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Mothers' and fathers' perceptions of parenting one-month old infants with respiratory distress syndrome or bronchopulmonary dysplasia

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University of Nebraska at Omaha

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MOTHERS' AND FATHERS' PERCEPTIONS OF PARENTING ONE-MONTH-OLD INFANTS WITH RESPIRATORY DISTRESS SYNDROME OR BRONCHOPULMONARY DYSPLASIA

A Field Project

Presented to the

Department of Psychology

and the

Faculty of the Graduate College

University of Nebraska

In Partial Fulfillment

of the Requirements for the Degree

Educational Specialist

University of Nebraska at Omaha

by

Nancy Marron

June, 1993
Acknowledgments

I would like to thank the members of my committee for their support and assistance with this project. Thanks to Dr. J. Michael Leibowitz and Dr. Kenneth E. Smith for their statistical advice; to Dr. Robert H. Woody for his persistence in keeping the project on schedule; and to Dr. Susan Epps for her excellent technical guidance, superb editing skills, and, above all, unending patience and encouragement. Special appreciation also is expressed to the parents who participated in the study.
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FIELD PROJECT ACCEPTANCE

Acceptance for the faculty of the Graduate College, University of Nebraska, in partial fulfillment of the requirements for the degree, Educational Specialist, University of Nebraska at Omaha.

Committee

<table>
<thead>
<tr>
<th>Name</th>
<th>Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michael Leinweber</td>
<td>UNMC Pediatrics</td>
</tr>
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</table>

Chairperson

Date

7-1-93
Chapter I

Introduction and Purpose of the Study

Recent significant advances in the field of neonatology have resulted in increased rates of survival of infants who are born prematurely (Avery & Taeusch, 1984). Although mortality rates have decreased, many of these children and their families may be faced with complications related to prematurity, extended hospitalization, numerous lifesaving medical procedures, and a lengthy recovery.

This research is part of a larger study funded by a research grant from the University of Nebraska Medical Center. The purpose of this research is to study the levels of parenting stress (which includes depression, attachment, restrictions imposed by parental role, sense of competence, social isolation, relationship with spouse, parental health, and life stress), anxiety, and health locus of control in parents of medically complex infants. This study included (Group 1) parents of 1-month-old infants hospitalized with a diagnosis of respiratory distress syndrome (RDS). Group 2 included parents of infants hospitalized for one month with a diagnosis of bronchopulmonary dysplasia (BPD). Measures were used to determine mothers' and fathers' levels of stress due to parents' characteristics or life stress events, together with levels of anxiety, and perception of their own control of their child's illness. In order to facilitate more positive outcomes for such infants and their parents, a wide range of health care and allied health care providers needs to understand the level of stress and anxiety experienced by parents and means to reduce it.
Chapter II
Literature Review

Several topics were reviewed in the literature for this study including respiratory distress syndrome, bronchopulmonary dysplasia, stress and anxiety of parents and families of premature infants, parent-infant attachment, parent-infant interaction, and health locus of control. A computerized search was conducted reviewing the medical literature (Medline) for the years 1989 through July of 1992 and the psychological literature (PsycLIT) for the years 1983 through July of 1992. Also reviewed were several earlier dated articles which were frequently referred to by recent research. Over 200 articles were reviewed.

Parent Reaction to Premature Birth

Previous research (e.g., Affleck, Tennen, & Rowe, 1991; Brooten et al., 1988; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Lowenthal, 1989) has described as very stressful the birth of a premature or otherwise medically at-risk infant who must remain in intensive care. Sources of stress for parents include their lack of preparation for premature birth, the violation of their expectations of a healthy infant, their doubts about the infant's ability to survive, and the overwhelming appearance of the neonatal intensive care unit (NICU) with its high number of staff, high-technology equipment, and loud alarms (Affleck et al., 1991; Affleck & Tennen, 1991; Brooten et al., 1988; Lowenthal, 1989; Patteson & Barnard, 1990).

Parental reactions to the birth of an ill infant often parallel the grief process experienced with the death of a loved one (Blacher, 1984; Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975; Ladden, 1990; Mercer, 1974; Sabbeth, 1984.) Parents of sick infants appear to grieve the shattered dreams of the joyous event of the birth of a normal, healthy child.
Parent/Premature Infant Bonding

Parent-infant bonding is often delayed because parents are hesitant to become attached to a child who subsequently might die (Blacher & Meyers, 1983; Harper, Sia, Sokal, & Sokal, 1976; Jarvis, Myers, & Creasey, 1989; Leander & Pettett, 1986; Plunkett, Klein, & Meisels, 1988). The importance of parent-infant attachment is well documented (Ainsworth, 1973; Ainsworth, 1979). Reactive attachment disorder or nonorganic failure to thrive (Drotar & Sturm, 1987; Leander & Pettett, 1986; Tibbits-Kleber & Howell, 1985) can ensue if a secure attachment fails to develop.

Another factor contributing to the lack of bonding is the NICU environment itself (Affleck et al., 1991; Blackburn & Barnard, 1985; Gottfried, 1985). Medically fragile infants typically have difficulty tolerating normal interactions such as being held or talked to. Infants with breathing disorders, such as respiratory distress syndrome or bronchopulmonary dysplasia, need to have individualized developmental care plans in order for health care providers as well as parents to respond appropriately to the infant's distress signals, thereby enhancing physiological stability (Als et al., 1986). It has been recommended that nursing procedures be grouped together so that the infant's sleep is not interrupted repeatedly (Viscardi & Fox, 1991). Infants who must expend a large amount of their energy on breathing are typically irritable and difficult to calm. When they become upset, blood oxygen levels can drop.

Also problematic is the crowded, noisy NICU, which offers little privacy for parents to interact with their baby. One method of beneficial interaction, called "kangaroo care," can be difficult to implement in a crowded nursery. This skin-to-skin contact between parent and infant has been shown to improve regulation of breathing and maintenance of temperature. There is less crying, more time in deep sleep, more time spent in quiet/alert state, and shorter hospitalizations. It has also been shown to

Preterm infants have been shown to be significantly less responsive to social stimulation than their fullterm peers (Crnic, Ragozin, Greenberg, Robinson, & Basham, 1983; Minde, Whitelaw, Brown, & Fitzhardinge, 1983). The infant's irritability, lack of response or synchrony (timing) of responses can create a feeling of rejection on the part of the parents, and may result in an attachment impairment. Parents also may be fearful of interacting due to their infant's fragile condition.

Parent-child interactions are affected by reciprocity (Bell, 1971; Collis & Schaffer, 1975; Korner, 1974; Stern, 1974). If a parent attempts to gain the attention of the child by talking, stroking, or other method and the child does not respond, the parent must work harder (Landry, Chapieski, & Schmidt, 1986). Parents of preterm infants are not readily reinforced for their attempts at interactions. Washington, Minde, and Goldberg (1986) found that low birthweight preterm infants assessed for temperamental characteristics were significantly more irritable than fullterm infants. The stress associated with parenting a chronically ill child can have far-reaching effects on parenting behavior and, as a result, on child development. In a study by Ventura (1981), parents who were depressed or anxious saw their infant as having a less desirable temperament.

Parents' Health Locus of Control

Parents of premature infants often feel a loss of control over the fate of their infant. The normal parenting role they were anticipating has been taken over by numerous medical care providers, most of whom are unknown (Affleck et al., 1991; Brooten et al., 1988; Perlman et al., 1991; Thomas, 1988). In addition, parents may feel stress from a lack of control over the extent of medical procedures used to prolong
the inevitable death of their child (Avery, 1985) or medical practices that may cause pain to the infant (Lawson, 1988).

Health locus of control, or how a person attributes health outcomes, has been shown in many studies to predict how a person will deal with a stressful health situation, or can even predict a health outcome. For example, in a study by Tinsley and Holtgrave (1989), mothers' degree of perceived control (or internal locus of control) over their child's health, predicted use of preventive health care such as well-baby checks and immunizations, and even predicted the child's health outcome. The more control the mother felt over her infant's health, the more likely she was to seek preventive health care. This extra care resulted in better health status for the child. Other studies found similar results regarding the connection between internal health locus of control and health outcomes in the areas of cardiology patients (Fleetwood & Packa, 1991), patients suffering from panic attacks (Katterndahl, 1991), back pain (Harkapaa, 1991), and multiple sclerosis (Wassem, 1991).

