# PATERNAL ROLE DEVELOPMENT AND ACQUISITION IN FATHERS OF PRETERM INFANTS: A QUALITATIVE STUDY

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#### VITA

Edward Allan Martinelli, Jr., son of Edward Allan Martinelli and Bonita Rae (Sommers) Martinelli, was born October 7, 1964, in San Francisco, California. He graduated high school from Jefferson Davis High School in Montgomery, Alabama in 1982. He attended the University of South Carolina at Sumter, and later graduated with a Bachelor of Science degree in Psychology, with a minor in History, from Brigham Young University, in 1990. He received a Master's Degree from Brigham Young University in 1995 in Counseling and Guidance. He entered Graduate School, Auburn University, in September, 1996. He interned at Brigham Young University's Counseling and Career Center in the 2002-2003 academic year, and is now employed by Brigham Young University's Accessibility Center as the Coordinator of Psychodiagnostic Services. He married the former Laurel Lee Chamberlain, daughter of Lee Cornell and Mary Joan (Coombs) Chamberlain, on January 15, 1994. He has three children: Emma Lee, born August 5, 1995; Edward Allan, III, born February 22, 1997, who passed away due to prematurity on July 12, 1997; and Charles Francis, born January 18, 2002.

#### DISSERTATION ABSTRACT

## PATERNAL ROLE DEVELOPMENT AND ACQUISITION

#### IN FATHERS OF PRETERM INFANTS:

## A QUALITATIVE STUDY

Edward Allan Martinelli, Jr.

Doctor of Philosophy, August 8, 2005 (M.Ed., Brigham Young University, 1995) (B.S., Brigham Young University, 1990)

# Directed by Scott A. Ketring

Fathers of preterm infants are under-represented in the literature on parents of preterm infants. The acquisition and development of the paternal role of fathers of preterm infants while their singleton child was hospitalized was explored through a semi-structured interview and qualitative analysis. Sixteen fathers of infants born at a tertiary care facility in the western United States were interviewed within six months of their infant's discharge. The average gestational age of the infants was approximately 27.5 weeks and no child was over 32 weeks gestational age. Issues related to the size and appearance of the infant, the fragility of the child, holding the infant, attachment and bonding, and support from outside sources were noted, as well as a potential model for paternal role acquisition and the moderating of life impacts on the fathers and their families.

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#### CHAPTER 1

#### Introduction

As many as 12% of babies born in the United States each year are born before completing 37 weeks of gestation (Martin et al., 2003), thus disrupting important fetal and parental developmental processes that occur throughout the forty weeks of a full-term pregnancy (Saunders, 1999). As with research on parents of full-term infants, research reflects a relative lack of interest in the role of fathers. Very few studies have included men, let alone focused on their experience. Consequently, most of the research conclusions about fathers have been based on either maternal report or on questionnaires derived from the emotional experiences of women. This study, therefore, hoped to gain an understanding of men's experiences during the transition to new fatherhood while their preterm child was hospitalized in a NICU.

Crisis

With the seminal article of LeMasters (1957) defining the transition to parenthood as a "crisis", others have worked to further describe and define this important developmental time. Bibring (1959) also described it as a crisis, but defined crisis thus:

Crises, as we see it, are turning points in the life of the individual, leading to acute disequilibria which under favorable conditions result in specific maturational steps toward new functions. We find them as developmental phenomena at points of no return between one phase and the next when decisive changes deprive former

central needs and modes of living of their significance, forcing the acceptance of highly charged new goals and functions.... Pregnancy as a major turning point in the life of the woman represents one of these normal crises, especially for the primigravida (first time parent) who faces the impact of this event for the first time (p. 119; in Osofsky, 1982, p. 225-226). (Osofsky, 1982, p.119)

While the view of parenthood transition as a time of crisis remains true for parents of preterm infants, the "crisis" of preterm birth also includes the typical definition of that which is "An emotionally stressful event or traumatic change in a person's life" (American Heritage Dictionary, 2000). As will be shown in this document through research reviews and statements of mothers of premature infants, the experience of having a preterm infant is unexpected and traumatic.

Maroney (20004) describes statements from mothers taken from an on-line discussion that emerged from a nurse in the group trying to help other professionals "imagine what it is like to have a preterm infant"; consequently, each statement starts with the stem "imagine." The statements represent a variety of precipitating events, hospital experiences, and medical problems with the infant, as well as the relationships between parents and staff, mother and father, and parents and the outside world. There is often no warning, little time to make decisions of incredible importance, with the life or death of the mother, child, or both, hanging in the balance. The mothers' statements describe more clearly than statistics or demographics the crisis nature of premature birth and parenting. For instance, it is one thing to state that preterm birth has associated risks, or that certain percentages pass away. It is quite another thing to consider it in the immediate moment, as one mother described: "Imagine the docs and nurses telling your

husband that it's either his wife or the baby or both that may not make it" (Brigitte, in Maroney, 2004).

#### Fatherhood

Historically, the focus of research has been on mothers and their developmental process. This is due in part to the assumption that mothers play a more important role in the child's development than does the father, whose importance has been noted simply as a breadwinner (Parke, 1981). However, fatherhood represents a time of adult development and of movement to a new social status. Fatherhood can also complete the self, make societal statements about one's manhood, and make for a time of generativity (Cowan, 1988; Erikson 1959). Cowan (1988) found three aspects of maturation during the attainment of new fatherhood: a) identity; b) locus of control; and c) self-esteem. Furthermore, societal expectations have moved beyond the basic breadwinner stereotype for fathers and include a more active, physically and emotionally involved role for fathers during the pregnancy.

As men meet the expectations of the new fatherhood role and begin to acquire the sense of generativity, they, like mothers, psychologically create a fantasy child that embodies the hopes, dreams, and expectations of the father-to-be (Stainton, 1985). Some portion of the self is connected or extended to this fantasy child. The term fantasy child refers to the expected way in which the upcoming newborn will look and behave. It is different for each individual, but shares some common expectations around what is typically seen. In some sense, the "Gerber baby" image encapsulates this fantasy child.

These fathers-to-be often think about being the protector of and provider to their family (Diamond, 1986). New fathers reported this protector role as the most deeply

ingrained and influential aspect of successful fathering (Shapiro, 1993), with stability in the relationship, financial security, and attaining a sense of closure about the childless portion of their life as important paternal readiness factors (May, 1982a). It has also been noted that fathering style has less to do with maternal satisfaction and more about agreement between the couple as to what the roles and style should be (May, 1982b).

# Preterm Fathering

In looking at the literature regarding fathers of preterm infants, Klaus and Kennell (1979) suggested a number of developmental tasks for new parents which can be applied specifically to fathers of preterm infants in exploring the various areas impacted by preterm birth both from global and stage perspectives. Many of the later stages involving acceptance of the fetus as an individual and early introduction to the baby are potentially disrupted by the preterm infant's arrival.

One factor that may result in a variety of difficult emotional tasks for the new father, and may in fact interrupt the developmental process of fatherhood, is the way in which the preterm infant differs from the vision of the fantasy child which has been previously created. What is known amongst those who have studied parents of preterm infants is that this fantasy child is almost nothing like what a preterm infant looks like (Coster-Schulz & Mackey, 1998; Fleischman, 1986; Herzog, 1982; Hynan, 1991).

Parents often use familiar items to give some scale or metric to their preterm infant's size, because the size of a full term baby does not allow for easy comparison: "Imagine a baby with a head smaller than a tennis ball, and a body shorter than your forearm" (Brooke, in Maroney, 2004). "Imagine taking adopted 8 week old kittens in for a well check and realizing that these tiny fuzz balls outweigh your preemies by at least a half a pound.

Imagine when your daughter asks how small she was as an infant, grabbing two pop cans, stacking them on top of each other and telling her THAT was how big she was" (Julie, in Maroney, 2004). "Imagine the nurse pulls back Saran Wrap for you to touch him, and you just can't bring yourself to do this; for your finger is longer and thicker than his arm, and his hand is only the size of your fingertip" (Marguerite, in Maroney, 2004).

The commonly experienced disappointment, anger, and grief (Hynan, 1991) that accompanies premature births is another factor that impacts the father's ability to maintain a stable relationship, view himself as family protector, breadwinner, and support giver, and find a purpose as he attempts to care for his child. Even the experience of first meeting the child can be a shocking experience: "Imagine a few months later that the father of your son tells you how grateful he was at the time that he was wearing a mask, because he saw how happy you were that your son was alive, and he couldn't bring himself to smile back, because he saw your tiny son as he was born, and wasn't sure that he would live for even an hour, and he just held on to your hand for dear life, and let you just be happy for now" (Marguerite, in Maroney, 2004). Preterm birth can effect employment: "Imagine your husband losing his job because of the birth of your premature baby" (Pauline, in Maroney, 2004). The overall emotional impact is powerful as well: "Imagine your husband finally coming to his knees and leaving the NICU, crying so hard he cannot breathe or stop. No matter how hard he tries... And you hold him realizing that this is the only other person on the planet who truly understands what you feel like." (Rene, in Maroney, 2004). Consequently, overall family adjustment and marital stability can be affected by neglecting the father of preterm infants (Miles, Funk, & Kasper, 1992). In summary, there is sufficient evidence to be interested in the

experiences of fathers of preterm infants; however, research studies are only now beginning to focus on this area.

Research into preterm parental role. Recently, two studies have explored parental role development in parents of preterm infants. Bacon (2000) explored the development of mothers using a semi-structured interview and a grounded theory approach. She found that mothers of preterm infants experienced more pronounced differences in maternal expectations, meaning that beliefs about what being a mother to a child would be like were vastly different from actual experience. Caretaking tasks were more complex and demanding, and concern about the infant took on an almost "obsessional" (p. 42) nature. Additionally, competence in the maternal role was plagued with a slowly developing, and often challenged, sense of competence in caring for the newborn. "Imagine missing your baby's first bath because the nurse couldn't wait until you were there" (Michele, in Maroney, 2004).

Bacon (2000) also noted that mothers of premature infants experienced more emotional impact from contact with the infant. They developed a sense of understanding the child's situation which led to a decision-making capacity that was lacking in early care. They mastered non-traditional and unexpected parenting tasks while in the NICU. Finally, they viewed external recognition as a parent as formative of their own maternal identity.

Fidler (2002) explored paternal impacts, using combined quantitative and qualitative components. One potential problem with his approach lies in the timing of the interviews. He queried fathers within one month of their child's admittance to the NICU. Since some of these children, given their gestational age, could be expected to remain in

the hospital for upwards of three months or more, this early inquiry may not have allowed fathers to consolidate their experience, or to be faced with all the vicissitudes of a NICU course. Loss of the expected experience and the idealized child were salient themes, and despite dealing with feelings of sadness, helplessness, and anger, the men Fidler interviewed were described as hiding deeper emotions often in an attempt to appear strong to others, particularly their partner. Many of Fidler's participants described difficulty feeling like a father, often describing caretaking activities that were absent. Many fathers described feeling overwhelmed by increased responsibilities, particularly in financial or employment-related areas.

Despite feeling overwhelmed, all of the participants dealt with the emotional experience, the increased pressure, and mounting responsibilities by turning inwards rather than reaching out. Often they viewed typical support groups of family, hospital staff, and friends as cold, uninterested, or more concerned with the mother. No follow-up of potential problems was conducted after the NICU course had been completed, or after the child was home.

