. Similarly, the parameters of the informed consent for which I asked each participant to provide did not allow me to use secondary sources, such as patient medical billing records, to verify the data obtained using the Demographic Information Form. Therefore, I had no way of insuring that the information mothers reported on the forms, such as employment status, annual household income, and the infant's type of medical insurance, was truly accurate.

Generalizability can also be viewed as a limitation in this investigation. First, the results did not capture the opinions of mothers who did not visit their infants frequently enough to be approached to participate in the study. This group of mothers may have very different opinions about the needs they find most important to have fulfilled. In reality, mothers who do not visit their infants frequently should be of great concern and priority to interventionists, as they may be experiencing high risk life conditions that are keeping them from visiting. Secondly, differences are evident when comparing the available characteristics of the total population of infants in the NICU during the time frame in which this study took place (see Table 5) and the characteristics of mothers who participated in the study and their infants (see Table 7). For instance, the majority of the babies in the NICU at the time of the study were female (56%), but the majority of the babies associated with the study were male (63%). In addition, the mean birth weight for the infants involved in the study was almost 450 grams less than the mean birth weight for the NICU's entire population. Therefore, it can be argued that the study's sample did not capture an accurate representation of the NICU's population in every regard, limiting generalizability to other mothers. Lastly, the majority of the mothers in this investigation gave birth to their infants in the participating hospital, an urban, inner city facility. The same findings may not be applicable to mothers in suburban and rural areas.

Finally, when reviewing Leske's (1991) definitions and the specific survey items representative of the five need subscales on the NICU Family Needs Inventory, substantial confusion can occur. Given the mediocre reliability results obtained for this study's sample, are the subscales really measuring needs in distinctively different areas? In general, are the subscales socially valid constructs? This confusion is particularly evident when reviewing many of the items in the Assurance and Support domains. For instance, item #2 on the inventory (see Appendix B) refers to the need to be told about the NICU environment before visiting the infant for the first time. This item is factored into the Support subscale; however, one could argue that this item really addresses an Assurance need. The existing ambiguity also makes it difficult for providers to draw any real practical conclusions from total subscale data. Examining the results obtained regarding individual statements is much more useful and easier to infuse into practice. Therefore, while the statistical basis for the placement of each item in its respective subscale has been clearly supported with a valid factor analysis, there remains uncertainty about the conceptual basis, as there seems to be a gray area in which subjectivity can become an issue.

Summary

While parents of infants hospitalized in the NICU share a common experience, each may react differently and require different supports to help meet their needs during this often stressful and emotionally overwhelming time. Supports offered by providers must be tailored to address specific needs; however, it is often hard to clearly discriminate between the specific types of needs parents possess. This examination of the needs of mothers with infants in the NICU revealed a somewhat small preference for the need to be assured about infant outcomes. Significant predictive relationships were also identified between annual household income and mothers' Support needs, and infant length of hospitalization and mothers' Information needs. These findings offer additional insight for interventionists to consider when providing support to families, including the decision to design and implement a formal NICU parent support program. Additional investigations, such as those analyzing various other parent and infant characteristics in relation to parents' needs, and studies that involve more in-depth discussions with families about their specific needs and how providers can effectively help meet those needs during this experience, are needed.

APPENDIX A:

Howell’s Sample Size Determination Method

HOWELL'S (2005) SAMPLE SIZE DETERMINATION METHOD

The steps in Howell's process are as follows:

1. Set alpha level (ά), defined as the probability of rejecting a null hypothesis that is really true, also known as a Type I error.
2. Select desired effect size (R^2) using Cohen's criteria (small = .02, Medium = .13, large = .26).
3. Identify the highest possible number of predictor variables (*p;* Cohen uses *u*, "mu") to be used in the analysis.
4. Calculate the proportion of variance explained relative to the error variance (f^2; equal to $R^2/1-R^2$).
5. Determine the number of participants (N) you can realistically involve in the proposed investigation.
6. Calculate the degrees of freedom, known as "nu" (v; equal to $N- p - 1$).
7. Calculate lambda [λ; equal to $f^2 (p + v +1)$].
8. Use p (u), v (can be rounded down to be conservative), and λ in conjunction with the power tables provided in Cohen (1988, p. 416-423) to predict the power of the multiple regression analysis with the proposed number of participants.