**Other Parental Stressors**

Other forms of stress for parents may be the financial burden of a hospitalized child. Lower socioeconomic status (SES) or income level has been associated with higher stress levels. Flynt and Wood (1989) found that mothers of children with moderate mental retardation were more stressed if they came from a lower SES group compared to mothers from higher SES. Phipps, Drotar, Joseph, Geiss, and Doershuk (1989) found that the level of family financial resources predicted mood disturbances of parents.

If the prognosis is indefinite or subject to several different professional interpretations, the parental stress is increased (Bernheimer, Young, & Winton, 1983). Additional stressors include the lack of time for other children in the family,
or the lack of opportunity to resume a normal social life (Affleck et al., 1991; Harding, Heller, & Kesler, 1979).

**Parental Coping**

Few studies have examined differences between mothers' and fathers' coping styles. Affleck et al. (1991) found that mothers reported more mood disturbance at discharge than did fathers. It was theorized that fathers may desire to minimize their outward emotional response to the crisis resulting in the appearance of fewer mood disturbances and that fathers tend to act as the more optimistic partner in order to give support to the more anxious and depressed mothers.

Affleck et al. (1991) also studied parents' coping responses. Those who coped well used cognitive adaptations such as downward comparisons in which they compared their infants with others in the NICU who were not as healthy. They found benefits in the birth crisis such as the strengthening of family ties. Parents also believed they had improved patience, tolerance, empathy, and a better sense of priorities as a result of their experience.

Crnic (1983) studied the relationship of stress and social support to attitude. Social support was found to moderate the effects of stress and to improve reports of life satisfaction. Patteson and Barnard (1990) found that multiple long-term contacts with parents were most effective in influencing favorable infant developmental outcomes. The type of intervention was not critical, but the long-term contact appeared to act as a social support system for the family.

Beckman and Pokorni (1988) followed 44 preterm infants to assess the amount of stress and support reported by primary caregivers over time. Informal social support resulted in lowered stress levels measured when infants were 3, 12, and 24 months of age. Although the level of stress varied over time, stress was related to child
problems (e.g., rehospitalization, etc.). Therefore, a family's needs are likely to change over time depending on the child's medical status. In some instances, more social support when the infant was one age was associated with decreased family stress at subsequent ages.

**Respiratory Distress Syndrome**

Infants in this study were diagnosed as having respiratory distress syndrome or the more serious bronchopulmonary dysplasia. Infants born prematurely are subject to respiratory complications. The most common source of mortality and morbidity in premature infants is respiratory distress syndrome (RDS), also known as hyaline membrane disease (Martin & Fanaroff, 1991; Hansen & Corbet, 1991; Viscardi & Fox, 1991). It occurs in approximately 1% of all newborns basically as a result of the deficient production of surfactant, a substance normally present in a fullterm infants that lines the inner surfaces of the lungs.

The air system of the lung consists of a tree-like formation of larger bronchioles, which branch into smaller alveoli, the terminal air cells (Ensher & Clark, 1986). With a surfactant deficiency, the alveoli can collapse when a neonate first expires air. Respiratory failure can follow as air cannot reach the collapsed alveoli, while the more proximal bronchioles take on too much air and become distended. As arterioles and capillaries are destroyed, there is less lung surface area and volume, and the exchange of gases becomes less efficient resulting in lowered oxygen levels in the bloodstream.

Production of surfactant does not begin until the 24th week of gestation (Hansen & Corbet, 1991) and the production system is not complete until 34 to 36 weeks (Ensher & Clark, 1986). Therefore, risk of RDS increases with shorter gestation, occurring in nearly 70% of infants born at 28 to 30 weeks (Martin & Fanaroff, 1991).
Symptoms visible in a newborn with RDS include grunting respirations, retraction of the chest area, increased breathing rate, and cyanosis (a bluish or grayish skin color due to decreased blood oxygenation). Presently available methods of preventing RDS include administering artificial surfactant at birth or a prepartum dose of glucocorticoid to encourage lung development (Martin & Fanaroff, 1991). These methods, together with others that prevent early labor, have reduced the severity of symptoms of RDS. However, since an increasing number of short-gestation preterm infants is being saved with advances in medical technology, RDS will remain a concern.

**Bronchopulmonary Dysplasia**

An uncomplicated case of RDS may begin to resolve within 72 hours (Martin & Fanaroff, 1991). However, when an infant has an acute case of RDS, it may become necessary to provide artificial means to assist breathing. Several methods can be implemented, each with its advantages and disadvantages that must be carefully weighed given the potential seriousness of the infant's disease.

Continuous positive airway pressure (CPAP) is a less invasive type of ventilation that helps to open the small alveoli and to keep them open during expiration (Viscardi & Fox, 1991). Intermittent positive pressure ventilation (IPPV) is used when CPAP is insufficient to provide sufficient oxygenation. IPPV uses peak inspiratory pressure (PIP) to deal with the stiffness of the lung tissue and decreased lung volume and to re-expand collapsed aveoli.

Positive end-expiratory pressure (PEEP) keeps the aveoli from collapsing when air is expired (Fox, Spitzer, & Shatack, 1988). Use of this type of ventilation has been linked with a more serious type of lung disease, bronchopulmonary dysplasia (BPD). It is an iatrogenic disease caused by life-saving techniques necessary for infants with underdeveloped lungs (Ensher & Clark, 1986). First named by Northway (1967), BPD
appears to be caused by the artificial introduction of a high percentage of supplemental oxygen, the positive pressure created by the ventilator, and the stress of the mechanical ventilation causing damage to airways. A diagnosis of BPD is typically delayed until an infant has remained ventilator dependent for 28-30 days and shows radiological signs of lung damage (Avery & Taeusch, 1984). Research continues to investigate the toxicity associated with various oxygen levels and the optimum pressure for providing adequate oxygenation yet avoiding lung damage.

High frequency ventilation has recently been used to avoid the lung damage caused by other forms of ventilation. Smaller volumes of air are induced at extremely rapid rates (60 has been shown to maintain adequate oxygen levels) using lower airway pressures which results in fewer complications such as pulmonary air leak (Clark, Gerstmann, Null & deLemos, 1992).

Infants with BPD have slower-than-normal alveolar growth and excess mucous production in the airways. The damage itself causes the infant to be ventilator dependent for a longer period of time. Infants with BPD usually have been born after a short gestation period, have low birthweight, decreased levels of oxygen in the blood, and difficulties with feeding and digestion. As a result, they often have extended hospital stays (Meisels, Plunkett, Roloff, Pasick, & Stiefel, 1986). Infants with BPD can experience many sequelae of the disease such as malnutrition and failure to thrive. They have a need for additional calories, yet cannot tolerate excess fluid. Decreased bone density due to calcium and vitamin D deficiencies can result in easily fractured bones (Korones, 1988).

BPD infants are at greater risk for growth retardation in their early years. Meisels et al. (1986) found that when compared to RDS infants, the BPD infants did less well on developmental and language measures. Type of lung disease may be a more
accurate predictor of cognitive development than prematurity or low birth weight alone. In a study of 236 very low birthweight surviving infants, Teberg, Pena, Finello, Aguilar, and Hodgman (1991) found that 60% developed BPD. These infants were smaller and had lower Apgar scores. (Apgar scores assess an infant's heart rate, color, reflex irritability, respiratory effort, and muscle tone at one and five minutes after birth (Ensher & Clark, 1986)). At one-year follow-up, 42% of the BPD infants had experienced abnormal development compared to 7% of the infants without BPD. Associated with poor outcome were intraventricular hemorrhage and seizures. Smyth, Tabachnik, Duncan, Reilly, and Levison (1981) found persistent respiratory symptoms and abnormal chest radiographs in follow-ups of 8-year-old children with BPD.

**Research Questions**

The current literature review strongly suggests that parents and families do experience stress and anxiety as a result of having an infant with chronic illness. This stress can affect the parent-infant interaction, which can, in turn, affect the development of the child. Additionally, factors such as health locus of control, social and emotional support, and socioeconomic status can affect stress levels.

Further research is necessary to examine the independent variable effects of parent (mother, father) and diagnosis (RDS, BPD). The literature review produced no studies comparing parents of infants with RDS to parents of infants with BPD.

The current research seeks to address the following specific questions:

1. What are the differences between mothers’ and fathers’ levels of stress, anxiety, and health locus of control? Are there main effects for parent gender?