In contrast, mothers appear more involved in infant care and they appear to be more connected to others; often reaching out to support networks. Fathers tend to be, as W. E. Freud (1995) described them, "lone wolves," burying themselves in other tasks to continue supporting the family system financially and to act as a steady support, even though this was an inaccurate portrayal of their internal experience. "Imagine thinking that you're (sic) fiancé is a really strong man because you don't see him cry only to find out from his mom that he's been crying on her shoulder when you're not around"

(Shauna, in Maroney, 2004). Fathers also appeared to struggle to find an actual NICUrelated purpose or task that they could contribute to.

# Proposed Study

The literature is limited regarding fathers of preterm infants, but the comments of their partners indicate a profoundly moving experience. A study specifically directed at preterm fathers' experiences, after the chaos of the NICU is over, has the potential for allowing for a better understanding of their experience. The proposed study intends to use a semi-structured interview to better understand the experiences of fathers in the NICU. Rather than use a quantitative method using instruments based on maternal experience or missing the powerful imagery and emotion that can come only from direct report, fathers were encouraged in this study to respond to questions that may have particular relevance to their lived experience. Their self-directed responses were then coded and commented on within a grounded theory approach to provide future investigators the basis for studying and enhancing the paternal development of preterm fathers.

This study asked fathers about their experience a few weeks post discharge, allowing the father to consolidate his experience and reflect on the developmental course. This is particularly important since many parents do not feel that the child is "theirs" until discharge (Cohen, 1982). Consequently, it is possible that a more developed paternal identity emerges at or near discharge. While it is likely that are similarities with the earlier studies cited, there is sufficient reason to believe that significant differences may emerge by a later interview date.

It is apparent that preterm birth and time in the NICU have significant impacts on the families of the infant. Fathers may be pulled in a variety of directions to care for the mother of the child and the infant. Emotional reactions may be muted or hidden but still felt deeply. Impacts to family life, employment, bonding and attachment, and paternal identity and role are part of this turbulent time. Rather than using maternal report of the fathers' experience or assuming that the maternal experience is the same for fathers, a study of their direct experience as a foundation for further inquiry was deemed necessary.

Consistent with the principles of grounded theory (Corbin and Strauss, 1990) no hypotheses are tested in a qualitative study; instead research questions are raised. The research questions for this study are a) What are the experiences of fathers of premature infants? b) What is their developmental course to fatherhood? c) Does the NICU experience interrupt their developmental course? and d) Are there any differences between their development and what is known about mothers' development from Bacon's (2000) study?

#### **CHAPTER 2**

#### Review of the Literature

Preterm infants, or preemies, are difficult to describe in words. The quality of their early existence is sometimes beyond the ability to convey to those who have not witnessed firsthand what it is like. If born before the 26<sup>th</sup> week of gestation, the mother may not be in maternity clothes. They are small; smaller than most people can even imagine. The early infant may easily be held in the palm of an average adult male hand. It is easy to sit the child in one's hand, hold her head with one's fingers and have her legs only extend half way down one's arm. Where a full-term infant may be nearly 20 inches long, a preemie may be just over half that. The head often appears grossly disproportionate to the rest of the body. The very little fat on the body keeps a preemie from having the typical "Gerber baby" appearance; instead being described as looking like "little Holocaust survivors" (Harrison, 1983). This appearance and fragility affects parenting and attachment for the new parents. It is not an equivalent process to parent a child who appears and acts according to socially built and maintained expectations, and one who violates many of these expectations in appearance, behavior, and prognosis.

As will be seen, a purely quantitative description masks the harsh realities of preterm birth and parenting. This literature review summarizes what is known about babies and their parents in general, and parents of premature infants more specifically. It

will combine quantitative and qualitative descriptors to integrate a more accurate presentation.

Very early preemies often appear a ruddy color, due to the translucent nature of their immature skin that allows blood vessels to have more effect on their appearance. The skin is very fragile, allowing easy tearing and bleeding. Nearly every internal organ is immature and needs assistance to sustain life. Furthermore, the technology used to assist life requires the smallest of tubes, constant monitoring to prevent bursting a lung or throwing balanced electrolyte and enzyme levels into precarious life-threatening disarray. The ventilator may cause the child to have an unnatural presentation in their breathing. The child may vibrate, in almost seizure-like movements, as the machine forces highly oxygenated air into their lungs often at hundreds of times a minute. The ventilator and other technology providing survival support hide the child's appearance.

Tubes and wires going in and out of the child are not uncommon. Blood products are often transfused and nutrition is intravenously provided. The child often cannot maintain its own body temperature and must be put under warming lamps to prevent hypothermia. There is every reason to understand that this is truly intensive medical care that is being provided. With all these invasive procedures, infection is always a possibility. Infection can kill a preemie in a matter of hours. It is possible for children who early in the day were reasonably stable and healthy to have a rupture in the intestinal wall, which creates an infection causing death in a matter of a few hours. The trauma of birth can cause brain hemorrhages that may have life-altering and permanent effect. Difficulties in eating are not uncommon. After months on ventilators and feeding tubes, the natural response to nurse can be lost and an oral aversion can develop. Reflux is not

uncommon amongst preemies, which is beyond the more common spitting up that fullterm babies experience.

Their immature nervous systems often make the slightest touch an experience in over-stimulation. Parents must navigate between not touching their child and over-whelming their child. The infant often experiences numerous blood draws, IV insertions and changes, physical and respiratory therapy, and sometimes surgery as part of their course in the unit. It is no easy thing to be a preemie or the parent of one. In nearly every way and in nearly every physiological system, the premature infant has some difficulty to overcome, some maturational need, and death is a present, though fluctuating, reality (Harrison, 1983).

Millions of babies are born each year and, consequently, millions of adults become parents. Certainly in a process that affects such a large group there are vast differences in experience. Similarities still emerge, however, which researchers have sought to understand. The developmental models of the last 50 years have described pregnancy and parenthood as crises, or developmental markers and turning points that significantly change the participants for the rest of their lives (Bibring, 1959; LeMasters, 1957). However, parents of preemie children also experience the term *crisis* beyond a set of developmental markers. It becomes a critical point at which life or death and various levels of mental and physical disability are affected.

Klaus and Kennell (1979) listed nine steps in parental preparation for typical childbirth and in bonding with the newborn. While these steps center on maternal experience, they also serve to include the fetus in the process and cover the time from before conception to antenatal care. They included: planning the pregnancy, confirming

the pregnancy, accepting the pregnancy, fetal movement, accepting the fetus as an individual, birth, hearing and seeing the baby, touching and holding the baby, and caretaking. The Klaus and Kennell model, through its more broad listing and larger number of stages, allows observations of where difficulties might arise in pregnancies that do not make it to term.

Throughout the present review, the descriptions of mothers and fathers who attempted to help professionals "imagine" what the experience is like, humanize the experience and reflect the deep and lasting impact it can have. The parents help reflect the critical and powerful images that go beyond the quantitative measures of length, weight, and days in the hospital. These descriptions help one come to the conclusion that the journey for parents of preterm infants is quite different from those of full-term parents.

### Preterm birth

About one in eight of all U.S. live births were preterm or occurred before the 37<sup>th</sup> week of gestation, and about 2% of live births were prior to the 32<sup>nd</sup> week (Martin et al., 2002). Preterm infants are at higher risk for long-term disabilities and fetal death and this increases proportional to the earlier they are born. The earliest that babies are categorized in national statistics is 23-24 weeks gestation (Martin et al, 2002). Recent studies have indicated that the limit of viability is now at 23 weeks (Alexander et al., 2003; Derleth, 1999).

In preterm birth, the typical or anticipated experience is disrupted across a wide spectrum. Onset of labor is sudden and the expected birth process evaporates, leaving parents in a state of fear concerning what possible outcomes exist for their child. As one

mother described her experience, "Imagine the only OB (obstetrician) visit your husband doesn't go to, the doctor tells you to rush right to the hospital. Imagine during the hour waiting, not only for the news but for your husband to arrive at the hospital, you plan your baby's funeral if she dies, name her if she turns out to be a him, pick out what she will wear to be buried in, pick out what he will wear to be buried in, pray for the best, but plan for the worst" (Michele, in Maroney, 2004).

It is not uncommon for a woman to need emergency transport to a hospital for highly technical care. The mother's and the child's life, or both, may be in jeopardy (Harrison, 1983). One mother's experience was particularly frightening: "Imagine hearing them (the doctors) talk about how much you are bleeding and that they can't tell what they are looking at because there is so much blood. Imagine they are piling towels and chucks (something to hold the towels) up against your bottom to soak up all the blood that is gushing out of you" (Beverly, in Maroney, 2004).

There is urgency to the care that is provided that goes beyond that which is provided for a full-term birth (Oehler, 1981b). After birth, the mother and child have very limited contact and hospitalization transforms the parenting and birth fantasy into a financial, emotional, and medical burden. Many parents experience depression and distress as they wait to see their children. (McGettigan, Greenspan, Antunes, Greenspan, & Rubenstein, 1994) As one mother described: "Imagine working really hard to wiggle your toes and move your legs to 'help' the epidural wear off so that you can go and meet your children" (Angie, in Maroney, 2004). While this report may seem typical, this particular mother was anxious to move because the preterm birth prevented her from seeing her child at delivery and before she can leave her room, and see her child, the

epidural must wear off. Unlike a full-term parent, the baby will not be brought to her, she must travel to it, and many times information that would calm fears about the status of the infant is sparse.

This situation, in turn, requires the father to provide more support at an earlier than anticipated stage of the pregnancy. At around 26-28 weeks gestation, fathers begin to anticipate and prepare for the birth, but the preterm arrival may elicit anger, stress, grief, and urgency (Herzog, 1982; Hynan, 1991). Financial arrangements must be made, work is disrupted, and privacy is lost (Harrison, 1983). Staff interactions will include many unfamiliar faces as a variety of medical personnel, potentially 20 individuals, may have direct care of the child, not including specialists (Zaichkin, 1996).

Popular self-help books have information about full-term birth, but information about preterm birth is lacking. In the self-help book "What to Expect When You're Expecting," lengthy descriptions of the tasks and roles of both the mother and the father, encapsulating the physical, emotional, and supportive potentiality of this important time of labor are available. The lengthy treatise in this popular book (nearly 20 pages) is contrasted by the combined one-page description of premature labor found in two sections of the book. Preterm labor is not discussed until the chapter describing the 7<sup>th</sup> month, or 32<sup>nd</sup> week, which can be up to eight weeks after some preterm infants are born. In the sections on preterm labor, there is no discussion of the role of the father (Eisenberg, Murkoff, & Hathaway, 1991).

### Neonatal Period

As the newborn arrives in very serious condition, parents often get very little time, if any, to view their baby before he or she is taken to the neonatal intensive care

unit (NICU) for stabilization and treatment. Some mothers have related not hearing the baby cry, which caused them to wonder if the child was born living (Harrison, 1983). Parents may have to wait an hour or more for the baby to be stabilized without news about condition or prognosis (Zaichkin, 1996). One mother sadly described: "Imagine the silent delivery room where you know, but ask if she is okay. Imagine looking into the face of the man you love more than anything in the world, and seeing his pain..." (Rene, in Maroney, 2004).

Researchers have indicated parents of preterm infants have four tasks that they must work through. First, they prepare for the potential loss of the child. Second, they acknowledge the failure to bring a healthy and on-time infant. Then the parents attempt to reassume the parenting relationship, and finally to understand the child's new needs and patterns (Kaplan & Mason, 1960). Some mothers have described these tasks in the following fashion: "Imagine how you felt when you said you wanted the baby now (at 22.6 weeks) and giving birth the very next day" (Brigette, in Maroney, 2004). "Imagine seeing your baby for the first time and crying 'I am so sorry my body failed you" (Jennifer, in Maroney, 2004). "Imagine being afraid to bond with your baby because you're not sure if she's going to make it and you feel this way for the next two months" (Shauna, in Maroney, 2004).