The following table represents the outcome of several power analyses conducted prior to the start of the investigation using Howell's method. An appropriate sample size to use in the study was determined based on the results of those analyses.

Assumptions Based on Howell's Power Analysis Model for Large and Medium Effect Sizes, ά = .05

R^2 =	0.13	0.26	0.13	0.26	0.13	0.26	0.13	0.26
p =	4	4	4	4	4	4	4	4
N =	35	35	40	40	45	45	50	50
f^2 =	0.15	0.35	0.15	0.35	0.13	0.35	0.15	0.35
v =	30	30	35	35	40	40	45	45
λ =	5.25	12.25	6.00	14.00	5.85	15.75	7.47	17.57
Power for ά < .05 =	.26-.38	~0.69	.38-.44	.76-.83	.26-.44	.76-.89	.44-.57	~0.92

APPENDIX B:

NICU FAMILY NEEDS INVENTORY

NICU FAMILY NEEDS INVENTORY

Please check (√) how IMPORTANT each of the following needs are to you.

	Not Important (1)	Somewhat Important (2)	Important (3)	Very Important (4)
1. To know the expected outcome for my infant. (A)				
2. To be told about the environment before going into the neonatal intensive care unit (NICU) for the first time. (S)				
3. To be able to visit at any time. (P)				
4. To talk to the doctor caring for my infant every day. (I)				
5. To have questions about my infant answered honestly. (A)				
6. To feel there is hope. (A)				
7. To have friends/family nearby for support. (S)				
8. To have a waiting room for the neonatal unit. (C)				
9. To have someone to help with transportation. (S)				
10. To be given directions about how I can provide care to my infant in the NICU. (S)				
11. To know which staff members could give information about my infant's health and general well-being. (I)				
12. To share my feelings about what has happened. (S)				
13. To have a specific staff person to call at the hospital when unable to visit. (I)				
14. To be assured that the best care possible is being given to my infant. (A)				
15. To have a support group of other families available. (S)				
16. To have classes about premature infants and their special care needs. (I)				
17. To have a private place to breastfeed or use a breast pump. (S)				

	Not Important (1)	**Somewhat Important (2)**	**Important (3)**	**Very Important (4)**
18. To help make decisions about my infant's plan of care. (I)				
19. To have another person with me when visiting my infant in the NICU. (S)				
20. To know exactly what is being done for my infant. (I)				
21. To have comfortable furniture in the waiting room. (C)				
22. To have a pastor, clergy, or other person from my church visit. (S)				
23. To be assured it is alright to leave the hospital for awhile. (A)				
24. To have a telephone near the waiting room. (C)				
25. To feel accepted by the hospital staff. (C)				
26. To feel it is alright to cry. (I)				
27. To be given information about individuals that could help with problems concerning my situation. (S)				
28. To have someone be concerned with my health. (S)				
29. To talk to the same nurse most of the time. (P)				
30. To have a bathroom near the waiting room. (C)				
31. To talk about the possibility of my infant's death. (S)				
32. To have comfortable chairs at my infant's bedside. (C)				
33. To be given reading material concerning my infant's medical concerns. (I)				
34. To have explanations given that are understandable. (A)				
35. To feel that the hospital personnel care about my infant. (A)				
36. To be allowed to help with my infant's physical care. (I)				
37. To be told about transfer plans while they are being made. (P)				
38. To receive information about my infant at least once a day. (P)				
39. To see my infant frequently. (P)				

	Not Important (1)	**Somewhat Important (2)**	**Important (3)**	**Very Important (4)**
40. To be told specific facts concerning my infant's progress. (A)				
41. To have the waiting room near the NICU. (P)				
42. To be recognized as important in my infant's recovery. (A)				
43. To receive help in responding to the reactions of my infant's sibling(s). (S)				
44. To be able to talk to other parents whose infant is in the NICU or has had a similar situation. (S)				
45. To be allowed to have my infant's sibling(s) visit. (S)				
46. To feel free to choose to stay or leave when my infant is experiencing painful procedures. (A)				
47. To have a place to sleep near the NICU. (S)				
48. To know why things were done for my infant. (I)				
49. To be called at home about important changes in my infant's condition. (P)				
50. To know that my infant is being treated for pain. (A)				
51. To have a place to be alone while in the hospital. (S)				
52. To know that my infant is being handled gently by healthcare providers. (A)				
53. To know how my infant is being treated medically. (I)				
54. To have the neonatal unit quiet and lights dimmed at regular times to let my infant rest. (S)				
55. To hold my infant in my arms and against my skin as soon as I can. (P)				
56. To see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using blankets to support my infant's body, and talking softly to my infant. (C)				