2. Are there differences among stress, anxiety, and health locus of control in parents of 1-month-old infants with RDS and parents of infants with BPD? Are there main effects for infant diagnosis?
Chapter III
Method

Participants

Included in the study were two independent groups. Group 1 consisted of mothers and fathers of 13 infants (5 females and 8 males) with respiratory distress syndrome (RDS) and no diagnosis of bronchopulmonary dysplasia (BPD). Group 2 included mothers and fathers of 11 infants (4 females and 7 males) with (BPD). Because BPD develops from respiratory distress syndrome, infants in Group 2 also may have had a diagnosis of respiratory distress syndrome. Infant demographic information is contained in Table I. The only statistically significant difference between groups was on infants' 5-minute Apgar score ($t(22) = 2.31, p = .03$).

Table II compares the couples' length of marriage or live-in relationship (three couples were not married but living together), annual family income, and Hollingshead Index (described on page 16). Tables III and IV compare demographic information for RDS vs. BPD mothers and RDS vs. BPD fathers. Table III displays information including parents' ethnicity and education. Table IV contains parents' religious preference and their frequency of church attendance. No significant differences were found on these demographics.
Table I

Demographic Characteristics of Infants, by Group

<table>
<thead>
<tr>
<th></th>
<th>RDS</th>
<th>BPD</th>
<th>$\chi^2(1, N=24)$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td>.01</td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Gestation Age at Birth in Weeks</td>
<td></td>
<td></td>
<td>1.16</td>
</tr>
<tr>
<td>$\bar{x}$</td>
<td>31.4</td>
<td>29.5</td>
<td></td>
</tr>
<tr>
<td>$SD$</td>
<td>4.5</td>
<td>3.7</td>
<td></td>
</tr>
<tr>
<td>Birth Weight in Grams</td>
<td></td>
<td></td>
<td>0.44</td>
</tr>
<tr>
<td>$\bar{x}$</td>
<td>1,619.0</td>
<td>1,449.8</td>
<td></td>
</tr>
<tr>
<td>$SD$</td>
<td>998.8</td>
<td>821.6</td>
<td></td>
</tr>
<tr>
<td>Apgar Score at 1 Minute</td>
<td></td>
<td></td>
<td>0.76</td>
</tr>
<tr>
<td>$\bar{x}$</td>
<td>5.2</td>
<td>4.5</td>
<td></td>
</tr>
<tr>
<td>$SD$</td>
<td>2.5</td>
<td>1.9</td>
<td></td>
</tr>
<tr>
<td>*Apgar Score at 5 Minutes</td>
<td></td>
<td></td>
<td>2.31*</td>
</tr>
<tr>
<td>$\bar{x}$</td>
<td>7.5</td>
<td>6.4</td>
<td></td>
</tr>
<tr>
<td>$SD$</td>
<td>1.2</td>
<td>1.3</td>
<td></td>
</tr>
<tr>
<td>Length of Hospital Stay in Days</td>
<td></td>
<td></td>
<td>1.54</td>
</tr>
<tr>
<td>$\bar{x}$</td>
<td>61.2</td>
<td>86.7</td>
<td></td>
</tr>
<tr>
<td>$SD$</td>
<td>55.6</td>
<td>24.8</td>
<td></td>
</tr>
</tbody>
</table>

*a* Respiratory Distress Syndrome (n = 13). *b* Bronchopulmonary Dysplasia (n = 11).

* $P = .0345$
### Table II

**Demographic Characteristics of Parent Participants, by Group**

<table>
<thead>
<tr>
<th></th>
<th>RDS (^a)</th>
<th>BPD (^b)</th>
<th>(\bar{X}) (18)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Length of Marriage in Months</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>87.4</td>
<td>61.3</td>
<td>0.94</td>
</tr>
<tr>
<td>(SD)</td>
<td>80.7</td>
<td>21.8</td>
<td></td>
</tr>
<tr>
<td><strong>Length of Live-In Relationship in Months</strong></td>
<td></td>
<td></td>
<td>(\bar{X}) (1)</td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>16.0</td>
<td>24.0</td>
<td>0.58</td>
</tr>
<tr>
<td>(SD)</td>
<td>1.1</td>
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<td></td>
</tr>
<tr>
<td><strong>Annual Family Income</strong></td>
<td></td>
<td></td>
<td>(\bar{X}) (22)</td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>22,019.69</td>
<td>29,000.00</td>
<td>1.43</td>
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<tr>
<td>(SD)</td>
<td>10,174.66</td>
<td>13,699.05</td>
<td></td>
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<tr>
<td><strong>Hollingshead Index of Social Status (^c)</strong></td>
<td></td>
<td></td>
<td>1.10</td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>32.3</td>
<td>38.3</td>
<td></td>
</tr>
<tr>
<td>(SD)</td>
<td>11.0</td>
<td>15.6</td>
<td></td>
</tr>
</tbody>
</table>

\(^a\) Respiratory Distress Syndrome \((n = 13)\). \(^b\) Bronchopulmonary Dysplasia \((n = 11)\).  
\(^c\) See Table VII for categories of Hollingshead Index of Social Status.
### Table III

**Demographic Characteristics of Parent Participants, By Parent and by Group**

<table>
<thead>
<tr>
<th></th>
<th>RDS a</th>
<th>BPD b</th>
<th>( \chi^2(1, N=24) )</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
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<tr>
<td><strong>Frequencies</strong></td>
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<td></td>
</tr>
<tr>
<td>Ethnicity:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>9</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Asian-American</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>African-American</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Native American</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Percentages</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First Marriage</td>
<td>Yes</td>
<td>84.6</td>
<td>63.6</td>
</tr>
<tr>
<td>Housing Situation</td>
<td>One-Family</td>
<td>61.5</td>
<td>72.7</td>
</tr>
<tr>
<td></td>
<td>Apartment</td>
<td>15.4</td>
<td>27.3</td>
</tr>
<tr>
<td></td>
<td>Mobile Home</td>
<td>23.1</td>
<td>0.0</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \bar{X} )</td>
<td>28.4</td>
<td>30.5</td>
<td>25.5</td>
</tr>
<tr>
<td>( \bar{SD} )</td>
<td>5.9</td>
<td>7.0</td>
<td>5.0</td>
</tr>
<tr>
<td>Number of Children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \bar{X} )</td>
<td>2.4</td>
<td>2.6</td>
<td>2.3</td>
</tr>
<tr>
<td>( \bar{SD} )</td>
<td>0.9</td>
<td>0.9</td>
<td>1.2</td>
</tr>
<tr>
<td>Years of Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \bar{X} )</td>
<td>12.5</td>
<td>13.0</td>
<td>13.6</td>
</tr>
<tr>
<td>( \bar{SD} )</td>
<td>1.1</td>
<td>2.2</td>
<td>3.1</td>
</tr>
</tbody>
</table>

\( ^a \) Respiratory Distress Syndrome (n = 13). \( ^b \) Bronchopulmonary Dysplasia (n = 11).
Table IV

Parent Religion Demographics, by Parent and by Group

<table>
<thead>
<tr>
<th></th>
<th>RDS&lt;sup&gt;a&lt;/sup&gt;</th>
<th></th>
<th>BPD&lt;sup&gt;b&lt;/sup&gt;</th>
<th></th>
<th>(\chi^2(1, N=24))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
</tr>
<tr>
<td>Religion - Frequencies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>9</td>
<td>9</td>
<td>8</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Catholic</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.92</td>
</tr>
<tr>
<td>Church Attendance -</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Times per Year</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>20.4</td>
<td>20.1</td>
<td>25.8</td>
<td>19.5</td>
<td></td>
</tr>
<tr>
<td>(SD)</td>
<td>21.5</td>
<td>21.4</td>
<td>25.3</td>
<td>25.8</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup>Respiratory Distress Syndrome \(n=13\).  <sup>b</sup>Bronchopulmonary Dysplasia \(n=11\).
Tables V and VI compare the same demographics as Tables III and IV, however differences between mothers and fathers within groups were measured. There were no significant differences between mothers and fathers within the RDS group or between mothers and fathers in the BPD group.

Socioeconomic status (SES) of the participants was measured by the Hollingshead Four Factor Index of Social Status (Hollingshead, 1975). It uses occupation, education, sex, and marital status to determine a level of social status. Occupation scores are multiplied by a factor weight of five, and education scores are multiplied by a factor weight of three. If both husband and wife are employed, a score is calculated by adding their scores and dividing by two to determine a single score for the couple. Those couples who were not married but living together were scored in the same manner. Scores can range from 8 to 60, with five major social strata as shown in Table VII.