Appearance. Preterm birth violates both the ideal of birth and child. The fantasies, or internal visualizations, that are created during pregnancy come to a quick end as the realities of hospitalization for mother and child burst upon the parents. While every parent has to make an adjustment to the realities of birth, parents of preterm infants have a more difficult time due to the major differences in the physical appearance of the

preterm child, the preterm child's health risk, and the isolative nature of the neonatal intensive care unit (Klaus & Kennell, 1979).

Initially the most stressful part of being a parent of a preterm infant is the child's appearance, which includes the baby's color, sickly appearance, and labored breathing (Hughes, McCollum, Sheftel, & Sanchez, 1994; Miles, 1989; Shields-Poë & Pinelli, 1997; Zaichkin, 1996). Even pictures are insufficient for some preterm parents: "Imagine that the Polaroid snapshot of your babies that your husband brought to you in recovery did nothing to prepare you for how really tiny your 26.5 weekers were" (Angie, in Maroney, 2004). It is not uncommon to see pictures of preterm infants where they are only slightly bigger than a dollar bill or an adult hand to give some scale for viewers. Others carry pictures of the father's wedding band over the infant's arm to the shoulder because they are so thin.

The child often appears dramatically different not just because of size, but also due to the thinness of the skin which can give the child a ruddy appearance, as well as the small and thin proportions of the child (Zaichkin, 1996). It can have a dramatic effect, even for close family members: "Imagine your mother-in-law viewing your 1 pound 14 ounce baby for the first time, and when you see her face she looks like she will vomit" (Colleen, in Maroney, 2004). The intense nature of the appearance has immediate effects on parents. Parental roles are altered as parents cope with not knowing how to help their child, not being able to hold their child, and not being able to protect the child from pain (Miles, 1989). As one mother described: "Imagine the nurses throwing you out of the NICU, because every time they try to put a new IV in, they blow a vein. And while your miracle cannot cry, because she is intubated, you see the absolute terror in her eyes. But

you cannot hold her, because this would cause her heart rate to drop" (Rene, in Maroney, 2004).

There is also an overarching sense of potential loss. Parents often have a high level of death expectation and tend to moderate this perception over time. The level of morbidity perception lacked correlation with the actual risk for the baby (Shields-Poë & Pinelli, 1997). Hence, parents may have a very present fear of loss without a sense of how to evaluate the reality or rationality of the experience.

Emotional impacts. The emotional difficulties can be quite heavy. Parents deal with four overarching emotions: Terror, grief, impotence, and anger (Hynan, 1991).

Terror emerges over the possible life and death consequences for mother and child. Grief is typically anticipatory in nature and often affects the marital relationship and interrupts family stability coupled with different coping styles. Anticipatory grieving is often longer for mothers. If the baby and mother are in separate hospitals, due to the birth circumstances or the hospital's capacity to care for the infant, grieving is more difficult. Often the father acts as an intermediary or umbilical, ferrying information about the child from the unit to the mother (Freud, 1995; Hynan, 1991). Impotence includes both the sexual impotence that can occur when an individual is in a stressful situation, along with the powerlessness to effect change in the system (Hynan, 1991; Stern & Larney, in Smith, 1999). Anger sometimes serves to free parents from this powerless ness and is sometimes directed towards staff and periodically is directed inward.

Anticipatory grief is often described by the parents of a preterm infant as a means of coping and preparing for the worst possible outcome (Cramer, 1976; Hynan, 1991). It often serves to insulate the parents from even greater pain. This grief work sometimes

results in the parents waiting to name the child, or waiting to inform family and friends of the birth, in case the infant dies (Hynan, 1991; Kaplan & Mason, 1960). As two mothers described: "Imagine being too scared to get attached to him... for fear that you might lose him" (Brooke, in Maroney, 2004). "Imagine waking up from a nightmare that your baby died..." (Michele, in Maroney, 2004).

Mothers are often worried about their baby but must quickly acclimate themselves to the surroundings of a very unfamiliar unit so as to initiate mothering tasks (Freud, 1989). Although the mother is not physically present with the infant, she is still connected emotionally and mentally. "[S]poradic contact between mother and baby necessarily mitigates against optimal mutual cathexis.... Parents cannot help feeling that they are guests of the hospital" (Freud, 1989, p. 487).

Separation from the child complicates this emotional experience. The initial concern of separation from the infant is exacerbated by problems with childcare for the premature infant's siblings, transportation to and from the hospital, or lack of economic resources (Affonso et al., 1992). Parents often feel like outsiders, powerless, and hampered in attempts to care for the child because of this separation (Nystrom & Axelsson, 2002; O'Donnell, 1990). One mother reported: "Imagine leaving that tiny baby at the hospital while you go home, with every fiber of your being telling you this is the wrong thing to do, that this isn't the way it should be happening" (Michele, in Maroney, 2004).

Coping. The typical parent looks to family members and close friends for information on caring for a newborn (Edwards, 1999). However, mothers of preterm infants report extended friends and family do not understand what they were experiencing

(Curran, Brighton, & Murphy, 1997). Fathers report more significant family life impacts and mothers tend to rely on fathers for physical health and emotional support. Nearly half of mothers report feeling guilty for not making it to term (Hughes & McCollum, 1994). This may be exacerbated by inaccurate comments: "Imagine a woman at the hospital who had been talking with your dad outside saying to you, 'I hear that you did a poor job of carrying that baby" (Cori, in Maroney, 2004).

Mothers have been shown to use more diverse coping strategies when compared with their partners in dealing with these difficulties. Mothers tend to use positive communication with their spouse, whereas fathers tend to use positive communication with the staff. Positive thinking as a coping strategy is exclusively used by mothers, whereas religious faith is commonly used by both parents. Mothers tend to use *escapeavoidance* strategies significantly more often than fathers, but males tend to use *problem-solving* techniques (Hughes, McCollum, Sheftel & Sanchez, 1994). Each strategy attempts to gain control of the situation and these rather oppositional approaches may be seen as complimentary, in terms of anticipating all possible contigencies, but they have the potential to produce conflict in the relationship (Hughes et al., 1994).

Parents also deal with competency issues when faced with the daunting environment of the NICU. Cohen (1982) reported that many parents do not feel that the child is theirs until they are home. As the parents extend their stay in the unit, concerns about how they will mother the child increase. The concerns of separation that were reported early in the hospital stay diminished and maternal tasks become the most frequently reported during the fifth and sixth week after birth and within the week before the baby's discharge from the hospital (Affonso et al., 1992).

Parents have often commented on how they feel more like patients than caregivers. The residual culture of the NICU, where parents weren't allowed on the unit until the 1960's, may partly explain this phenomenon (O'Donnell, 1990). Given the highly specialized nature of the care the child receives in the NICU, parents often struggle to find a task that is theirs alone or one that they feel competent to handle. Some of the guilt and inadequacy described previously can paralyze parents in their attempts to make contact with their child. The infant's immature systems often require the parent to initiate the parent-child interaction, while full-term infants tend to initiate these first moments (Kennell, 1978).

W. E. Freud (1989) observed parents in the NICU and felt that "technical advances had outstripped the psychological side of medical care," (p. 486) and that the NICU setting was vastly underprepared to meet parents' needs. Parents spend much of their energy worrying about the child, even when they aren't present, and the surroundings of the NICU are "strange... often bewildering and frightening" (p. 487). The father suffers as the less-than-ideal child was a "blow to his self-image of virility" (p. 490).

This difficulty in parental ownership, power, and control (Cohen, 1982) would suggest that some of the stages suggested by Kaplan and Mason (1960) may not reach final resolution until some time near or after discharge. Yet, even discharge is not the end of difficulties, as one mother described: "Imagine having to have your own intensive care ward at home to have your family all together again" (Angie, in Maroney, 2004).

The literature about coping has predominantly focused on the maternal experience. When there have been studies about parents, the focus has remained on

mothers. A very telling example of this is found in a recent book describing the experiences of parents in the NICU that portrayed itself as a book on how parents cope. The focus of the book, however, was on the mother-child dyad. Only one of the 9 chapters specifically explored the paternal response. Despite using the term parents throughout the book, whenever examples were provided they invariably focused on maternal reactions or report. While there are things known about the transition to fatherhood, there has been little work done specifically with fathers of preterm infants. Nevertheless, a review of the typical transition to fatherhood and then the literature on preterm fathers gives information that may be used to formulate useful questions for understanding the experiences of preterm fathers.

#### Transition to Fatherhood

The nine to ten month process that results in a newborn human child has brought forth theories about the transition to parenthood for both men and women. Until recently, the research has focused on the maternal experience. Fathers have been seen as builders of a support network for the mother-child bond. Fathers' importance often lay in the breadwinner role (Diamond, 1995; Dollahite & Hawkins, 1998; Parke, 1981). As research interests shifted to the paternal experience, it was noted that fatherhood represented more than a time of financial obligation. Cowan (1988) noted that new fatherhood represents a maturational attainment of identity, power, and self-esteem. It is also a time where one passes on to the next generation the knowledge one has gained. It becomes a time for caring and nurturing others (Erikson, 1959).

In the 1970's and 1980's, male pregnancy involvement research yielded distinctive styles of involvement. Ambivalence to the pregnancy is common (May,

1982c; Obrzut, 1976), especially during the first few months. By the third trimester, or 25<sup>th</sup> week, the pregnancy becomes "real" and involvement in the pregnancy increases (Sherwen, 1986).

Using a qualitative grounded theory approach, May (1982c) queried first time fathers and described a three phase development for full-term fathers. The phases for women's transition, which focus on adjustment, realization, and direction of attention are consistent with what May uncovered. The *announcement phase*, which varies in length and is characterized by reaction to the announcement of the pregnancy, varies depending on desire for the pregnancy and is followed by the second, or *moratorium phase*, which typically occurs between 12<sup>th</sup> and 25<sup>th</sup> week, and is characterized by a "putting aside" of conscious thought about the pregnancy. Tending to coincide with lack of evidence of pregnancy, it concludes for men when more visible signs of the pregnancy emerge. The duration of this phase was quite variable, lasting from a few days to entire months. The final *focusing phase* describes the negotiation of the father's role in labor and the pregnancy and begin to think of themselves as fathers. However,

"with the exception of childbirth preparation classes, a father has few opportunities to learn ways to be an involved and active partner in this rite of passage into parenthood. The tensions and apprehensions of the unprepared, unsupportive father are readily transmitted to the mother and may increase her fears. His own self-doubts and fear of inadequacy, may be realized if he is not supported. Self-confidence comes from achieving realistic goals and earning the approval of others" (Saunders, 1999, p. 213).

Not only three phases, but three styles of relationships involvement describe the different ways in which fathers' structure and implement relationships with the mother of the child (May, 1980). The *observer style*, so named because the father is supportive and happy with the pregnancy, but may avoid more active involvement in a variety of activities including classes, choices about later care, or even in prenatal care. The father with the so-called *expressive style* is often more fully involved and typically displays a more strong emotional response. Individuals with this style may experience more psychosomatic, symptoms (Klein, 1991) similar to the mother's physical symptoms, known as couvade symptoms. The final, *instrumental style*, is more task oriented and these men are more protective and supportive as they attempt to manage the pregnancy. None of these was particularly better than another, but congruence with the mother's desires and expectations helped the transition.