Legend: The 5 Subscales of the instrument are: (A)= Assurance, (P)= Proximity, (I)= Information, (C)= Comfort, and (S)= Support

APPENDIX C:

DEMOGRAPHIC INFORMATION FORM

DEMOGRAPHIC INFORMATION FORM

1. **Age: ________** years

2. Race: ***(Check one box)***

☐ 1- White
☐ 2- Hispanic American
☐ 2- Black
☐ 2- Asian
☐ 2- Other

3. Marital Status: ***(Check one box)***

☐ 1- Married or other live-in relationship
☐ 2- Single, divorced, separated or widowed

4. Highest Level of Education Completed: ***(Check one box)***

☐ 1- Less than high school graduation
☐ 2- High school diploma or GED
☐ 3- College Degree (AA or higher)

5. How many family members do you have living in your household? ***(Note: Do not include non-relative housemates or roommates, but do include your infant/s)***

____

6. How many of the family members living in your household are children under the age of 18?

____

7. Are you currently employed?
(Check one box)

☐ 1-Yes ☐ 2-No

If yes, in what type of work?

____

8. What is your combined household yearly income ***(Note: include income of all family members living in your household)*?** ***(Check one box)***

☐ 1- Less than $10,000
☐ 2- Between $10,000 and $30,000
☐ 3- Between $30,000 and $70,000
☐ 4- Greater than $70,000

9. What type of health insurance does your baby have? ***(Check one box)***

☐ 1- none
☐ 2- private
☐ 3- public medical assistance

10. How often do you visit your baby in the hospital? ***(Check one box)***

☐ Daily
☐ 3-5 days per week
☐ 2 or less days per week

11. How long does it take you to get to the hospital, from the time you leave your house to the time you arrive at the hospital? ____________ minutes

12. How do you usually get to the hospital to visit your baby? ***(Check one box)***

☐ 1- Drive in your own car
☐ 2- Get a ride from a friend or family member
☐ 3- Public Transportation (bus, metro, taxi)

13. When do you prefer to visit your baby? ***(Check one box)***

☐ 1- Early morning (before 9:00 a.m.)
☐ 2- Morning (between 9:00 a.m. and 12:00 p.m.)
☐ 3- Afternoon (between 12:00 and 5:00 p.m.)
☐ 4- Evening (between 5:00 and 9:00 p.m.)
☐ 5- Late night (after 9:00 p.m.)
☐ 6- Weekends

APPENDIX D:

INFANT HEALTH INFORMATION FORM

INFANT HEALTH INFORMATION FORM

1. Birth weight ___________grams

2. Gestational Age __________ weeks *(Note: Use GA by date unless there is a 2 week or more discrepancy between age by date and age by exam—then use age by exam)*

3. Birth type *(circle one)*: single twin triplet quad quint

   If multiple, birth order _______

4. Length of stay in the NICU _________days

5. Hospital of birth ____

6. History of: ventilation ☐ Yes ☐ No oscillator ☐ Yes ☐ No

7. Current respiration *(circle one)*: room air O2 hood nasal canula

8. Current bedding *(circle one)*: open crib isolette KDC table

9. Current feeding *(circle all that apply)*: TPN tube feed nipple feed

10. Presence of Condition(s) with High Probability of Developmental Delay *(check all that apply)*:

☐ Bronchopulmonary dysplasia (BPD)

☐ Intraventricular hemorrhage (IVH)
Grade *(circle one)*: III or IV

☐ Periventricular Leukomalacia (PVL)

☐ Congenital infection
Specify: ______________________

☐ Effects of maternal drug abuse

☐ Prematurity with LBW <1,200 g

☐ Surgical necrotizing enterocolitis (NEC)

☐ Acquired Immune Deficiency Syndrome (AIDS)

☐ Inborn errors of metabolism
Specify: ______________________

☐ Neurodegenerative disorder
Specify: ______________________

☐ Seizures

☐ Severe encephalopathy

☐ Sensory Impairment
Specify: ______________________

☐ Chromosomal disorder
Specify: ______________________

☐ Severe congenital malformation
Specify: ______________________

Developmental Delay Index Score: ☐

APPENDIX E:

RANDOMIZATION TABLES FOR INFANT SELECTION IN CASES OF MULTIPLE BIRTHS

TWINS

Participant Number	**Birth Order of Infant to Select**
1	2
2	2
3	1
4	1
5	1
6	1
7	2
8	2
9	1
10	1
11	1
12	2
13	2
14	2
15	2
16	2
17	2
18	2
19	1
20	2
21	1
22	1
23	1
24	1
25	1
26	1
27	2
28	1
29	2
30	2
31	1
32	1
33	2
34	2
35	2
36	1
37	2
38	2
39	1
40	1
41	2
42	2
43	2
44	2
45	2
46	1

TRIPLETS

Participant Number	**Birth Order of Infant to Select**
1	3
2	2
3	2
4	2
5	3
6	1
7	1
8	3
9	2
10	3
11	3
12	3
13	1
14	3
15	2
16	2
17	2
18	1
19	2
20	2
21	2
22	3
23	3
24	1
25	1
26	3
27	2
28	2
29	2
30	1
31	3
32	3
33	2
34	3
35	3
36	2
37	1
38	1
39	2
40	3
41	1
42	1
43	2
44	2
45	3
46	2

APPENDIX F:

CONSENT FORM

CONSENT FORM

Project Title	An Examination of the Needs of Mothers with Infants in the Neonatal Intensive Care Unit
Why is this research being done?	This is a research project being conducted by the Department of Special Education at the University of Maryland, College Park. We are inviting you to participate in this research project because you are the mother of an infant hospitalized in the neonatal intensive care unit (NICU) at the UMMS Hospital for Children. The purpose of this study is to identify the needs that mothers feel are most important to have fulfilled while their infants are in the NICU. Another objective of the study is to determine whether or not certain parent and infant characteristics are related to parent opinions about those needs.
What will I be asked to do?	Participation in this study will take approximately 30 minutes. If you agree to participate in this study you will be asked to fill out a survey about your feelings about the importance of having certain needs met while your baby is in the NICU. You will read statements on the survey about various needs, such as the need to have other family members visit your infant while he or she is in the NICU, and then rank your opinion about the importance of those statements. You will be asked to provide some demographic information about you and your family (e.g. your age, race, etc.) too. This will help us describe the general population of people who participated in our study. You will also be asked to grant the investigator permission to review your baby's medical records in order to obtain information about his or her health.
What about confidentiality?	We will do our best to keep your personal information confidential. To help protect your confidentiality, all surveys and data forms used in this study are anonymous and will not contain information that may personally identify you. A code will be placed on the surveys and other forms used to collected data. We will keep a list of the participants’

	names separate from your responses on the survey and demographic form, as well as on the form used to collect data about your infant's health. Through the use of an identification key, the researcher will be able to link your survey to your identity and only the researcher will have access to the identification key. This will help to ensure that your opinions and family information are kept confidential. All study-related documents will be kept in a locked file cabinet at all times, again with only the researcher having access to that file cabinet. If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.
What are the risks of this research?	While participation in this study may help you identify your own unique needs, upon doing so, you may feel that those needs are not being adequately met. These feelings may cause psychological distress. In such a case, you will be asked whether or not you would like to be linked with a hospital social worker that can assist you with your concerns. The social worker may also be able to provide you with resources to help meet your needs. Such a referral would be completely confidential, voluntary, and unrelated to the study. In addition, while the study involves the collection of data on the health status of your infant, his or her medical record may also contain confidential personal information about you (i.e. sexually transmitted disease diagnoses, AIDS status, substance abuse). Therefore, while it will not be recorded on study-related documents, the investigator reviewing your infant’s medical record may view this information. There is also a risk of accidental disclosure of study-related data. However, in order to avoid the potential risk of loss of confidentiality, all study surveys and data forms will be coded with participant numbers and kept in a locked file cabinet.