Littman and Parmelee (1978) developed a 10-item Postnatal Complications Scale, which notes the complications that occurred during the infant's first month of life. NICU medical records for both groups of infants were reviewed; Table VIII lists the frequency of complications. The only significant difference between the two groups was
### Table V

Demographic Characteristics of Parent Participants, by Group

<table>
<thead>
<tr>
<th></th>
<th>RDS (^{a})</th>
<th>BPD (^{b})</th>
<th>(\chi^2(1, N=24))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
</tr>
<tr>
<td><strong>Frequencies</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>9</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Asian-American</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>African-American</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Native American</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Percentages</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First Marriage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>84.6</td>
<td>84.6</td>
<td>63.6</td>
</tr>
<tr>
<td>Housing Situation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One-Family</td>
<td>61.5</td>
<td>69.2</td>
<td>72.7</td>
</tr>
<tr>
<td>Apartment</td>
<td>15.4</td>
<td>7.7</td>
<td>27.3</td>
</tr>
<tr>
<td>Mobile Home</td>
<td>23.1</td>
<td>23.1</td>
<td>0.0</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>28.4</td>
<td>30.5</td>
<td>25.5</td>
</tr>
<tr>
<td>(SD)</td>
<td>5.9</td>
<td>7.0</td>
<td>5.0</td>
</tr>
<tr>
<td><strong>Number of Children</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>2.4</td>
<td>2.6</td>
<td>2.3</td>
</tr>
<tr>
<td>(SD)</td>
<td>0.9</td>
<td>0.9</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>Years of Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>12.5</td>
<td>13.0</td>
<td>13.6</td>
</tr>
<tr>
<td>(SD)</td>
<td>1.1</td>
<td>2.2</td>
<td>3.1</td>
</tr>
</tbody>
</table>

\(^{a}\)Respiratory Distress Syndrome (n = 13). \(^{b}\)Bronchopulmonary Dysplasia (n = 11).
Table VI

**Parent Religion Demographics, by Group**

<table>
<thead>
<tr>
<th>Religion</th>
<th>Mothers</th>
<th>Fathers</th>
<th>RDS (^a)</th>
<th>BPD (^b)</th>
<th>(\chi^2(1, N=24))</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>2.00</td>
</tr>
<tr>
<td>Protestant</td>
<td>9</td>
<td>9</td>
<td>8</td>
<td>8</td>
<td>0.42</td>
</tr>
<tr>
<td>Catholic</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>0.81</td>
</tr>
</tbody>
</table>

\(1(24) \quad 1(20)\)

<table>
<thead>
<tr>
<th>Church Attendance - Times per Year</th>
<th></th>
<th></th>
<th>(\chi^2(1, N=24))</th>
</tr>
</thead>
<tbody>
<tr>
<td>(\bar{X})</td>
<td>20.4</td>
<td>20.1</td>
<td>0.04</td>
</tr>
<tr>
<td>(SD)</td>
<td>21.5</td>
<td>21.4</td>
<td>0.58</td>
</tr>
<tr>
<td></td>
<td>25.8</td>
<td>19.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>25.3</td>
<td>25.8</td>
<td></td>
</tr>
</tbody>
</table>

\(^a\)Respiratory Distress Syndrome (n = 13). \(^b\)Bronchopulmonary Dysplasia (n = 11).
Table VII

Categories of Hollingshead Social Strata

<table>
<thead>
<tr>
<th>Social Strata</th>
<th>Range of Computed Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major business and professional</td>
<td>55 - 66</td>
</tr>
<tr>
<td>Medium business, minor professional, technical</td>
<td>40 - 54</td>
</tr>
<tr>
<td>Skilled craftsmen, clerical, sales workers</td>
<td>30 - 39</td>
</tr>
<tr>
<td>Machine operators, semiskilled workers</td>
<td>20 - 29</td>
</tr>
<tr>
<td>Unskilled laborers, menial service workers</td>
<td>8 - 19</td>
</tr>
</tbody>
</table>
in the greater number of surgeries performed on the BPD infants ($\chi^2(1, N = 24) = 4.11, p = .043$). Table IX shows other infant diagnoses.

The importance of social support and its potential to mitigate the stress and anxiety experienced by parents of medically fragile infants is of interest to health care providers who work with these parents. Therefore, participants were asked to report information regarding their sources of social support (See Table X) and emotional support (See Table XI). Comparisons were made between RDS mothers and BPD mothers and between RDS fathers and BPD fathers. Tables XII and XIII show the same information when the comparison is between RDS mothers and fathers and between BPD mothers and fathers. RDS mothers reported significantly more support from relatives than RDS fathers.

Procedure

In an effort to obtain participants for this study, the principal investigator (PI) attended the weekly NICU psychosocial rounds where unit staff discussed family issues. When an infant met the initial criteria of being in intensive care for 1 month, nurses were questioned about whether the family would be appropriate for the study. Exclusionary criteria included congenital anomaly or parenting by a single parent. If nursing staff viewed the family as excessively stressed or angry, the parents were not
Table VIII

Postnatal Complications\textsuperscript{a}, by Group

<table>
<thead>
<tr>
<th>Complication</th>
<th>RDS\textsuperscript{b}</th>
<th>BPD\textsuperscript{c}</th>
<th>$\chi^2(1, N=24)$</th>
</tr>
</thead>
<tbody>
<tr>
<td>No First Feeding within 48 Hours of Birth</td>
<td>2</td>
<td>1</td>
<td>0.22</td>
</tr>
<tr>
<td>Hyperbilirubinemia/Exchange Transfusion</td>
<td>10</td>
<td>8</td>
<td>0.06</td>
</tr>
<tr>
<td>Infection</td>
<td>11</td>
<td>9</td>
<td>0.03</td>
</tr>
<tr>
<td>Noninfectious Illness</td>
<td>3</td>
<td>4</td>
<td>0.51</td>
</tr>
<tr>
<td>Respiratory Distress</td>
<td>12</td>
<td>11</td>
<td>0.88</td>
</tr>
<tr>
<td>*Surgery</td>
<td>2</td>
<td>6</td>
<td>4.11*</td>
</tr>
<tr>
<td>Temperature Disturbance</td>
<td>7</td>
<td>5</td>
<td>0.17</td>
</tr>
<tr>
<td>Ventilatory Assistance</td>
<td>0</td>
<td>11</td>
<td>1.85</td>
</tr>
<tr>
<td>Convulsion</td>
<td>0</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Metabolic Abnormality</td>
<td>0</td>
<td>1</td>
<td>1.23</td>
</tr>
</tbody>
</table>

Total Score

\begin{align*}
\bar{X} & = 5.2 \\
SD & = 1.5
\end{align*}

\[1 \ (22)\]

\textsuperscript{a}Postnatal Complications Scale (Littman & Parmelee, 1978).

\textsuperscript{b}Respiratory Distress Syndrome ($n = 13$). \textsuperscript{c}Bronchopulmonary Dysplasia ($n = 11$).

*\(p = 0.043\).
Table IX

Frequency of Other Diagnoses, by Group

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>RDS(^a)</th>
<th>BPD(^b)</th>
<th>(\chi^2(1, N=24))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory Distress Syndrome (n = 13)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retinopathy of Prematurity I</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Retinopathy of Prematurity II</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Retinopathy of Prematurity III</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Retinopathy of Prematurity IV</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Retinopathy of Prematurity V</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Cytomegalovirus</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Meningitis</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Apnea/Bradycardia</td>
<td>3 (2, 0.09)</td>
<td>2 (0.50)</td>
<td></td>
</tr>
<tr>
<td>Sepsis</td>
<td>4</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Biliary Atresia</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Diaphragmatic Hernia</td>
<td>0</td>
<td>2</td>
<td>2.58</td>
</tr>
<tr>
<td>Necrotizing Enterocolitis</td>
<td>2 (1.85)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Periventricular Leukomacia</td>
<td>1</td>
<td>1</td>
<td>0.02</td>
</tr>
<tr>
<td>Meconium Aspiration</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Patent Ductus Arteriosus</td>
<td>5</td>
<td>2</td>
<td>1.19</td>
</tr>
<tr>
<td>Small for Gestational Age</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Prematurity</td>
<td>8</td>
<td>10</td>
<td>2.74</td>
</tr>
<tr>
<td>Other Diagnosis</td>
<td>7</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Intraventricular Hemorrhage I</td>
<td>3 (0.84)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Intraventricular Hemorrhage II</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Intraventricular Hemorrhage III</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Intraventricular Hemorrhage IV</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Heart and Lung Machine</td>
<td>3</td>
<td>0</td>
<td>0.84</td>
</tr>
</tbody>
</table>