May (1984) later observed that emotional involvement in pregnancy correlated with readiness for fatherhood. Four factors contribute to emotional involvement in the pregnancy. Financial security (May, 1982b; Obrzut, 1976; Sherwen, 1986), a desire to be a parent, closure of the childless portion of the significant relationship, and stability within that relationship have been identified as important (May, 1982a; 1984). A planned pregnancy also contributes to involvement (Leonard, 1976; May, 1984). Relationship roles like providing and nurturing the mother and the pregnancy also emerge with the bread winner role continuing to develop (Diamond, 1986). Societal forces have led, as well as required, fathers to be more involved in the pregnancy, childbirth, and early parenting. This has been manifest in attendance at prenatal visits, birthing classes, participation in cutting the umbilical cord, and in early childcare tasks (Yogman, 1982).

Both mothers and fathers begin to psychologically create a fantasy child that embodies and encapsulates the hopes, dreams, and wishes of the parents (Stainton, 1985). Parents imbue the child with future characteristics and capacity, envision future athletic prowess, personality, and shared activities and interests as the child grows. This fantasy process elicits the extension of the self to the psychologically created child. Erikson (1959) viewed this investment from the parents' self as an important expression of generativity. Hence, the fantasy child is an inner picture of what the child will look and act like. It captures the hopes and dreams of the parents along with the societal norms and expectations of birth. As one expectant mother described: "Imagine going in at 23 weeks for an ultrasound to find out your dream has come true... you're having a boy and a girl. Imagine looking over at your husband during this ultrasound and he has tears in his eyes because now you have the perfect family" (Christie, in Maroney, 2004).

Thus, it is not surprising that attachment to the child can be quite strong even early in the pregnancy (Cranley, 1981; Lumley, 1982), and the foundation for the transition to fatherhood is laid in early childhood. Childhood play and experiences with one's own father influence the developmental process (Colarusso & Nemiroff, 1988). As a young male grows, the societal and familial expectations are planted that later blossom as parental identity development is enacted. It is not uncommon during the pregnancy for men to reevaluate their own experiences with their father and it has been shown that a sense of connection with their own father assists men in their capacity to be emotionally involved with their children (Herzog, 1982).

Cowan (1988) found three aspects matured during the attainment of new fatherhood: a) identity; b) locus of control; c) self-esteem. Adding a significant aspect to

the self contributed to a father's overall identity, but this was not simply an additive process. Instead, fathers integrated the new roles with pre-existing aspects and reorganized the manifestations of themselves in these settings. The paternal identity also attested to one's manhood and provides for an actual completion of the self.

Men's experience and adaptation along thee major dimensions—psychological, sociocultural, and marital—predicts strongly men's adaptation to pregnancy and early parenting (Grossman, Eichler, & Winickoff, 1980). Simply applied, the more anxious a man is, the more likely psychological difficulties would develop. Consequently, while pregnancy is a worrisome time, the anxiety can prove maladaptive to fostering good relationships between fathers and both their partners and child. Thus, the new father wrestles with past and current relationships, societal expectations, their own fantasies and conceptualizations of the paternal role, as well as their ability to mix and meld these psychological tasks into a cohesive personal identity.

Fathers believe that they will involve themselves in nurturing, teaching, and providing, but tend to actually perform fewer activities after birth than they anticipated (Obrzut, 1976). Despite the various roles and expectation that fathers-to-be perceive from a variety of sources, there does not appear from the research to be one best role to take. The amount of support given has been shown to be not as important as the agreement between the partners of the nature of the father's role (Fishbein, 1984). Thus, even when a father performs very few activities, but is in an agreed upon stance with the partner, he experiences better relationships, and less role anxiety, than those who had not negotiated the role expectation with their partner.

In summary, fathers of full term infants have transitions to make requiring their attention and energy, while fathers of preterm infants have similar transitions with the added stress that accompanies preterm birth. Summarizing the literature focusing on fathers of preterm infants makes this clearer.

Preterm father literature. In one of the earliest studies of fathers of preterm infants, Gaiter and Johnson (1983) explored early experiences in the NICU, noting that prior to their study, "no one has yet described the kind of contact fathers have on first meeting their preterm baby in the nursery" (p. 387). Fathers who touched their infants during the first visit were more likely to visit more often; even more often than the mothers of similarly ill newborns. Later, Rapacki (1991) described one father's harried attempts to visit the hospital, finish work commitments, prepare the home for eventual discharge, and emotionally support the mother. For fathers of preterm infants this is a process that can go on for months. As one father described: "Imagine that every one of these mom's imagines is partnered by a dad who has to be strong, and hide his feelings. Imagine his wife thinking he doesn't care because he only cries when he's alone" (Alan, in Maroney, 2004). Each is a daunting task in itself.

The father's role changes considerably. If the premature baby is in a different hospital from the mother, the father will be the one to keep close and direct contact with the baby. He has the burden of supporting and emotionally carrying his wife. He has the discussions with doctors and hospital staff. He has the preoccupation with the survival of his infant. During this crisis, there can be an intense sense of ownership, of bonding by the father. The mother may be too terrified to bond with an infant who may die, or she may experience the infant as

also having failed her. The father has to be available for her feelings to the sacrifice of his own (Tracey, 2000, p. 43).

According to W. E. Freud (1995), fathers of preterm infants deal with three common traumas: First, is prematurity itself. Second, is what is entitled *NICU culture-shock*, (p. 235) or the way one negotiates the adjustment to the NICU. The final trauma is the shared responsibility of caring for a child who is at-risk, and this child may be quite ill for either the child's or the parent's entire life. Thus, while Freud's (1995) observations of these traumas tend to indicate that there are similarities between mothers' and fathers' experiences, there remain potential differences that prior studies have yet to quantify or qualify.

W. E. Freud (1995) felt that preterm birth "puts an end to the hope for a perfect and healthy family" (p. 236). Thus, the preterm father is ostracized by so-called "real" men, loses face, may imagine that his spouse no longer wants him, and may even consider suicide. He stated: "I think we tend on the whole still to overestimate the emotional resilience of fathers on account of their 'halo' of manliness, whereas it can safely be assumed that the prospect of an at-risk pregnancy elicits consternation and bewilderment" (p. 237).

Unlike mothers, fathers experience a role paradox. Doctors, nurses, and specialists may cause the father to feel uncomfortable and threatened, given the level of expertise they possess in caring for the infant, that the father lacks. The mother has the potential to provide breastmilk and other caring, while the father may feel isolated, which Freud (1995) viewed as a reflection of how he views the infant (in an isolette), and even went so far as to call the NICU an "antiseptic prison" (p. 239). When the mother is not present,

the father realizes that he has some role to perform, likely more consistent with what is viewed as a mothering role, and for this he is ill prepared. The father may play the role of "umbilical," or the connection with the ill mother and child. This is particularly salient if the mother and infant are cared for in different hospitals. Although ill prepared for this role, he is often made the "missing link" when the mother is unable to come to the unit. Yet, he must convey information, both qualitative and quantitative, of the child's status, while attempting to be emotionally strong and unaffected by what he has seen and experienced. Freud encourages staff to engage the father in any type of caring activity that he is willing to participate in to facilitate role development.

Whereas full-term fathers seemingly have some capacity to financially meet the new families needs, this becomes particularly difficult for preterm fathers. Not only does the median cost of a preterm infant's care approach \$50,000, but it can run as high as nearly one million dollars for very early, ill preterm infants (Rogowski, 1999). While the average stay of nearly 2 months is likely to disrupt work schedules, the capacity to facilitate family financial independence is practical and is at least symbolically manifest in the new father's life. This has led some to postulate that fathers of preterm infants overcompensate by throwing themselves into work while the child is in the NICU, both to maintain the financial base for the family, while also showing a means of doing something productive and to gain a measure of control. In fact, the "save at any price" mode of NICU care is something for which fathers may feel they alone will have to pay (Freud, 1995, p. 238). It is unlikely that the plans for the new child included these financial aspects; however, these must be grappled with while still transitioning to other roles of life.

Preterm father paternal roles. Vine (1995) felt that the father may feel threatened by the new roles that are placed upon them without warning or consent. This is particularly true since fathers tend to be early visitors to the NICU; often earlier than the mother. Preterm parents' role in the NICU has experienced a dramatic evolution in the last 30 years. Until the 1970s, parents and other non-medical professionals were excluded from the NICU (O'Donnell, 1990). In fact, as NICUs involved more technology and more specialized personnel, the parents lost much of their care-giving role (Plaas, 1994). Through the development of regional centers to care for more critically ill infants, parents were separated by mileage also. It wasn't until research in the 1970's and 1980's that attitudes began to change. Parents were invited into the nursery and were seen as vital to the infant's development. In 1975, the first parent support group was established (Plaas, 1994).

These changes have helped ameliorate, but not eliminate, the barriers to parenting that Griffin (1990) described as physical, mechanical, emotional, and professional. Miles and Mathes (1991) found that parental role alterations were viewed as one of the most stressful parts of having a child in the NICU. They also found that only about half of parents had any preparation or assistance related to these aspects of NICU environment.

The research on parental impacts, role impacts, and potential barriers to parental development has led to recent research into the experiences and role acquisition of parents of preterm infants. In 2000, Bacon used a semi-structured interview with 20 mothers of preterm infants to elicit themes of maternal role acquisition. She interviewed mothers after the child had been discharged from the NICU and found that overall development of the maternal role was possible, but that the emotional impact was

profound. Mothers focused on issues of contact with the infant, decision making, mastery of new and non-traditional care-giving activities, and the obtaining of external recognition and validation of maternal identity.

Fidler (2002) initiated one of the first preterm parenting studies to focus exclusively on men and their experiences. Participants reported themes consistent with other literature, including: loss of the ideal birth and child; feeling unprepared, helpless, and angry; and struggling to remain in control and "strong." Staff was often seen as more parent-like, and important milestones were lost (cutting the cord, holding the child right after birth). Financial and other responsibilities were perceived to increase, and much of the overall impacts were dealt with alone. Most fathers felt "overlooked" by the staff in lieu of the mother's needs. They also reported feeling guilty for not being at the hospital more, but often expressed financial or other family responsibilities as precipitating factors.

As noted earlier, parents often don't feel like the child is theirs until discharge (Cohen, 1982), yet all of Fidler's participants were contacted early in the NICU course. It is possible that the full impacts of preterm birth and the transition to new fatherhood had yet to be realized. All were contacted within a week of the birth of the child, and a third within 48 hours. At least a month was the expected hospital stay for all infants, with some anticipating 3 months of NICU care. None of the children had critical problems and none was born before the 30<sup>th</sup> week of gestation.

From the literature, it is possible that fathers have some similarities in their role acquisition, but it also apparent that they may have very different experiences as well. It appears that a next, reasonable step in attempting to understand and prepare to meet the

needs of fathers of preterm infants, would be to directly inquire about their experiences. Unlike Fidler's (2002) study, the current investigation made concerted efforts to recruit fathers of preterm infants born before 30 weeks. Further, fathers were interviewed after the child has been discharged, allowing the full impact of the NICU environment to be realized, and for the paternal role to find expression both in the NICU and in the home. Conclusion

Reviewing the literature on full- and pre-term birth has focused on the disruption and chaos that accompanies the delivery and the ways in which preterm birth may disrupt typical parental development. In the neonatal period following delivery, the first meeting of the child occurs and adjustments are made to the appearance, potential loss, and the critical nature of the child's needs. Parents work to cope with these impacts, but the literature has predominantly focused on the experiences of the mother. A brief description of the typical transitions made by fathers was compared with what is known and hypothesized about preterm fathers. The lack of direct inquiry into the fathers experience leads to the conclusion that fathers of preterm infants need to be directly contacted and interviewed to ascertain the applicability of models that are predominantly maternally based. A grounded theory study was determined to be the best design for providing the foundational work for later quantitative inquiry.