What are the benefits of this research?	This research is not designed to benefit you or your baby. However, even if this research does not help you personally, the results may help the investigator learn more about the support needs of families with infants in the NICU. We hope that, in the future, other people might benefit from this study through improved understanding of these needs. This may help hospital staff organize and implement support programs.
Do I have to be in this research? May I stop participating at any time?	Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify, nor will it affect the care that your child receives in the NICU.
What if I have questions?	This research is being conducted by Dr. Paula Beckman at the University of Maryland, College Park. If you have any questions about the research study itself, please contact Dr. Beckman, Department of Special Education, University of Maryland, College Park, Maryland, 20742; (email) pbeckman@umd.edu; (telephone) 301-405-6492. If you have questions about your rights as a research subject or wish to report a research-related injury, please contact: Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742; (e-mail) irb@deans.umd.edu; (telephone) 301-405-0678. This research has been reviewed according to the University of Maryland, College Park procedures for research involving human subjects.

Statement of Age of Subject and Consent [*Please note: Parental consent always needed for minors.]*	*Your signature indicates that:* *you are at least 18 years of age or an emancipated minor;* *the research has been explained to you;* *your questions have been fully answered; and* *you freely and voluntarily choose to participate in this research project.*		
Signature and Date *[Please add name, signature, and date lines to the final page of your consent form]*	**NAME OF SUBJECT**		
	SIGNATURE OF SUBJECT		
	DATE		

APPENDIX G:

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA) AUTHORIZATION FORM

Health Insurance Portability and Accountability Act
AUTHORIZATION TO OBTAIN, USE AND DISCLOSE PROTECTED HEALTH INFORMATION FOR RESEARCH

Name: ____

Date of Birth: __________**Medical Record Number**: __________SSN: __________

Federal laws require that hospitals, researchers and health care providers protect the privacy of information that identifies your child and relates to your child's past, present and future physical and mental health or conditions, or the provision of health care. If you agree to participate in this research, protected health information will be used and shared with others. The following questions and answers provide more specific information about how your child's information will be used, protected and shared.

THE INFORMATION WILL BE USED OR DISCLOSED TO PERFORM THE FOLLOWING RESEARCH STUDY:

UMB IRB Number: H-27336
"An Examination of the Needs of Mothers with Infants in the NICU"

The protected health information to be Used or Disclosed:

- Your child's medical records from University of Maryland Medical System relating to eligibility for the study and participation in the study including: doctors' notes or medical summaries related to diagnosed medical conditions, and current and past medical statuses.

THE FOLLOWING ARE AUTHORIZED TO USE OR DISCLOSE THE INFORMATION:

- UMMS Medical Records staff
- UMMS NICU staff
- Dr. Brenda Hussey Gardner and her research team.

THE FOLLOWING ARE AUTHORIZED TO RECEIVE SOME OR ALL OF THE INFORMATION:

- Federal and state agencies that have authority over the research, UMMS/UPI/VAMHCS, or patients (for example the Department of Health and Human Services, the Food and Drug Administration, the National Institutes of Health, the Office of Human Research Protections, the Department of Social Services or other governmental offices a required by law)
- Hospital or other accrediting agencies
- Representatives of Federal agencies, the University of Maryland College Park and University of Maryland Baltimore Institutional Review Board, University of Maryland Baltimore Research Compliance offices, and/or University of Maryland Baltimore (UMMS/UPI/VAMHCS) Legal Counsel may review records in order to meet federal or state regulations.

EXPIRATION DATE FOR THIS AUTHORIZATION

This authorization will not expire.

ADDITIONAL INFORMATION ABOUT THIS AUTHORIZATION

- You can change your mind and not let the researcher disclose or use your child's protected health information (revoke the Authorization). If you revoke the Authorization, you must send a written letter to: Dr. Brenda Hussey Gardner, Department of Neonatology, University of Maryland Medical System, Baltimore, Maryland, 21201 to inform her of your decision. If you revoke this Authorization, researchers may only use and disclose the protected health information already collected for this research study. If you change your mind and withdraw the authorization, you may not be allowed to continue to participate in the study.
- You have the right to choose not to sign this form. However, if you decide not to sign, you cannot participate in the research. Refusing to sign will not affect the present or future care you/your child receive at this institution and will not cause any penalty or loss of benefits to which you are otherwise entitled.
- Once your child's health information has been disclosed to anyone outside of the UMSOM/UPI, UMMS/VAMHCS, the federal law designed to protect your privacy may no longer protect the information. The researchers are required to take reasonable steps to protect your child's health information by using and disclosing it only as described in this Authorization.
- Subject to certain legal limitations, you have the right to access your child's protected health information that is created during this research that relates to your treatment or payment, provided your right to access is not exempted by law. In some cases, you may access this information only after the study analyses are complete. To request this information, you will need to contact the UMB Privacy Officer at (410-706-0337).