\(^a\)Respiratory Distress Syndrome (n = 13). \(^b\)Bronchopulmonary Dysplasia (n = 11).
### Table X

**Social Network Characteristics of Parent Participants, by Parent and by Group**

<table>
<thead>
<tr>
<th></th>
<th>RDS&lt;sup&gt;a&lt;/sup&gt;</th>
<th>BPD&lt;sup&gt;b&lt;/sup&gt;</th>
<th>1 (22)</th>
<th>1 (19)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
<td>Fathers</td>
</tr>
<tr>
<td><strong>Social Network Size</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \overline{x} )</td>
<td>29.0</td>
<td>19.6</td>
<td>19.8</td>
<td>18.6</td>
</tr>
<tr>
<td>SD</td>
<td>34.4</td>
<td>29.9</td>
<td>27.8</td>
<td>29.6</td>
</tr>
<tr>
<td>Health Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \overline{x} )</td>
<td>10.2</td>
<td>8.4</td>
<td>11.9</td>
<td>6.4</td>
</tr>
<tr>
<td>SD</td>
<td>5.4</td>
<td>6.0</td>
<td>11.1</td>
<td>5.6</td>
</tr>
<tr>
<td>Relatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \overline{x} )</td>
<td>12.8</td>
<td>8.9</td>
<td>14.3</td>
<td>11.9</td>
</tr>
<tr>
<td>SD</td>
<td>5.7</td>
<td>4.8</td>
<td>13.8</td>
<td>14.6</td>
</tr>
</tbody>
</table>

<sup>a</sup> Respiratory Distress Syndrome (n = 13).  
<sup>b</sup> Bronchopulmonary Dysplasia (n = 11).
Table XI

**Emotional Support Characteristics of Parent Participants, by Parent and by Group**

<table>
<thead>
<tr>
<th>Emotional Support Source - Frequencies</th>
<th>RDS a</th>
<th>BPD b</th>
<th>( \chi^2(1, N=24) )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
</tr>
<tr>
<td>Minister, etc.</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Marriage/Family</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Counselor</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Psychologist/</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Parent Group</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

aRespiratory Distress Syndrome (n = 13). bBronchopulmonary Dysplasia (n = 11).
Table XII

Social Network Characteristics of Parent Participants, by Group

<table>
<thead>
<tr>
<th></th>
<th>RDS a</th>
<th>BPD b</th>
<th>t (22)</th>
<th>t (19)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
<td>Fathers</td>
</tr>
<tr>
<td>Social Network Size</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>29.0</td>
<td>19.6</td>
<td>19.8</td>
<td>18.6</td>
</tr>
<tr>
<td></td>
<td>34.4</td>
<td>29.9</td>
<td>27.8</td>
<td>29.6</td>
</tr>
<tr>
<td>Health Care</td>
<td>10.2</td>
<td>8.4</td>
<td>11.9</td>
<td>6.4</td>
</tr>
<tr>
<td></td>
<td>5.4</td>
<td>6.0</td>
<td>11.1</td>
<td>5.6</td>
</tr>
<tr>
<td>*Relatives</td>
<td>12.8</td>
<td>8.9</td>
<td>14.3</td>
<td>11.9</td>
</tr>
<tr>
<td></td>
<td>5.7</td>
<td>4.8</td>
<td>13.8</td>
<td>14.6</td>
</tr>
</tbody>
</table>

aRespiratory Distress Syndrome (n = 13). bBronchopulmonary Dysplasia (n = 11).

*Significant at the .05 level.
**Table XIII**

**Emotional Support Characteristics of Parent Participants, by Groups**

<table>
<thead>
<tr>
<th></th>
<th>RDS a</th>
<th></th>
<th>BPD b</th>
<th></th>
<th>(\chi^2(1, , N=24))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
<td>Fathers</td>
<td>RDS</td>
</tr>
<tr>
<td>Minister, etc.</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>0.18</td>
</tr>
<tr>
<td>Marriage/Family</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Counselor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologist/</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Group</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>0.00</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>0.54</td>
</tr>
</tbody>
</table>

\(a\) Respiratory Distress Syndrome (n = 13). \(b\) Bronchopulmonary Dysplasia (n = 11).
approached for participation. This exclusion could have an impact on the representiveness of the sample. However, there were ethical concerns about potentially exacerbating parents' stress or anger by requesting their participation.

If nurse approval was obtained, the PI met with the primary nurse or nurse caring for the baby to arrange a meeting time with the parents. The researcher made herself available 24 hours a day requesting the nurses to page her when the selected parents were visiting their infant. When the researcher met with the parents, the study was explained in detail and an informed consent form was discussed and signed. At this point, all parents accepted the invitation to participate. However, one father who had begun to answer the surveys did not complete them; therefore, this couple was dropped from the study. When meeting with the parents, a concerted effort was made to be sensitive to their current life situation. It was emphasized that all information would be held in strict confidence and that any comments they made regarding the quality of care their child was receiving would not be relayed to hospital staff under any circumstances.

The researcher then conducted an informal interview to obtain demographic information. The three measures and an open-ended question the parents were to complete were explained in detail. Parents had the option to complete the protocols immediately in the hospice room or by their baby’s bedside. They also could take them home if they preferred and return them in a postage paid envelope.

Instrumentation

Measures used were the Parenting Stress Index (Loyd & Abidin, 1985); the Multidimensional Health Locus of Control Scales (Wallston, Wallston, & DeVellis, 1978); the State-Trait Anxiety Inventory (Spielberger, 1980); and a “Most Important Problem” question.
**Parenting Stress Index (PSI).** The Parenting Stress Index was designed to identify parent-child systems that are at-risk for inappropriate parenting behaviors or child behavior problems due to a high level of stress within the system. Developed by Abidin in 1983 and revised by Loyd and Abidin in 1985, the PSI includes 47 items in the child domain; these were not included in the current research. The parent domain includes 54 items measuring depression, unhappiness, and guilt; parent attachment; restrictions imposed by parental role; sense of competence, social isolation, relationship with spouse, and parental health. An optional life stress scale is also included. The manual lists three total score levels: High, Normal, and Extremely Low. A high total score suggests that a parent requires further professional consultation. Reliability coefficients for the parent subscales range from .55 to .80.

For the purpose of the current research, four questions in the parent domain were excluded since they were inappropriate for the parents' current circumstance (e.g., “When my child came home from the hospital;” their child was hospitalized. Average scores for the other items in each of the sense of competence and depression subscales were calculated and used for the four excluded questions.

**Multidimensional Health Locus of Control Scales (MHLC).** The Multidimensional Health Locus of Control Scales were developed by Wallston, Wallston, and De Vellis in 1978 and contains 18 items designed to assess people's beliefs about whether they have control over health-related issues (internal locus of control), if they believe that health is a matter of luck and is beyond their control (chance locus of control), or if they believe that their health is under the control of powerful others such as physicians and nurses (powerful others locus of control). Internal consistency reliabilities for the three subscales range from .67 to .75. There were 18 statements in three categories of health locus of control (Internal, Chance, and Powerful Others) used in the current
research. The statements were altered slightly to direct the answer toward the infant's health rather than the respondent's. Parents were asked to use a 5-point Likert scale to indicate their extent of agreement or disagreement with each statement.

**State-Trait Anxiety Inventory (STAI).** The State-Trait Anxiety Inventory, created by Spielberger and revised in 1980, is a self-report measure that assesses state and trait anxiety. It has been used extensively in both research and clinical practice. State anxiety may be described as the way a person feels at the present time. Trait anxiety is how a person feels generally or over a long period of time. The STAI consists of 20 statements measuring state anxiety and another 20 measuring trait anxiety. Statements such as "I feel strained" are ranked by the respondent on a 4-point scale ranging from "Not at all" to "Very much so." The participant receives an S-Anxiety score and a T-anxiety score ranging from 20 to 80. Internal consistency reliabilities range from .83 to .92.