Consistent with the principles of grounded theory (Corbin & Strauss, 1990) no hypotheses were tested in the present study; instead research questions were raised. The research questions that guided this study are a) What are the experiences of fathers of premature infants? b) What is the developmental course to fatherhood for fathers of preterm infants?; c) Does the NICU experience interrupt fathers' of preterm infants'

developmental course?; and d) Are their any differences between fathers' development and what is known about mothers' development from Bacon's (2000) study?

#### CHAPTER 3

#### Method

The journeys through pregnancy and parental role acquisition are common processes that have been researched for many years. A growing literature base has developed over the last 30 years regarding the development of both fetus and the birthing couple, and how this common process is affected by the early or premature arrival of the infant. Hospitals and neonatal intensive care units have attempted over recent years to include parents and to be more developmentally supportive (O'Donnell, 1990). However, much of the research work in these units, and therefore many of the policies and procedures, is based on maternal report and have a maternal focus.

## Conceptual Focus of the Study

In the present study, fathers of preterm infants were interviewed specifically about their reactions to preterm birth, their relationship with their infant, and their time in the neonatal intensive care unit (NICU). The openness of the interview serves as the basis of gaining a better understanding of the oft-neglected fathers' experience and the process of becoming a father, or in assuming the paternal role, while the infant is in the NICU.

Better and more inclusive policies and procedures for the entire family may then be constructed. Rather than use similarly structured and maternally based quantitative measures of the NICU experience, a qualitative design was chosen to allow for a more powerful and rich description of what men struggle with at this time.

This study attempts to explore, describe, and create a grounded theory from the experiences of fathers of preterm infants while both deal with the environment of the neonatal intensive care unit. More specifically, the study describes the development of paternal identity and paternal role acquisition amongst these fathers in this unique situation and setting. It is based on the method and study by Bacon (2000) of mothers in similar circumstances. This chapter explains the method and procedure to be used in obtaining this information.

### Rationale for Qualitative Method

As noted earlier, this study is interested in the lived experience of fathers of premature infants. The experience of nurturing a preterm infant is a highly charged and emotional experience. Just as the fathers cannot escape the presence of these emotions and the values that they hold, neither can researchers approach these fathers objectively. Approaching these fathers from a presumed objective stance would be misleading, if not diminishing of their experience. "Assumptions structure all research, and the least we can do is to recognize this and theorize the impact of these assumptions." (Banister, Burman, Parker, Taylor, & Tindall, 1994, p. 50). Making explicit these assumptions is a possibility provided for within the qualitative paradigm. One is not detached but confronts the agenda, assumptions, and meaning making that are a part of the experience and all these are brought to the inquiry.

The meaning that fathers have attributed to the birth of their child and the meaning they have made about their role as father are central to the investigation at hand. Meaning is often uncovered in the linguistic forms used via interpretative and qualitative analysis. Polkinghorne (1988) noted: "Experience is meaningful and human behavior is

generated from and informed by this meaningfulness. Thus, the study of human behavior needs to include an exploration of the meaning systems that form human experience." (p. 1). Linguistic and qualitative analysis is particularly relevant for discovering fathers' meaning-making of their NICU experience.

It is quite possible that the views of these fathers would not be as meaningfully represented in a numerical format as through the qualitative descriptions that are possible through semi-structured interviews. In fact, quantitative measures are often constructed after qualitative measures, given that themes, constructs, and overall experience are elicited from the participants. Additionally, the richness and depth of the experience is best drawn forth with a qualitative method.

# Methodology Overview

Qualitative research methods have arisen partly out of dissatisfaction with quantitative methods. Some have found quantitative methods lacking in meaning, context, and inauthentic. Thus, qualitative methods seek to reinvigorate the data with each of these missing qualities while still remaining empirical. In fact, the theories emerge from the data rather than being forced upon the data (Glaser, 1992; Neuman, 2000). Qualitative methods are those which obtain and present findings not arrived at through statistical methods. While there are a variety of qualitative methods (Neuman, 2000), grounded theory methods will be employed in this study. A grounded theory is one that is developed from an inductive study of the phenomenon. Originally proposed in 1967, it is a systematic means of data collection and analysis that leads to the discovery and development of an inductively and phenomenologically based description of the observations (Glaser & Strauss, 1967).

Over the years there has been a steady progression of acceptance of both the qualitative method and grounded theory usage, most often in new areas of interest (Glaser, 1992; Strauss & Corbin, 1998). Glaser (1992) recommended researching "...areas that need opening up as the richest focus for grounded theory or a field with sparse amount of literature, so contributions are clear and strong." (p. 34). The prior chapter has indicated how this describes the area of preterm infant fathering.

The qualitative method is appropriate when one "attempts to understand the meaning or nature of experience of persons with problems" (Strauss & Corbin, 1998, p. 11). Often involving getting out into the field of study, a perceived plus from doing research in the confines of a laboratory, it is excellent for looking at areas where little is known about the experience. The data can be direct observations, field notes, or in this case, direct experiences of interviews and the tape-recorded interview texts (Strauss & Corbin, 1998).

The objective view, that is a hallmark of the quantitative method, is not sought in the same way or in the same sense given that the objective view is believed to be impossible because the investigator already has a relationship to the participants. Instead, an active theoretical interpretation occurs as the investigator reasons on the "particulars" to the "generalities." "Particulars" are parts of the greater whole (or "generalities") that affect and are affected by the investigator. In fact, "...qualitative research...purpose is not to test hypotheses..." as this requires pre-conceived notions about the outcome of the research that frustrate both the process and outcome of the research (Strauss & Corbin, 1998, p. 41). This is not to say that the current researcher has no pre-conceived ideas. It is

a part of the qualitative method to attempt to delineate and identify these assumptions prior to the study. These are outlined later in this chapter.

# Sampling

Qualitative sampling is concerned with obtaining a representativeness of concepts in their various forms. Consequently, appropriate data sampling is obtained when evidence of the phenomenon of interest is found, as well as when it is either not found or disconfirmed. Thus, qualitative sampling is found in its purposefulness, not its randomness. Sites, participants, and demographic qualities are chosen that will provide maximum opportunity for emergent categories and themes (Strauss & Corbin, 1998).

Samples can also evolve as the work progresses given that new directions for data collection may emerge as early data are analyzed. Samples are not limited to prespecification criteria as in quantitative research. Additionally, qualitative sampling is not as concerned with generalizability as in the quantitative method. Specification, instead, occurs as one notes under what circumstances, and with what associated outcomes or interactions, the conditions exist (Strauss & Corbin, 1998). However, this is not to indicate that some meaningful transferring cannot occur. In fact, understanding the parts or particulars well, allows one to understand the whole. Finally, since the sampling method seeks out both disconfirmation of the concepts and seeks out variation in the concepts, depth and breadth of understanding of the developing theory occurs which allows for a greater sense of the whole.

*Project sampling.* As noted above, participants were fathers of premature infants; those born prior to the 37<sup>th</sup> week of gestation. While roughly 12% of all live births are preterm, about 2% occur before the 32<sup>nd</sup> week. It was hypothesized that earlier premature

birth is more likely to produce significant impacts to the acquisition of the paternal role, hence more effort was made to find fathers of earlier gestational aged children. However, to allow for the variation necessary for good theory sampling, a reasonable mix of children from various gestational ages were sought. Additionally, it was decided to include participants who had their child discharged from the neonatal intensive care unit (NICU) allowing for the impacts of the NICU to have surfaced. The fathers of deceased children were not interviewed.

The parent support group at University Hospital in Salt Lake City, Utah, was contacted for assistance in recruiting fathers. Although there are other NICUs in the surrounding area, University Hospital had a number of unique features helpful to the sampling of the study. First, the NICU is a large unit with the capacity to care for over 40 preterm infants at a time. Second, the unit admits some of the more seriously ill and early babies from the surrounding Intermountain West region of western Colorado, Utah, Nevada, southern Wyoming, and southern Idaho. This provided a more heterogeneous group to sample from. Finally, the representativeness of the sampling is held together better by using one hospital as opposed to many. This is due to the differences in NICU environments. Using a variety of hospitals would introduce between unit variables that aren't as numerous in a single site study. Differences in staff training, unit policies, the service area covered and the associated population demographics become confounding variables. By focusing on one hospital, these variables do not have to be explained later and the focus can remain on the emergent themes and descriptions.

Using a cut-off of six months post infant discharge, the parent care coordinators identified parents and infants who met the criteria and they made some of the initial

contact with the parent about participation. A flyer was placed on the parent support group bulletin board requesting volunteers (see Appendix C) and a presentation was made by the principal investigator at the monthly dinner meeting of the group where fathers are more likely to attend and at the discharge meeting of parents of preemies who anticipate discharge. These were held on the first and fourth Wednesdays. After initial contact and willingness were ascertained by the parent support group coordinators, the parent's name and phone number was given to the principal investigator to arrange an interview time.

Interviews were held at the home of the subject, with as much privacy as was possible. At the interview, a consent form was reviewed and signed and then a brief demographic form was filled out (see Appendix B and D) and the interview began. The interview was similar to the one used in the Bacon (2000) study. Bacon's interview structure was the direct result of the on-line experiences of her advisor, Dr. Mara Stein, with parents of preterm infants in 1997. The interview structure was employed by Dr. Mara Stein and Dr. Deborah Davis in the gathering of data for a book on the emotional experiences of parents of preterm infants (Stein, 2004).

The semi-structured interview is similar with the one significant change being that a question about breastfeeding the infant was replaced from the maternal interview with a question about impact to employment on the paternal interview (see Appendix A).

Follow-up questions served as guides to eliciting further information about the experience. Grounded theory methodology encourages an open stance by the investigator to allow for new themes to emerge and for disconfirmation of pre-existing bias. The interview was digitally recorded for later transcription. The transcription was performed

by a court-reporter-trained transcriptionist, with the forwarded transcription reviewed by the principal investigator for accuracy.

Setting of the unit. The participants were all fathers of infants hospitalized at the University of Utah's University Hospital Neonatal Intensive Care Unit. It is a Level III unit, meaning that it is "...equipped to diagnose and treat all perinatal problems; provides intensive care for infants requiring technological support or surgery." (Zaichkin, 1996, p. 435). The unit can care for 48-50 infants at one time and is divided into four basic care units defined by their room number. Room 1 is for those infants just born and requiring the most intensive and dedicated care. The nurse to infant ratio is nearly one-to-one. Once stabilized, the child moves to Room 2 where the care is still intensive, but there are more infants to nurses. As the child progresses, grows, and prepares for discharge, the infant will be moved to rooms 5 and 6. Here, three or more babies will be cared for by one nurse.

Parents are welcome on the unit at any time of the day, excepting shift changes which last an hour from 6:45 a.m. to 7:45 a.m. and at the same time in the evening. When new babies are admitted or as special procedures are performed, parents may also be asked to leave the rooms affected. The rooms at the hospital are family and developmentally friendly, meaning that parents are encouraged to interact with their children. Sound abatement, diffuse lighting, and carpeting are all used to minimize sound and light impacts to the developing infant. Many of the rooms can be closed off from others to control noise and give privacy.

The unit also has supportive areas like a private room for mothers pumping breast milk, a parent lounge to place lunches and other materials, a parent computer for

accessing e-mail and other support sites, as well as a small kitchenette for preparing meals without having to leave the unit. A private bereavement room is also available for those dealing with the loss of an infant.