My signature indicates that I authorize the use and disclosure of my protected health information for the purposes described above. I also permit my doctors and other health care providers to disclose my protected health information for the purposes described above.

Signature: ____________________________ Date: _______

Name (printed) _____________________________________

APPENDIX H:

MULTIPLE REGRESSION CORRELATION AND MODEL SUMMARY TABLES

Parent Category Analysis (Stage 1)

Dependent Variable = Assurance

Correlations

		ASSURANCE	Annual Income	Age	Race
Pearson Correlation	ASSURANCE	1.000	.057	.055	.005
	Annual Income	.057	1.000	-.418	-.254
	Age	.055	-.418	1.000	.221
	Race	.005	-.254	.221	1.000
Sig. (1-tailed)	ASSURANCE	.	.354	.358	.487
	Annual Income	.354	.	.002	.044
	Age	.358	.002	.	.070
	Race	.487	.044	.070	.
N	ASSURANCE	46	46	46	46
	Annual Income	46	46	46	46
	Age	46	46	46	46
	Race	46	46	46	46

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.057	.003	-.019	.19428	.003	.142	1	44	.708
2	.104	.011	-.035	.19578	.008	.329	1	43	.569
3	.104	.011	-.060	.19809	.000	.003	1	42	.954

1 Predictor: (Constant), Annual Income

2 Predictors: (Constant), Annual Income, Age

3 Predictors: (Constant), Annual Income, Age, Race

Dependent Variable = Proximity
Correlations

		PROXIMITY	Annual Income	Age	Race
Pearson Correlation	PROXIMITY	1.000	.080	-.008	-.070
	Annual Income	.080	1.000	-.418	-.254
	Age	-.008	-.418	1.000	.221
	Race	-.070	-.254	.221	1.000
Sig. (1-tailed)	PROXIMITY	.	.300	.480	.323
	Annual Income	.300	.	.002	.044
	Age	.480	.002	.	.070
	Race	.323	.044	.070	.
N	PROXIMITY	46	46	46	46
	Annual Income	46	46	46	46
	Age	46	46	46	46
	Race	46	46	46	46

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.080	.006	-.016	.28719	.006	.280	1	44	.599
2	.084	.007	-.039	.29040	.001	.034	1	43	.854
3	.101	.010	-.061	.29338	.003	.129	1	42	.721

1 Predictor: (Constant), Annual Income
2 Predictors: (Constant), Annual Income, Age
3 Predictors: (Constant), Annual Income, Age, Race

Dependent Variable = Comfort
Correlations

		COMFORT	Annual Income	Age	Race
Pearson Correlation	COMFORT	1.000	.186	-.050	-.082
	Annual Income	.186	1.000	-.418	-.254
	Age	-.050	-.418	1.000	.221
	Race	-.082	-.254	.221	1.000
Sig. (1-tailed)	COMFORT	.	.108	.370	.294
	Annual Income	.108	.	.002	.044
	Age	.370	.002	.	.070
	Race	.294	.044	.070	.
N	COMFORT	46	46	46	46
	Annual Income	46	46	46	46
	Age	46	46	46	46
	Race	46	46	46	46

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.186	.035	.013	.50419	.035	1.579	1	44	.215
2	.189	.036	-.009	.50978	.001	.040	1	43	.842
3	.193	.037	-.032	.51537	.002	.071	1	42	.791

1 Predictor: (Constant), Annual Income
2 Predictors: (Constant), Annual Income, Age
3 Predictors: (Constant), Annual Income, Age, Race

Dependent Variable = Support
Correlations

		SUPPORT	Annual Income	Age	Race
Pearson Correlation	SUPPORT	1.000	.462	-.207	-.187
	Annual Income	.462	1.000	-.418	-.254
	Age	-.207	-.418	1.000	.221
	Race	-.187	-.254	.221	1.000
Sig. (1-tailed)	SUPPORT	.	.001	.083	.107
	Annual Income	.001	.	.002	.044
	Age	.083	.002	.	.070
	Race	.107	.044	.070	.
N	SUPPORT	46	46	46	46
	Annual Income	46	46	46	46
	Age	46	46	46	46
	Race	46	46	46	46