The "Most Important Problem" (MIP) question asks the parents "What is the one most important problem/concern you have had in the past month?" Answers were coded into several categories such as "Difficulties with Finances," which could include problems with the ability to pay medical bills or not being able to make more money to help the family. The category, "Issues Related to Other Children in the Family" could include dividing time between children in the family or struggling with decisions to leave children with a sitter. Other categories were "Marital Stresses," "Conflicts with Extended Family," "Future Health/Disability of the Baby." These categories were developed after all surveys were completed. A complete list of the categories is shown in Table XIV. Parents' responses are shown in Table XV. Not all parents listed a most important problem, while others listed more than one. The most frequently reported concerns were present health status of the infant (53.8 percent of the RDS mothers
listed present health status of their infant as their primary concern), emotional
stressors, financial matters, and other children at home. These findings are consistent
with Bernheimer, Young, & Winton (1983) who found that an indefinite prognosis or
lack of time for other children in the family were significant stressors.

Insert Tables XIV and XV about here

All measures completed by parents were independently scored by at least two
researchers. In cases in which there was not 100% scorer agreement, a third scorer
rechecked each protocol to determine if calculation errors had been made. On measures
that involved subjective decisions, such as Hollingshead job classifications, the final
score was decided by consensus agreement by at least two scorers. This process resulted
in 100% interrater agreement.
### Table XIV

#### Most Important Problem Categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial</td>
<td>medical bills, expense of providing services for child.</td>
</tr>
<tr>
<td>Other Children at Home</td>
<td>dividing time between new baby and other children, disciplining of children.</td>
</tr>
<tr>
<td>Marital Stresses</td>
<td>parents have no time alone, accepting new lifestyle.</td>
</tr>
<tr>
<td>Conflicts with Extended Family</td>
<td>family's interference with decisions.</td>
</tr>
<tr>
<td>Future Health: Death</td>
<td>wondering if baby will survive.</td>
</tr>
<tr>
<td>Future Health: Disability</td>
<td>will baby be disabled later in life.</td>
</tr>
<tr>
<td>Future Health: Unknown</td>
<td>questions regarding baby's future health.</td>
</tr>
<tr>
<td>Future Medical Interventions/Complications</td>
<td>what medical treatment will be necessary in the future.</td>
</tr>
<tr>
<td>Present Health of Baby</td>
<td>not knowing how sick the baby actually is.</td>
</tr>
<tr>
<td>Waiting for Baby to Come Home</td>
<td>concerns about caring for the infant at home.</td>
</tr>
<tr>
<td>Frustration Because Baby Not Home</td>
<td>impatient to have baby at home or anxious about home care of baby.</td>
</tr>
<tr>
<td>Negative Emotions</td>
<td>anger, guilt, frustration with medical limitations.</td>
</tr>
<tr>
<td>Work-Related Stressors</td>
<td>struggling with decision to return to work.</td>
</tr>
<tr>
<td>Increased Parenting Demands</td>
<td>more responsibility than imagined.</td>
</tr>
<tr>
<td>Parents' Health Status</td>
<td>parents' illnesses.</td>
</tr>
<tr>
<td>Child Care</td>
<td>finding qualified babysitter.</td>
</tr>
<tr>
<td>Fatigue</td>
<td>lack of sleep.</td>
</tr>
<tr>
<td>Other</td>
<td>doctor was not prepared for the birth.</td>
</tr>
</tbody>
</table>
Table XV

Percentages of Parents' Indication of Most Important Problem/Concern

<table>
<thead>
<tr>
<th></th>
<th>RDS a</th>
<th>BPD b</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
</tr>
<tr>
<td>Financial</td>
<td>30.8</td>
<td>0</td>
</tr>
<tr>
<td>Other Children at Home</td>
<td>15.4</td>
<td>0</td>
</tr>
<tr>
<td>Marital Stresses</td>
<td>7.7</td>
<td>0</td>
</tr>
<tr>
<td>Conflicts-Extended Family</td>
<td>7.7</td>
<td>0</td>
</tr>
<tr>
<td>Future Health-Death</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Future Health-Disability</td>
<td>0</td>
<td>7.7</td>
</tr>
<tr>
<td>Future-Unknown</td>
<td>7.7</td>
<td>0</td>
</tr>
<tr>
<td>Future Medical Treatment</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Present Health of Baby</td>
<td>53.8</td>
<td>23.1</td>
</tr>
<tr>
<td>Wait-Baby to Come Home</td>
<td>7.7</td>
<td>0</td>
</tr>
<tr>
<td>Frustration-Baby Not Home</td>
<td>15.4</td>
<td>15.4</td>
</tr>
<tr>
<td>Negative Emotions</td>
<td>46.2</td>
<td>23.1</td>
</tr>
<tr>
<td>Work-Related Stressors</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Parenting Demands</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Parent Health Status</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Child Care</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Fatigue</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>7.7</td>
<td>38.5</td>
</tr>
</tbody>
</table>

Note. Some parents reported more than one problem/concern.
Chapter IV

Results

Scores from the Parenting Stress Index converted to percentile ranks are reported in Table XVI. According to Loyd & Abidin (1985), low scores are considered to be from the 1st percentile to the 19th; the normal range is from the 20th through the 89th; and the 90th through the 99th percentile is considered in the high range signifying that further counseling should be recommended. None of the groups of participants in this study received scores in the clinically significant range when compared to the PSI norms. In fact, all are within the average range with the exception of the Depression subscore which was below average, meaning that the parents were less depressed than average parents from the norming sample.

\[\text{Insert Table XVI about here}\]

Table XVII displays the percentile ranks for scores received by parents on the State-Trait Anxiety Inventory. These scores are based on percentile ranks for normal adults from 19 to 39 years of age (Spielberger, 1983). All parent participants in the current study received scores within one standard deviation of the mean.

\[\text{Insert Table XVII about here}\]

Results of the Multidimensional Health Locus of Control measure are reported in z-scores in Table XVIII. Standardization sample norms reported for this measure are as follows: Internal, 25.1 (SD = 4.9); Powerful Others, 20.0 (SD = 5.2); and Chance,
Table XVI

Parenting Stress Index Scores (Percentile Ranks)

<table>
<thead>
<tr>
<th></th>
<th>RDS \textsuperscript{a}</th>
<th>BPD \textsuperscript{b}</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
</tr>
<tr>
<td>PARENT DOMAIN</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression, Unhappiness, Guilt</td>
<td>15</td>
<td>25</td>
</tr>
<tr>
<td>Parent Attachment</td>
<td>50</td>
<td>80</td>
</tr>
<tr>
<td>Restrictions Imposed by Parental Role</td>
<td>44</td>
<td>44</td>
</tr>
<tr>
<td>Sense of Competence</td>
<td>40</td>
<td>50</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>53</td>
<td>62</td>
</tr>
<tr>
<td>Relationship with Spouse</td>
<td>40</td>
<td>43</td>
</tr>
<tr>
<td>Parental Health</td>
<td>75</td>
<td>58</td>
</tr>
<tr>
<td>LIFE STRESS</td>
<td>27</td>
<td>23</td>
</tr>
</tbody>
</table>

\textbf{Note.} Data analysis was conducted on raw scores. Table values were converted to percentile ranks.

\textsuperscript{a} Respiratory Distress Syndrome \((n = 13)\). \textsuperscript{b} Bronchopulmonary Dysplasia \((n = 11)\).
Table XVII

State-Trait Anxiety Inventory Scores

<table>
<thead>
<tr>
<th></th>
<th>RDS  (^a)</th>
<th></th>
<th>BPD  (^b)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
<td>Fathers</td>
</tr>
<tr>
<td>State Anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>40.7</td>
<td>37.5</td>
<td>39.4</td>
<td>39.0</td>
</tr>
<tr>
<td>(\text{SD})</td>
<td>16.1</td>
<td>11.2</td>
<td>11.4</td>
<td>7.1</td>
</tr>
<tr>
<td>Trait Anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\bar{X})</td>
<td>38.5</td>
<td>38.8</td>
<td>39.0</td>
<td>35.0</td>
</tr>
<tr>
<td>(\text{SD})</td>
<td>11.1</td>
<td>6.7</td>
<td>11.7</td>
<td>8.8</td>
</tr>
</tbody>
</table>

\(^a\)Respiratory Distress Syndrome (\(n = 13\)). \(^b\)Bronchopulmonary Dysplasia (\(n = 11\)).
Participants' scores for Internal locus of control ranged from 1.27 to 1.86 standard deviations below the mean. Scores for Powerful Others and Chance were within one standard deviation of the mean.