Participants. Sixteen 16 fathers were needed to reach the point where no new themes were emerging. Additionally, this was close to the number of participant mothers in the Bacon (2000) study. Sixteen is also the typical approximate number of interviews in grounded theory studies (Creswell, 1998). The participants were an average 31.4 years of age ranging from 22 to 40. They had been with the mother of the child an average of 5.8 years, ranging from 1 to 17 years. The infants studied weighed an average of 2 pounds 3 ounces at birth with an average gestational age of 27 weeks 4 days at birth. The range for weight and age was 1 pound 1 ounce to 3 lbs 2 ounces and between 23 and 32 weeks gestational age. The infants spent an average of 87 days in the hospital with a range from approximately 1 month to 4.5 months. Six of the participants were first-time fathers.

Each interview took an average of 90 minutes to complete, and occurred an average of two months post-discharge. The shortest interview was 50 minutes long and the longest was 105 minutes. It became apparent from the interviewer's own experience and with other parents that comparatively these individuals who were interviewed had a relatively easy course with their child. Children with more severe needs, particularly those requiring surgery, are referred to Primary Children's Hospital. Only one child had an experience with necrotolizing enterocolitis (NEC), a particularly serious ailment where the walls of the intestines adhere and tear allowing for a serious infection in the abdomen. Even this occurrence did not require surgery and was treated with antibiotics.

This is a relatively common concern for infants born this early. A few of the infants had patent ductus arteriosis (PDA), a condition where a small duct near the heart doesn't close as usually occurs with full-term infants. The condition causes poor blood flow and blood oxygenation leading to many difficulties for the infant.

A few of the participants' children were sent for a brief stay to Primary

Children's Hospital, which is nearly next door to University Hospital in Salt Lake City.

Typical reasons were hernia surgeries or similar procedures to fix reflux problems.

Nearly all of the participants spent all of their time at University Hospital, and all spent the majority of their time at the University setting. In some sense, these fathers' experiences represent what might be termed a "best-case scenario" for children born this early. This is particularly true of the infants born before 26 weeks. Both the parent care coordinator, who is the mother of a preterm infant nearly 20 years ago and has worked on the unit for over a decade, and the parents commented on the ease of their experience compared to others. Most of these other parents have children who need more surgical intervention and were consequently transferred to Primary Children's Hospital. This is not to say that these fathers' experiences were easy, just easier than might typically be expected. Nevertheless, even under these conditions, their report gives a view of how significantly preterm birth can impact a family and father.

# Conceptual Framework and Questions

The semi-structured interview focused initially on the story of the delivery and first encounters with the infant (seeing, holding, emotions, etc.). An overall sense of the course of the infant's care was also obtained. These served to create a context, as well as an initial comfortableness in talking about the child and the parent's experience.

Questions were asked about work, family relationships, emotional impacts, and support networks. An opportunity at the end of the interview was given for the father to speak about anything that they wanted to mention that is not included in the questionnaire, although this was only used by one father to encourage strength and faith in others.

As was noted earlier, analysis of early interviews sometimes leads to new questions or directions of inquiry. This is a natural part of grounded theory work in that it not only provides for a breadth of observation, but it can serve to either confirm or disconfirm emerging concepts and themes. In short, data analysis and further data selection are interwoven processes in the approach. In addition to making comparisons and hypotheses, it is expected that a researcher will actively look for disconfirming instances of the phenomena. This serves to enrich the developing theory.

Each interview was transcribed and then analyzed or coded according to three types of coding: open, axial, and selective. Coding was managed through notes and memos which serve as a written record of the analysis and contain actual products of coding such as labels, paradigms, and indications of process (Strauss & Corbin, 1998). This process ceased when the researcher achieved "saturation" (Glaser & Strauss, 1967). This occurred when the interviews ceased to provide any further directions or new concepts, and when disconfirming evidence ceased to emerge. A final validation of saturation is completed when the resulting theory was adequately validated against the collected data or interviews.

The Researcher's Assumptions

The process of the literature review increases one's sensitivity to a variety of issues related to the phenomena of interest. In this study, the process of the review

highlighted a number of issues that fathers, full-term and pre-term, wrestle with. Further, the mere fact that the principal investigator is currently a father leads to certain assumptions about fatherhood, the process by which that occurs, and emotional concerns that may be present. These assumptions are even more pronounced given that the investigator has fathered both a preterm infant and full term children.

This fact, in and of itself, does not necessarily preclude one from carrying out an effective study. As noted earlier, objectivity in the sense of distancing one self from the phenomena is not the purpose or function of grounded theory analysis. Instead, the elicitation of variation, depth, and richness of report is paramount (Strauss & Corbin, 1998). Given this goal, the prior experience and familiarity with the environment could assist in the data collection. A significant amount of time (8 years) has passed since the preterm birth of the investigator's child, which allows for some appropriate distance to be maintained. The investigator's child was hospitalized in an entirely different hospital setting and passed away after 20 weeks resulting in a different experience from those being investigated.

The subjects were informed that the investigator had fathered a preterm infant, although none were aware of the gestational age, or ultimate outcome of the child. Avoiding bias regardless of the researcher's background or subject familiarity was a desired goal and was safeguarded in two primary ways. First, the researcher remained open and gave credence to the participant's alternate views, since these facilitate adequate and accurate theory development. Second, the researcher actively sought out disconfirming instances of the potential biases.

# Data Analysis

Both quantitative and qualitative analysis procedures seek for patterns in the data. They differ, however, with respect to how this pattern is expressed. Qualitative research uses ordinary language; whereas quantitative research employs numerical expression.

Grounded theory analysis is based on three types of coding: open, axial, and selective (Strauss & Corbin, 1998).

Simplistically, coding and analysis begin with labeling emergent concepts. These concepts are then organized into high order categories, which are then synthesized into a few salient constructs. These constructs and their inter-relationships lie at the core of grounded theory and its application (Glaser & Strauss, 1967; Strauss & Corbin, 1998). It is important, as well, to understand that this process does not begin when all data have been collected. Rather, a *constant comparative* method is employed whereby this coding is alternated among the various types as data is being collected. This allows for a more dynamic and responsive approach to emerging themes, which yields a broader, deeper, and more active approach to the data collection.

Throughout the analytic process of coding, it is important to remember that each posited concept or category, regardless of abstraction level, does not directly correspond to the piece of data which generated the concept. Instead, the context is reflected in the segment and in the interview as a whole. The atomistic and isolative nature of data is not assumed in this method. Rather, the context is of equal importance.

*Open coding*. Once the transcripts were available the data was initially interpreted through the process of open coding. Comparisons were made with initially formulated concepts for similarities and differences. Once identified, these categories became the

basis for the sampling noted above. As the interviewing continued, categories were watched for as a means of understanding them better and to see if there was disconfirmation or conditions when the categories or processes are changed.

How the category manifests itself, how it differs from other categories, and a better understanding of the category, is all a part of eliciting the breadth that is central to grounded theory. This categorization also informs when saturation has occurred since new concepts cease to emerge. Thus one interviews, analyzes, and then interviews again so as to know what to listen for. This constant comparative process assists the researcher to avoid subjectivity and bias (Corbin & Strauss, 1990).

Axial coding. Axial coding is the "process of relating categories to their subcategories... linking categories at the level of properties and dimensions" (Strauss & Corbin, 1998). Subcategories serve to answer questions about the over-arching categories and give richness to the description and understanding. It essentially involves four tasks:

a) describing the properties of the categories; b) identifying the context or situations where the category occurs; c) relating the category to the subcategories through relational statements; and d) looking back at the data set (the interviews) for how the major categories relate (Strauss & Corbin, 1998).

As noted previously, in an interview the absence of a category or a different description of a process occurs. This does not necessarily indicate that a developing hypothesis should be discarded. Instead, the researcher evaluates whether the hypothesis has been proven false, or if the absence or variation merely indicates different conditions or contexts for occurrence.

Selective coding. Selective coding takes all of the categories and unifies them around a central core issue. In this particular study, that is likely to relate to paternal role or identity. This type of coding occurs at later stages of the study as consistent categories, along with their descriptions are needed. The process is much like axial coding but at a more abstract level. At this level of involvement, the researcher moves to an implicit understanding of the phenomena and becomes able to relate the circumstances and contexts in such a way as to relate "the story" of the events. Thus the various parts interact, the conditions and varieties of interaction are explained, and what the researcher has come to know is made explicit and relational for others to understand.

#### Conclusion

Unlike quantitative analysis, where replication is a criterion of successful analysis and structure, qualitative analysis strives for verification. Since it is impossible to find situations which exactly match the original study's conditions, instead one strives to delineate the conditions, guidelines for data acquisition, and theoretical perspective for future researchers. The developed theory attempts to describe in rich detail and explanation what has been observed, how it relates and explains the phenomena, and is applicable to similar situations (Corbin & Strauss, 1990).

From the aforementioned goals, evaluating a grounded theory study may appear difficult. Corbin and Strauss (1990) have given criteria for judging such a study. A reviewer can evaluate the validity, reliability, and credibility of the data that was used. The plausibility and value of the emergent theory can be judged. Adequacy of the process used to generate the theory and the empirical grounding of findings are the final criterion for evaluation.

#### CHAPTER 4

#### Results

This chapter is outlined to introduce the participants and their children and to set a context for the major themes found in the analysis. In this study, a number of minor themes were noted along with an overall approach to fathering preterm infants from birth to discharge. These themes will be explained through description and supporting participant statements which exemplify the experiences in the interviews.

# Participant Demographics

Parents. Sixteen fathers of preterm infants who had been hospitalized at University Hospital at the University of Utah in Salt Lake City agreed to participate. The sample was predominantly Caucasian (88%) with two Hispanic fathers. One of the Hispanic fathers indicated that his use of the English language was limited and that during his child's stay whenever medical information was shared an interpreter was brought in by the hospital. All but one father was married to the mother of the child. The one non-married couple was engaged to be married. The average age of the fathers was 31.8 years and ranged from 22 to 40 years old. The fathers had been with their partners an average of 5.8 years, ranging from 1 to 17 years. Six of the participants were first time fathers. (See Appendix E).

All 16 fathers had graduated from high school, with two having had some college experience. Six had graduated with a four-year degree, and two had post-graduate

experience. The fathers ranged widely in their employment. Seven of the fathers were employed in white-collar jobs, with eight employed in blue-collar situations. One father was a student who was working part-time in sales at the time of the interview.

The income levels of the father were not ascertained but, given that the investigator visited each home, some rough estimate can be provided. Two of the fathers would likely be considered upper middle-class or higher. They lived in very nice neighborhoods and described their incomes as above average. Three fathers would likely be considered lower middle class or lower. One of these fathers was a student, another was working in heavy construction and had been recently laid off. The last of these three fathers noted that he was receiving financial and food assistance through his church community. The other eleven fathers would likely be described as middle class by their homes, employment settings, and the financial situations they described during the interviews.

Nine of the fathers were from the Salt Lake County area. Four other fathers were from other parts of Utah. The three remaining fathers were from Idaho, Wyoming, and Oregon. Ten of the fathers were members of The Church of Jesus Christ of Latter-day Saints, or Mormons, the predominant religious denomination in the area. One father indicated that he was "Christian," one was Catholic, and the other four indicated "None" or "N/A" on religious affiliation.

Seven mothers were taken by helicopter to University Hospital from other medical centers for delivery. Another seven mothers were taken by ambulance from another hospital to University Hospital. Three of the mothers were driven to the hospital by the father of the child. One of the mothers was originally taken by helicopter and then

released, only to have to travel by ambulance shortly thereafter, hence the previous accounting summing to more than the original number of participants. All but one father was present for the birth of their child.