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.462	.213	.196	.46002	.213	11.944	1	44	.001
2	.462	.214	.177	.46527	.000	.013	1	43	.909
3	.468	.219	.163	.46928	.005	.268	1	42	.607

1 Predictor: (Constant), Annual Income
2 Predictors: (Constant), Annual Income, Age
3 Predictors: (Constant), Annual Income, Age, Race

Dependent Variable = Information

Correlations

		INFORMATION	Annual Income	Age	Race
Pearson Correlation	INFORMATION	1.000	-.174	.014	-.159
	Annual Income	-.174	1.000	.210	-.275
	Age	.014	.210	1.000	.194
	Race	-.159	-.275	.194	1.000
Sig. (1-tailed)	INFORMATION	.	.127	.464	.149
	Annual Income	.127	.	.083	.034
	Age	.464	.083	.	.100
	Race	.149	.034	.100	.
N	INFORMATION	45	45	45	45
	Annual Income	45	45	45	45
	Age	45	45	45	45
	Race	45	45	45	45

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.174	.030	.008	.25204	.030	1.336	1	43	.254
2	.181	.033	-.013	.25468	.003	.115	1	42	.736
3	.220	.048	-.021	.25570	.015	.665	1	41	.419

1 Predictor: (Constant), Annual Income
2 Predictors: (Constant), Annual Income, Age
3 Predictors: (Constant), Annual Income, Age, Race

Infant Category Analysis (Stage 2)

Dependent Variable = Assurance

Correlations

		ASSURANCE	DD Risk Index Score	Birth weight (gms)	Length of Stay (days)
Pearson Correlation	ASSURANCE	1.000	.118	-.145	-.047
	DD Index Score	.118	1.000	-.419	.330
	Birth weight (gms)	-.145	-.419	1.000	-.503
	Length of Stay (days)	-.047	.330	-.503	1.000
Sig. (1-tailed)	ASSURANCE	.	.217	.168	.380
	DD Index Score	.217	.	.002	.014
	Birth weight (gms)	.168	.002	.	.000
	Length of Stay (days)	.380	.014	.000	.
N	ASSURANCE	46	46	46	44
	DD Index Score	46	46	46	44
	Birth weight (gms)	46	46	46	44
	Length of Stay (days)	44	44	44	44

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.118	.014	-.010	.19334	.014	.594	1	42	.445
2	.158	.025	-.023	.19459	.011	.464	1	41	.500
3	.218	.048	-.024	.19470	.023	.951	1	40	.335

1 Predictor: (Constant), DD Index Score
2 Predictors: (Constant), DD Index Score, Birth weight (gms)
3 Predictors: (Constant), DD Index Score, Birth weight (gms), Length of Stay (days)

Dependent Variable = Proximity
Correlations

		PROXIMITY	DD Risk Index Score	Birth weight (gms)	Length of Stay (days)
Pearson Correlation	PROXIMITY	1.000	.055	-.038	-.094
	DD Index Score	.055	1.000	-.419	.330
	Birth weight (gms)	-.038	-.419	1.000	-.503
	Length of Stay (days)	-.094	.330	-.503	1.000
Sig. (1-tailed)	PROXIMITY	.	.360	.401	.271
	DD Index Score	.360	.	.002	.014
	Birth weight (gms)	.401	.002	.	.000
	Length of Stay (days)	.271	.014	.000	.
N	PROXIMITY	46	46	46	44
	DD Index Score	46	46	46	44
	Birth weight (gms)	46	46	46	44
	Length of Stay (days)	44	44	44	44

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.055	.003	-.021	.28783	.003	.125	1	42	.725
2	.057	.003	-.045	.29128	.000	.011	1	41	.916
3	.150	.023	-.051	.29201	.019	.794	1	40	.378

1 Predictor: (Constant), DD Index Score
2 Predictors: (Constant), DD Index Score, Birth weight (gms)
3 Predictors: (Constant), DD Index Score, Birth weight (gms), Length of Stay (days)