Results of t-test and chi square analyses revealed few significant differences between mothers in Group 1 and Group 2 and between fathers in Group 1 and 2 on demographic variables as previously shown (See Tables III, IV, X, & XI). Therefore, the two groups were collapsed into one group of 24 mothers and another group of 24 fathers. T-test comparisons were conducted to determine if there were significant differences between the new groups (mothers, fathers) in each of the three measures. Table XIX shows the results for the Parenting Stress Index. Fathers received significantly higher scores for the Parent Domain total (t (23) = 2.15, p = .042) and for the Parent Attachment subscore (t (23) = 4.68, p = .000+). Results for the Health Locus of Control Scales are shown in Table XX. Fathers reported significantly higher scores on Internal Locus of Control (t (23) = 2.24, p = .035). Table XXI displays the results for the State-Trait Anxiety Inventory, which shows that there were no significant differences between mothers and fathers on State or Trait Anxiety.
Table XVIII

**Multidimensional Health Locus of Control z-Scores**

<table>
<thead>
<tr>
<th></th>
<th>RDS a</th>
<th></th>
<th>BPD b</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td>Mothers</td>
<td>Fathers</td>
</tr>
<tr>
<td>Internal</td>
<td>-1.81</td>
<td>-1.27</td>
<td>-1.86</td>
<td>-1.68</td>
</tr>
<tr>
<td>Powerful Others</td>
<td>-.21</td>
<td>-.30</td>
<td>-.29</td>
<td>-.53</td>
</tr>
<tr>
<td>Chance</td>
<td>.28</td>
<td>.39</td>
<td>.33</td>
<td>.14</td>
</tr>
</tbody>
</table>

\(^{a}\)Respiratory Distress Syndrome (n = 13). \(^{b}\)Bronchopulmonary Dysplasia (n = 11).
Table XIX

T-Tests for Paired Samples of Mothers vs. Fathers for Parenting Stress Index

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mothers (N = 24)</th>
<th>Fathers (N = 24)</th>
<th>t (23)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( \bar{x} )</td>
<td>( s )</td>
<td>( \bar{x} )</td>
<td>( s )</td>
</tr>
<tr>
<td>*PARENT DOMAIN</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression, Unhappiness, Guilt</td>
<td>109.1 16.2</td>
<td>116.9 13.0</td>
<td>2.15</td>
<td>.042*</td>
</tr>
<tr>
<td>*Parent Attachment</td>
<td>14.8 4.5</td>
<td>16.2 3.2</td>
<td>1.40</td>
<td>.175</td>
</tr>
<tr>
<td>Restrictions Imposed by Parental Role</td>
<td>11.0 2.7</td>
<td>14.4 3.0</td>
<td>4.68</td>
<td>.00+*</td>
</tr>
<tr>
<td>Sense of Competence</td>
<td>17.5 3.7</td>
<td>18.0 3.1</td>
<td>.65</td>
<td>.519</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>26.4 5.2</td>
<td>27.5 3.6</td>
<td>1.17</td>
<td>.253</td>
</tr>
<tr>
<td>Relationship with Spouse</td>
<td>12.0 3.5</td>
<td>13.4 3.7</td>
<td>1.24</td>
<td>.227</td>
</tr>
<tr>
<td>Parental Health</td>
<td>14.5 3.2</td>
<td>15.9 3.9</td>
<td>1.53</td>
<td>.139</td>
</tr>
<tr>
<td>LIFE STRESS</td>
<td>12.9 2.6</td>
<td>11.6 2.5</td>
<td>1.60</td>
<td>.124</td>
</tr>
<tr>
<td></td>
<td>2.8 2.3</td>
<td>2.4 1.7</td>
<td>.79</td>
<td>.440</td>
</tr>
</tbody>
</table>

*Significant at the .05 level.
### Table XX

T-Tests for Paired Samples of Mothers vs. Fathers for Health Locus of Control

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mothers (N = 24)</th>
<th>Fathers (N = 24)</th>
<th>t (df = 23)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal Locus of Control</td>
<td>16.2 3.0</td>
<td>18.0 4.1</td>
<td>2.24</td>
<td>.035*</td>
</tr>
<tr>
<td>Powerful Others Locus of Control</td>
<td>18.7 3.3</td>
<td>17.8 3.7</td>
<td>.84</td>
<td>.409</td>
</tr>
<tr>
<td>Chance Locus of Control</td>
<td>17.4 3.1</td>
<td>17.3 3.9</td>
<td>.13</td>
<td>.901</td>
</tr>
</tbody>
</table>
Table XXI

**T-Tests for Paired Samples of Mothers vs. Fathers for State-Trait Anxiety Inventory**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mothers (N = 24)</th>
<th>Fathers (N = 24)</th>
<th>t (23)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X</td>
<td>SD</td>
<td>X</td>
<td>SD</td>
</tr>
<tr>
<td>State Anxiety</td>
<td>40.1</td>
<td>13.8</td>
<td>38.2</td>
<td>9.4</td>
</tr>
<tr>
<td>Trait Anxiety</td>
<td>38.8</td>
<td>11.1</td>
<td>37.0</td>
<td>7.8</td>
</tr>
</tbody>
</table>
When mothers and fathers within groups were compared on demographic variables (see Tables V, VI, XII, and XIII), few significant differences were found. Therefore the groups were collapsed into two groups of parents by diagnosis (RDS group, N = 26; BPD group, N = 22). Tables XXII, XXIII, and XXIV show the results of t-test comparisons of these groups on the Parenting Stress Index, Health Locus of Control, and State-Trait Anxiety Inventory. There were no significant differences between the RDS group and the BPD group on the three measures and their subscores.

Insert Tables XXII through XXIV about here
Table XXII
T-Tests for Independent Samples for Parenting Stress Index, by Group

<table>
<thead>
<tr>
<th>Variable</th>
<th>RDS a</th>
<th>BPD b</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$\bar{X}$</td>
<td>SD</td>
</tr>
<tr>
<td>PARENT DOMAIN</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression, Unhappiness, Guilt</td>
<td>15.8</td>
<td>3.4</td>
</tr>
<tr>
<td>Parent Attachment</td>
<td>13.3</td>
<td>2.2</td>
</tr>
<tr>
<td>Restrictions Imposed by Parental Role</td>
<td>17.8</td>
<td>3.2</td>
</tr>
<tr>
<td>Sense of Competence</td>
<td>27.8</td>
<td>3.4</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>12.7</td>
<td>2.5</td>
</tr>
<tr>
<td>Relationship with Spouse</td>
<td>15.2</td>
<td>2.9</td>
</tr>
<tr>
<td>Parental Health</td>
<td>12.2</td>
<td>1.5</td>
</tr>
<tr>
<td>LIFE STRESS</td>
<td>2.9</td>
<td>1.9</td>
</tr>
</tbody>
</table>

a Respiratory Distress Syndrome ($n = 26$). b Bronchopulmonary Dysplasia ($n = 22$).
Table XXIII

T-Tests for Independent Samples for Health Locus of Control, by Group

<table>
<thead>
<tr>
<th>Variable</th>
<th>RDS $^a$</th>
<th>BPD $^b$</th>
<th>t (22)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Internal</td>
<td>17.7</td>
<td>2.9</td>
<td>16.5</td>
<td>3.1</td>
</tr>
<tr>
<td>Powerful Others</td>
<td>18.7</td>
<td>2.9</td>
<td>17.8</td>
<td>1.5</td>
</tr>
<tr>
<td>Chance</td>
<td>17.5</td>
<td>1.9</td>
<td>17.0</td>
<td>3.2</td>
</tr>
</tbody>
</table>

$^a$Respiratory Distress Syndrome ($n = 26$). $^b$Bronchopulmonary Dysplasia ($n = 22$).
Table XXIV

T-Tests for Independent Samples for State-Trait Anxiety Inventory, by Group

<table>
<thead>
<tr>
<th>Variable</th>
<th>RDS(^a)</th>
<th>BPD(^b)</th>
<th>(t) (22)</th>
<th>(p)</th>
</tr>
</thead>
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<tr>
<td></td>
<td>(\bar{X})</td>
<td>SD</td>
<td>(\bar{X})</td>
<td>SD</td>
</tr>
<tr>
<td>State Anxiety</td>
<td>39.1</td>
<td>9.3</td>
<td>39.2</td>
<td>5.8</td>
</tr>
<tr>
<td>Trait Anxiety</td>
<td>38.7</td>
<td>7.5</td>
<td>37.0</td>
<td>8.2</td>
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</table>

\(^a\)Respiratory Distress Syndrome (n = 26). \(^b\)Bronchopulmonary Dysplasia (n = 22).
When the Respiratory Distress Syndrome (RDS) group was compared to the Bronchopulmonary Dysplasia (BPD) group, there were no significant differences between groups on the three measures used in this study. Possibly at this early stage (one month of hospitalization) the differences in diagnosis are more salient to hospital staff and researchers than they are for parents. Additional stress may be experienced by parents of BPD infants at a later date when they more fully realize the implications of serious lung disease.