Infants. The preterm infants spent an average of 87 days in the University of Utah Neonatal Intensive Care Unit (NICU), ranging from 38 to 169 days. Nine infants were female and 7 were male. The average birth weight of the infants was 2 pounds 3 ounces, ranging from 1 pound 3 ounces to 3 pounds 2 ounces. The infants were an average gestational age of 27 weeks 4 days at birth, ranging from 23 weeks to 32 weeks. Only three infants were 30 weeks gestational age or older, making this one of the youngest groups of infants ever studied with their parents. Overall, the infants were a typical weight for their gestational age.

Participant selection and interviews. Participants were obtained through the Parent Care Coordinator at University Hospital. This parent support group has been at the hospital for 30 years and is housed on the unit. Volunteers within the program provide weekly meetings for the parents of preterm infants and hosts informational seminars regarding insurance, CPR, and discharge. The principal investigator visited two of the weekly meetings on the first and fourth Wednesday of each month between July and December 2004. These meetings were chosen because fathers had been more frequent attendees.

The Parent Care Coordinator maintained a log of willing participants. Upon discharge of the infant from the hospital the contact information was forwarded to the principal investigator. Contact was then made within four days of receipt of the contact information and an appointment was set up at the participants' convenience. Once a

willing participant had agreed to be interviewed the Parent Care Coordinator was informed so that no further follow-up was needed.

The interviews lasted approximately an hour and a half each. The earliest interview occurred 20 days post-discharge, with the latest occurring 176 days post discharge from the hospital, with an overall average of 66 days after the discharge of the infant from the NICU. Most interviews took place on weekends and all occurred in the father's home. At the time of the interview, consent forms were signed, a demographic sheet was completed, and the semi-structured interview was recorded using a digital recorder. This recording was then given to a certified transcriptionist who returned the transcription and voice file within a week. The transcriptions were reviewed for accuracy by listening to the original file while reading the transcript and a final copy of the interview was printed for analysis.

The interview transcriptions yielded over 500 pages of information. Each of the fathers described the preterm birth of their child as a foreign situation; one that they were unprepared for even though eleven had children prior the preterm birth. The circumstances that brought about the preterm delivery were quite different.

# Thematic Analysis

Analysis of the interviews yielded two types of information. First, an overall sense of what fathers of preterm infants experience was obtained through retelling the overall experience. The initial question in the interview was to describe the way in which the preterm birth had occurred including the early labor and delivery of the infant.

Fathers were asked to describe their first meeting the child, and typical events such as holding the infant, the child's hospital stay, the mother's discharge, and the infant's

eventual release from the hospital. They were also queried about how they felt about their child as well as when and how they felt connected to the infant. Second, within the context created by the telling of their story it was apparent that these sixteen fathers had a similar approach to coping with the time their child was on the unit. Despite the fact that each infant had a different set of circumstances and the specifics of each families' structure varied, an overarching approach to dealing with preterm birth and an infant's hospitalization emerged.

The predominant themes reported by the fathers will be described first to set the context of their experience. Following this, the issues that impacted the fathers' approach to caring for their child, their family relationships, and the attempts they made to normalize and establish routine will be discussed. It will be presented in an approximate chronological order to facilitate the later discussion as to how it serves to develop and work from birth of the child to the homecoming and transition to home life.

Every father interviewed described four themes or events. These important markers in their paternal development were: a) the way the father perceived the size of their child, which was related to the delivery and the first sight of the child; b) the first time the father held the infant, which for preterm fathers occurred in two ways: through an initial lifting the infant experience that was followed later, sometimes months later, by a more typical holding interaction; c) a description of how and when the fathers came to know that the child knew them as a parent; and finally, d) the support the fathers experienced from sources other than their spouse.

# Size and Appearance

The first theme that every one of the fathers described, when asked to relate the first time they saw their child was the relative size of their infant. While a few fathers did not view the small size of their child as problematic, it remained a significant event in their early experience. It did not seem to matter if the first sight occurred in the delivery room or in the room in which preterm infants are stabilized and spend their initial time in the unit. As a first-time father commented:

I had no idea how small a baby could be and still be alive. That was amazing. I put my hand up over her and that was her. That was the size of her. And that to me was just almost too much. She was too tiny.... The size of her just... everyone that saw her just couldn't believe it. I went in eight or nine times with just different people that came and every one of them just sat there and no words... just a lot of tears and questions and faces. I don't know. Their faces were just blank. (Evan, first time father of a 28 weeker)

This perception was not limited to those who were first-time fathers. A father of two other children commented about seeing his 28 week gestational age baby:

I just remember thinking that he is really small compared to our other kids. Our first child was nine and a half pounds, 23 inches long and he was a toddler. (laughs) I don't know that I needed to carry him to the nursery. He probably could have walked there. And she (pointing to his daughter) was ten and a half pounds and looked like the Michelin baby's daughter. Just rolls of fat. But this one was -- he was just really -- I mean 15 inches and 2 pounds 13 ounces..... It was a little bit of a shock. But I was in shock anyway from the whole experience.... I had

never seen babies that small before.... When I saw some babies in there I could not believe they were still breathing and alive and how small they were compared to what I was used to. (Daniel)

Often fathers would make this comment in their description of first seeing their child in the unit, but sometimes it was related as part of the delivery of their child. A first time father of a 25 week baby described his daughter's delivery and first seeing her on the unit:

So I came in (to the delivery room) and just held her (his wife's) hand and you know we were just -- here it comes, it is going to happen. And it was not -- it was not even five minutes and they said "Okay, dad, stand up. Here it comes." And I had somebody else's camera, I am going to take a picture when they pulled her out and showed it. But I sat up and they pulled (my daughter) out and I was stunned. I couldn't. I didn't even take a picture.... But once I saw her when she was in the ICU she just looked like a teeny, teeny, little baby. It's hard to explain. She definitely looked human; just small. Everything on her was just so small. And she's hooked up to all of these things. That is hard to see. All of these IVs. And that was hard to see. (Burt)

Fathers also indicated that in this initial meeting they were struck by the relative size of the child to them. Additionally, they noticed the amount of technological support that was necessary:

It is impossible. You just look at this thing about the size of your palm and wonder if it is going to make it. She had a tube down her and her chest is going up and down. That is encouraging but that is not her. And she already has IVs in both

arms and through her umbilical cord and lights on her feet and everything is checked and monitors that when she was that small it covered her whole abdomen. You just don't know what to think. (Daniel, father of 28 weeker)

Another father described it this way:

She was really small. The nurse thought it was funny because I am big and to hold this little tiny baby and she was only two pounds. And it was kind of funny to do that. So I could hold her like this. (holds hands out) I could lay her right here and her feet would come to here. (indicates about the wrist area) In fact, it is easier to hold her with one hand than two, because my hands are too big. I could almost put my fingers around her chest. She was just really small. But my wedding ring would fit on her arm all the way to her shoulder. (Orville, father of a 28 weeker)

Finally, one father explained how the size and sight of the infant is also related to the technology involved: "Just the size of it. And, you know, monitors' beeping, wires, noises, the whole thing. I was like wow. It was like a science project, you know." (Henry, dad of a 27 weeker)

Fragility

The second theme that fathers described was related to the size of their infant.

Each father commented that their child appeared very fragile. Fathers described that they not only noticed the frail nature of the infant, but they worried that their relative size to the infant might cause them to injure the child if held. This perception made approaching the child somewhat difficult, even under the best of circumstances:

She looked like a fetus. She looked like a baby that is human but she had still not developed. Her skin was translucent and her eyes were closed and they were sealed shut like a puppy dog, you know. And almost like a starved little Ethiopian you might say.... I think the scariest thing was she was so, so small. I mean 1 pound 14 ounces is small but when we saw her, her skin was still translucent and when they had touched her she was bruising. And the ventilator was breathing for her and she was not breathing on her own. She was so, so fragile to me. That was kind of unnerving. (Francis, father of 23 weeker)

One first time father, who was particularly quiet and sparse in his comments, described the first meeting with his son:

Q. Describe for me the first time that you saw him?

Sad. He had all of those hoses, all of those IVs.

Q. Any first thoughts when you saw him?

How is he doing? And is he going to make it? Just all of those kind of questions. (Ned, father of 25 weeker)

Some attempts were made to interact with the child, but the perceived fragility was often seen as a barrier:

You can't do anything, you just look at him. I played with his hand a little bit. But I was afraid to touch him because he was so small. I don't know if I grasped it when I first saw him. It was so unreal.

Q. So what did he look like to you?

It was just scary. He looked like a baby but slightly littler than others.

Q. Any first thoughts come to your mind?

Just wondering how in the heck we are going to make it through this. I am looking at him going, "No way. When do we get the disappointing news?" (Paul, dad of 24 weeker)

As a final example, one father reported: "I was worried to pick her up because I was scared that I would break her or something. I was worried to touch her too much" (Larry, dad of 29 weeker). One father seemed to be describing both his child and himself when he stated, "...even now I see how my wife, she can change clothes so quick and force his hand in there and I am still thinking that he was a piece of glass and I am really fragile with him" (Henry, dad of 27 weeker).

Fighting. Interestingly, although the preterm infant was described in terms of size and fragility, fathers also viewed their children as strong. Despite their precarious medical conditions, fathers were keenly aware of the strength needed by the child to survive. Their descriptions were always couched in the sense that the children were fighting to stay alive or they were "tougher than (they look)":

The hardest part was the first ventilator that they put him on is the vibrating, like his whole body was shaking. And they've got the lights on and that part was kind of — that was probably the most scariest part.... Basically, what went through my mind is that I felt that you know— it's a matter of fighting — you know fighting — like he was fighting for his life. Like there was so much shit going on all at the same time that like anything could fail and go wrong, and send the whole thing off-kilter in a moment. That is basically what it was like. (Henry, father of 27 weeker)

And a father described his third daughter this way:

She was so bloody and everything. But she is so tiny. I mean she looked like she would fit in the hand of the doctor—the doctor that was delivering.... She had a big nose and big head. But the most I remember is she being mad. She was moving all over and she cried a little bit. She still had some fluid on her lungs. But she cried a little bit and she was moving a lot. That made me feel good that she was fighting.... She was moving and kicking and everything. Even though she was so tiny. That made me feel good that she was going to be fine. She was going to be fighting. (Jorge, father of 28 weeker)

# Finally:

She obviously was a fighter. I wasn't worried about it. I figured that she would do just fine.... I changed her diaper the first day. That was hard because she is so small. In your mind, you're like, "Don't break her." I do remember when they pulled her out, I mean they yanked her out. She is pretty tough. You have to remind yourself, she is tougher than she looks. (Orville, dad of 28 weeker)

This fragility seemed to affect not only some fathers' attempts to bond with their children, but also the visits they had. Daniel described:

For the first month I never get to hold him because he was so small. Just the thought of holding him scared me because I literally could have held him in one of my hands he was so small.

# Q. You were frightened of hurting him?

Yeah, hurting him. And all of the wires and the tubes.... Actually for the first little while I was paranoid to be in the NICU.... Especially in room one where all of the brand new babies are coming in. [This is the room of the unit right off of

the delivery areas.].... Oh, I didn't like being in there. I would go in because I wanted to see how he was doing, but the other half of me couldn't wait until I could get out.... I kind of have those same feelings when our first boy was born because I had never held a newborn and it took a little bit getting used to. But having a two and a half pound baby is a whole different ball of wax than trying to get used to holding a ten and a half pound baby.... So yeah I didn't even dare touch him. In fact, even after a month I didn't really want to, but I thought I probably should because I am the dad and I need to start bonding with my child. But there at the end— it was probably the last couple of weeks that I really started holding him and enjoying him and I wasn't quite so nervous when I would hold him. (father of 28 weeker)

## First Holding and Second Holding

The time it took to get used to approaching and holding their child varied from father of father. The time on the ventilator was a common factor in this effort to bond. The third theme described by fathers dealt with the holding of their infant. Fathers described two different types of events when they described holding their child.