Dependent Variable = Comfort
Correlations

		COMFORT	DD Risk Index Score	Birth weight (gms)	Length of Stay (days)
Pearson Correlation	COMFORT	1.000	.166	.009	-.176
	DD Index Score	.166	1.000	-.419	.330
	Birth weight (gms)	.009	-.419	1.000	-.503
	Length of Stay (days)	-.176	.330	-.503	1.000
Sig. (1-tailed)	COMFORT	.	.135	.476	.126
	DD Index Score	.135	.	.002	.014
	Birth weight (gms)	.476	.002	.	.000
	Length of Stay (days)	.126	.014	.000	.
N	COMFORT	46	46	46	44
	DD Index Score	46	46	46	44
	Birth weight (gms)	46	46	46	44
	Length of Stay (days)	44	44	44	44

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.166	.028	.004	.50630	.028	1.192	1	42	.281
2	.187	.035	-.012	.51045	.008	.319	1	41	.575
3	.297	.088	.020	.50243	.053	2.319	1	40	.136

1 Predictor: (Constant), DD Index Score
2 Predictors: (Constant), DD Index Score, Birth weight (gms)
3 Predictors: (Constant), DD Index Score, Birth weight (gms), Length of Stay (days)

Dependent Variable = Support

Correlations

		SUPPORT	DD Risk Index Score	Birth weight (gms)	Length of Stay (days)
Pearson Correlation	SUPPORT	1.000	.078	-.039	-.248
	DD Index Score	.078	1.000	-.419	.330
	Birth weight (gms)	-.039	-.419	1.000	-.503
	Length of Stay (days)	-.248	.330	-.503	1.000
Sig. (1-tailed)	SUPPORT	.	.302	.399	.053
	DD Index Score	.302	.	.002	.014
	Birth weight (gms)	.399	.002	.	.000
	Length of Stay (days)	.053	.014	.000	.
N	SUPPORT	46	46	46	44
	DD Index Score	46	46	46	44
	Birth weight (gms)	46	46	46	44
	Length of Stay (days)	44	44	44	44

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.078	.006	-.018	.51739	.006	.260	1	42	.613
2	.079	.006	-.042	.52365	.000	.002	1	41	.967
3	.333	.111	.044	.50152	.104	1.697	1	40	.036

1 Predictor: (Constant), DD Index Score
2 Predictors: (Constant), DD Index Score, Birth weight (gms)
3 Predictors: (Constant), DD Index Score, Birth weight (gms), Length of Stay (days)

Dependent Variable = Information
Correlations

		INFORMATION	DD Risk Index Score	Birth weight (gms)	Length of Stay (days)
Pearson Correlation	INFORMATION	1.000	.033	.051	-.320
	DD Index Score	.033	1.000	-.381	.322
	Birth weight (gms)	.051	-.381	1.000	-.499
	Length of Stay (days)	-.320	.322	-.499	1.000
Sig. (1-tailed)	INFORMATION	.	.418	.372	.018
	DD Index Score	.418	.	.006	.018
	Birth weight (gms)	.372	.006	.	.000
	Length of Stay (days)	.018	.018	.000	.
N	INFORMATION	43	43	43	43
	DD Index Score	43	43	43	43
	Birth weight (gms)	43	43	43	43
	Length of Stay (days)	43	43	43	43

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.033	.001	-.023	.25188	.001	.044	1	41	.835
2	.076	.006	-.044	.25440	.005	.191	1	40	.665
3	.362	.131	.064	.24087	.125	5.618	1	39	.023

1 Predictor: (Constant), DD Index Score
2 Predictors: (Constant), DD Index Score, Birth weight (gms)
3 Predictors: (Constant), DD Index Score, Birth weight (gms), Length of Stay (days)

Across Category Analysis (Stage 3)

Dependent Variable = Support

Correlations

		SUPPORT	Annual Income	Length of Stay (days)
Pearson Correlation	SUPPORT	1.000	.460	-.248
	Annual Income	.462	1.000	-.200
	Length of Stay (days)	-.248	-.200	1.000
Sig. (1-tailed)	SUPPORT	.	.001	.053
	Annual Income	.001	.	.097
	Length of Stay (days)	.053	.097	.
N	SUPPORT	46	46	44
	Annual Income	46	46	44
	Length of Stay (days)	44	44	44

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.462	.213	.195	.46027	.213	11.401	1	42	.002
2	.489	.239	.202	.45833	.025	1.355	1	41	.251

1 Predictor: (Constant), Parent Annual Household Income

2 Predictors: (Constant), Parent Annual Household Income, Infant Length of Stay in NICU

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