When RDS and BPD groups were collapsed in order to compare mothers to fathers, there were several statistically significant findings. Fathers in this study received significantly higher scores in the Parent Domain of the Parenting Stress Index (PSI) than mothers. Higher scores on this measure translate to higher levels of dysfunction. Fathers were significantly less attached to their infants ($p = .00+$), and although no other subscore differences were significant, all father scores were higher than the mothers' which may indicate more stress in each area. Only in the Life Stress subscore did they report slightly less stress. It is important to recall, however, that scores for both mothers and fathers were well within the average range when compared to the standardization sample for the PSI.

The importance of parent-infant attachment or bonding has been well documented by researchers such as Ainsworth (1973, 1979). Yet it is often difficult to bond with an infant due to the distractions in a neonatal intensive care unit (Affleck et al., 1991; Blackburn & Barnard, 1985; Gottfried, 1985). Premature infants often have difficulty tolerating normal interactions (Als et al., 1986), are less responsive (Crnic et al., 1983; Minde et al., 1983), and therefore parents can feel rejected by their child,
which further interferes with the bonding process. Parents may be less likely to attach to their infants when they fear that the child may die (Blacher & Meyers, 1983; Harper et al., 1976; Jarvis et al., 1989; Leander & Pettett, 1986; Plunkett et al., 1988). Results of the present study indicate that health care providers in the NICU should ensure that fathers are encouraged to participate in the care of their infant in order to foster father-infant attachment.

In this study, the level of attachment of the participants to their infants was in the normal range. In fact, they did not report more stress than the typical parent on all areas measured. Other possible sources of parental stress, such as sense of competence, restrictions caused by the parental role, and social isolation, were also within normal limits. Depression, cited by other researchers (Blacher, 1984; Drotar et al., 1975; Ladden, 1990; Mercer, 1974; Sabbeth, 1984) to be evident in most parents of ill newborns, was not found in the current sample of parents. In addition, participants' scores on the STAI indicate that they felt no more anxiety than typical parents, with scores within a standard deviation of the mean. In retrospect, it would have been valuable to ask these parents what methods they used to cope with their infant's illness. Affleck et al. (1991) suggested that downward comparisons to sicker infants in the NICU helped parents cope.

It can be speculated that at this early stage of their infant's life (one month of age), the parents have been so focused on their infant's survival that they have not yet had time to experience the measured stresses such as competence as a parent (their parenting skills have not yet been "tested"), social isolation, or even depression. They may also have a high degree of social support from hospital staff and friends immediately after the birth and during hospitalization. After an infant had been in the hospital for one month, the initial shock and depression may have weakened. Also, it may not be soon
enough for the parent to begin considering the full impact of having a medically fragile infant. These infants are still under the care of the NICU and the parents have not yet experienced taking care of the baby by themselves which may eventually lead to more depression. In the larger study where the same measures are repeated at 1 month and 6 months post discharge, it will be important to determine how these scores change over time.

In a study by Tinsley and Holtgrave (1989), mothers' perceived control over her child's health was correlated with her likelihood of seeking preventive health care for her child and the child's actual health outcome as a result of the preventive care. Parents in the present study had a low Internal Locus of Control score (ranging from 1.27 to 1.86 standard deviations below the mean), which correlates with research that has indicated that parents with infants in an NICU often feel a loss of control over the fate of their infant, with hospital staff having total control (Affleck et al., 1991; Brooten et al., 1988; Perlman et al., 1991; Thomas, 1988).

Fathers were more in control over the outcome of their infant's illness than were mothers ($p = .04$), but both were nearly two standard deviations below the norm suggesting little sense of personal control over their infant’s outcome. NICU staff should continue to implement methods of including parents in devising and following individualized developmental care plans (cf. Als et al., 1986). Parents should be allowed and encouraged to take an active part in decision making and infant care whenever possible. Ongoing professional development in the provision of supportive health care should be incorporated into training programs.

Parents' low level of internal locus of control in this study is somewhat contradicted by their average score (33rd to 50th percentile) on the Sense of Competence subscore of the PSI. This inconsistency may be a result of the phrasing of
the questions on each measure. The Health Locus of Control Scale contains statements such as “I am in control of my child’s health,” and “The main thing that affects my child’s health is what I myself do.” Agreement with statements such as these may be difficult when a parent’s infant is a patient in an NICU. PSI statements are somewhat more general such as “I feel I am a very good parent (or better than average or average parent)” and may be answered in a more positive manner, especially when they have not yet had an opportunity to act as parent to their infant.

When parents were asked to list their main problem or concern, the item reported most often (ranging from 23.0 percent of RDS fathers to 53.8 of RDS mothers) was the present health of the baby. Also highly reported were negative emotions such as anger, guilt, and frustration with medical limitations. Analysis of these data is restricted because several parents reported more than one problem or concern while others did not list their main problem. However, it is informative to compare this information to the results of the PSI which addresses some of the same issues as the Most Important Problem (MIP) question. For example, while negative emotions were listed as issues for parents, their scores on the Depression, Unhappiness, Guilt subscore were in the low range, meaning they were not feeling much of these emotions. Relationship with Spouse on the PSI did compare favorably with Marital Stresses on the MIP, with little marital conflict reported.

In some hospitals, the staff's main concern is with the patient and parents are merely tolerated and not made to feel welcome in the NICU. The health care providers who work in the NICU in this study have received training in how to deal with the emotions of the parents of their patients. Future studies should include samples of parents from several hospitals in order to control for the possible confound of staff who have been trained to support the parents. Such studies would help to establish how such
training affects the wellbeing of parents of critically ill infants. In addition, results of such studies would be beneficial to trainers of health care professionals in order to develop models of providing emotional support to parents to foster resilience and to reduce their stress and anxiety.

In research with populations such as the RDS and BPD groups studied herein, numerous factors tend to interfere with the analysis of potentially informative data. The number of participants in the entire population is limited, and obtaining the participants' cooperation in the completion of such a study can be difficult considering the stress they are experiencing due to the illness of their infant. The resulting low number of participants makes it impossible to accomplish desired analysis of the data collected. Due to the small sample size, it was not possible to obtain results of the planned MANOVA to determine interaction effects of parent gender and infant health status. For the same reason, multiple regression analysis of the additional demographic variables such as social network size, emotional support, Hollingshead Index, etc., was not appropriate. Future studies with a larger sample size would enhance the generalizability of the project results.

Also problematic in the present study was the restrictiveness of the sample. All potential participants were first screened by the nursing staff. If they viewed the parents as excessively stressed, they were excluded from consideration. This exclusionary criterion may have contributed to a biased sample of parents who are less stressed than the actual population. Such screening of participants, however, was ethically necessary in order to avoid potentially placing parents at risk for emotional distress.

Implications for the hospital involved in this study are that the staff should continue to use strategies to decrease the anxiety and stress of parents. They should
encourage behaviors that actively promote parents' sense of control over their baby's care. Parents need to feel welcome in the NICU and be full participants in the care of their infants to the greatest extent possible. Psychologists can take an active part in inservice for NICU staff on methods of enhancing parent control and coping strategies.

Knowledge of research regarding the experiences of parents with infants with lung disease can be beneficial for school psychologists. The Education for All Handicapped Children Act (20 U.S.C. Sec. 1400 et seq., 1975) was amended in 1986 (Public Law 99-457) to include 3- to 5-year-olds and provides federal incentives to states who offer services for children from birth to two years of age. The Individuals With Disabilities Education Act Amendment of 1991 (PL 102-119) further emphasized the national commitment to family centered services. In order to better serve all children and families as required by the law, school psychologists should have an understanding of the unique caregiving demands of parents whose infants suffered lung disease. When writing an Individualized Family Service Plan, as required by PL 99-457, psychologists can become collaborative partners with families to facilitate enablement and empowerment.
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The principal investigator (PI) for the larger study was Susan Epps.