Since the children were on ventilators, the ability to hold the child close was difficult early on, if not impossible. When asked about the first time they held their child, over three-quarters of the fathers described this as merely lifting the child up so that bedding underneath could be changed. They didn't describe this type of first experience as particularly meaningful. It was, however, memorable because it provided them with the first tangible evidence of how light their child was, and reinforced the idea of

fragility. For some fathers, the second, more stereotypical holding, did not occur for up to three months.

It was scary because his body was so small. Any effort I made to support him seemed like it folded him in half. I couldn't get the weight distribution just right, with the ventilator tubes and the IV and the cords and all of that stuff. I was trying to hold him. I felt like he was folding in half; like he didn't have any structure to him. Which kind of made me feel bad. But the sensation that I had was he was weightless. It was like a helium filled balloon. There is almost no weight to the kid at all. (Kris, dad of 24 weeker)

Again, for first time fathers and for those who had experienced a previous child, the expectations of holding their infant close were different than what they experienced in the unit.

It was not a real special moment like you would hope when you first hold your baby because you can't cuddle them or anything. You are just scared to death -- she is so fragile and you have to put your arms through the thing. (The incubator has small doors to put your hands through, which makes movement around the child awkward.) It is not like she's out of this thing, she is just in there (the incubator) and you are just holding her three inches off of the thing. So it wasn't as special as you would hope. (Burt, dad of 25 weeker)

But the experience of holding the child is described quite differently when, rather than simply lifting the child up, it is more like the typical experience of holding them close. Additionally, it was often seen not just for the bonding or attachment qualities, but

also as a marker of the infant's progress. For some fathers, they had been waiting a significant amount of time for this event to occur:

I mean it was a huge deal for us to be able to hold him.... It was not real comfortable. The CPAP (a different type of breathing apparatus) was not a comfortable device. So it is not like it was a real sort of warm bonding experience. Our kid is pretty much knocked out and on this horrible thing. But just to be able to hold him and feel his weight and realize to me it was a bigger deal to get to that point than having recognized this milestone of holding him than the holding him was. Just the fact that I CAN hold him. For the last three months we've been without that experience. (Kris, dad of 24 weeker)

Thus, the very possibility to hold the child is meaningful to the fathers. Having been denied that possibility due to the child being on a ventilator, fathers tended to describe this event as a milestone or a marker in the child's progress to discharge. It also conveyed the move to a more normal experience. One father of other children described it in these terms:

I mean it was — I think that it was maybe the first time that I felt like — okay this is going to be — she is going to be okay. She is going to be all right. She looked healthy to me.... I remember thinking, "Okay. This is getting a little more normal." I think that you can feel closer to your child once you are able to hold it versus just see them through glass or touch their hand through the incubator. It was a comforting experience. (Alan, father of 29 weeker)

While a first time father stated:

You know, I don't know, probably not, but in my mind I thought it was some kind of — it was like I was able to communicate. So you know that you could feel that. I hope that he could feel that.

# Q. What were you communicating?

That I was his dad you know. And I was going to take care of him and I was here for him and stuff. (Henry, dad of 27 weeker)

It was great. You can actually hold him. You were still scared oh, gosh you are still scared. And you thought that you were going to break him any time you moved him. But it wasn't... before you thought you were handling some sort of explosive; if you moved him wrong you didn't know what would happen but after it is still scary. (Ned, dad of 25 weeker)

# Attachment/Eye Contact

Fathers were specifically asked about becoming connected to their children. They were asked about when they first felt connected and when they felt their child seemed to know them. In every case this related to a response in the child to their presence. Twelve of the fathers indicated that this connection occurred due to the child responding to them visually. Although they noted that they knew their child's vision was not fully developed, they commented that when the child seemed to focus on them when they spoke to the child they felt a deeper connection. The other four fathers talked about a similar connection related to the child turning toward them when they spoke. As one father explained:

I have a hard time connecting with my children on an intimate level until I can start getting eye contact. I don't know. That is just me I guess. It is not like you

don't love your child. You start to feel that I have a little more of a connection here. Now that you can see me and you have a smile. (Alan, dad of 29 weeker) While other fathers explained it this way:

I remember I came in after he was two or three weeks old and he was always really alert which surprised me. His eyes were always open and he was always looking around. I didn't know that he was actually looking at anything other than maybe the lights on the ceiling. I remember my wife was holding him. And I sat down on the chair next to her. And I said, "How are you doing (states name)" ... or I said his name and he turned his head and looked right at me. And I thought he could see me. He is looking right at me. He stared right at me. And I looked at my wife and I said, "Do you see that he is looking right at me."... It was a neat experience. I guess that was kind of my first real connection with him. (Daniel, dad of 28 weeker)

This recognition was described by another father in a similar way:

Well, it is funny because one time when I went to the ICU, my wife said that when I talk, she (his daughter) kind of started looking around, she kind of recognized my voice. And she's like "She's recognizing your voice." But I didn't feel that. One time I was here and I started talking and she was looking for me and when I got close to her she was just looking at my face and I was moving my face and my eyes. I felt that connection right there. (Jorge, dad of 31 weeker)

### Support

Each of the sixteen fathers also described the support they received. There were no specific questions regarding support, but they were asked to describe any changes in

their marital, social, and church affiliations. In each case, marital support, or that support which they provided to their partner, was described during the preterm labor and delivery of their child. The marital support will be described later in relationship to their overall approach to the experience.

Support from sources outside the marital relationship came from a variety of arenas and manifest itself in a variety of ways. Sometimes the support was simply others being at the hospital with the parents, but the support also was evident in taking care of other children at home, preparing the house for the infant's discharge, and in delivering meals to the family. Of these outside sources, fathers described the support they received from four sources: Family, Friends and Religious Groups, the Hospital Staff, and Employers.

Family support. All fathers indicated that their families had been supportive. No specific type of help was mentioned by all the fathers; however, it appeared that family visited early in the experience, and this was particularly true for first time fathers. The support ranged from calls and visits, to help with other children, driving a parent to the hospital, etc. Representative examples include this statement from a first time father:

I brought everybody in and it was just like, go get somebody and bring them back because I had to be there (he had to escort any visitors to the unit)— it kind of got a little monotonous. Not that I didn't like seeing the baby. I am just sick of walking everybody back. My brother sat there with her. It was really cool. We had a lot of support with our families. (Burt, father of 25 weeker)

Even fathers who were older and had other children felt this support and found it meaningful.

Well, it was very emotional. And I am pretty sure that I was tearing up and stuff. And I am glad that my dad was there because of course as a kid you look to your dad for strength and stuff. It was awesome that he was there. (Francis, dad of 23 weeker)

Friend and religious support. Friends and church groups also were instrumental in providing support. Sometimes this support was simply an interest in the welfare of the child. Neighbors and co-workers would often ask about the progress of the newborn. Some would help with transportation, child-care, and good wishes. Two fathers related that babysitting had been organized for other children while the preterm infant was in the hospital.

Religious support was evident in two key ways. In one setting, they provided "temporal" support in organized meal delivery to the family while the baby was in the hospital and during the first few weeks home. Secondly, prayers were very important in this relationship, and some assisted with religious ceremonies performed for the infant and family.

Every Mormon father related some instance where a religious ceremony, or blessing, was administered to the mother and infant. The Catholic father also described a similar incident, but in his case this blessing was given to his wife and child while she was pregnant and in preterm labor. She had lost much of her amniotic fluid and it was thought that she would lose the child. Consequently, she was given the sacrament of the sick, or last rites, for the child. One of the fathers, who indicated he was "Christian" on the demographic sheet, indicated that his church group had been praying for his child. The remaining fathers made no mention of church support.

In the Mormon faith, providing a blessing for individuals maybe more common than in other faiths, and does not require a request for a priest or other outside source because the belief is that a worthy male who has been ordained holds priesthood authority and is capable, depending on worthiness, of giving their child or other family members a blessing for health and strength. Further, it is common for newborn children to be given "a name and a blessing" a few weeks or months after birth. There is an expectation in Mormon culture that the father of a Mormon family will administer these ordinances as needed, with another priesthood holder assisting.

This ordinance of blessing the sick child provided a sense of peace and reassurance that what would follow would be "OK." None of the fathers that described this reaction felt that their child would be devoid of future difficulties, but felt that the child would survive, and that the family would be strengthened to take on and deal with the difficulties that may follow. As one father described:

After the blessing I felt such a calmness that things will work out somehow that I was not like... I was unnerved by what she looked like but I just felt a calm that everything was going to work out.... I felt that calm --- that things will work out. Now, that things are going to work out to me didn't mean that she was going to be perfect and have zero problems, but that was going to be a baby that we can love and take care of and things will work out. (Francis, father of 23 weeker)

It is important to understand that for many of these fathers the church affiliation and neighborhood friends are one and the same group. In Utah and Idaho, a region where a plurality, if not majority, or Mormons reside in communities, a typical Mormon congregation can be the size of part of a neighborhood, whereas outside of Utah and

Idaho a congregation with similar numbers of Church members could cover an entire county. Consequently, in the areas where the Mormon fathers lived, these units and their members can be very close. It can create a kind of sub-culture within the area they reside. A father in Idaho explained his congregation's efforts for his family in this way:

We come home in April and our (congregation), you know without our knowing anything about it... our (congregation) had a spaghetti fundraiser for him (his son). Just because they -- they knew that things were serious and that we were going for be without income for a while. And I remember they had it on a Monday and we went to church that Sunday and we knew nothing about it until our neighbor next door came up to me in church and handed me a flier that said "Spaghetti Fundraiser for (our son)" at their house at such and such a time.

And it shocked me. I thought, "Oh, my word. How nice." And I looked at him and I said, "Are we supposed to come?" And he said, "It is for your baby isn't it?" I feel kind of strange going and having a fund-raiser for us for our little boy. Anyway, we went and we had -- I don't know how many people were there. One of the people in our (congregation) works for (a soda distributor) and they had the (soda) machine set up there. ...the grocery store in town, donated the spaghetti and stuff for it. There were a lot of people there. I couldn't believe how much money they had raised to help with his medical bills and stuff.

There were people there that I knew kind of casually. I knew them by name but really hadn't talked to them a whole lot that were there supporting us and some of the -- a lot of the people gave cash because they didn't want to know -- they didn't want us to know who or what or who had given. You know a lot of

them wrote checks and it surprised us how much some people gave and some people that were -- I used to be Executive Secretary (a clerk with knowledge of finances) in our (congregation) and I knew about some of the situations that some of the families in our (congregation) were in and they were in dire needs too and how much that they had given to us. So it was kind of humbling knowing that, you know, they needed the money just as bad as we did but they were willing to give that much money to us. It meant a lot. (Daniel, dad of 28 weeker)

One of the doctors at the hospital organized meal support for a Catholic couple. The father described how the physician called the Mormon congregation near where they lived and asked them to support the family with meals while the child was in the hospital. The father's occupation took him out of town on a fairly regular basis and the mother was dealing with post-partum depression. The assistance was greatly appreciated. He commented:

It was just amazing the generosity from those people that we had never met or anything like that.

And then the Catholic Church did the same thing. (My wife) wasn't able to be alone with the baby 24/7, but yet I needed to go to work to pay the bills. The Catholic Church doesn't do this normally. They set up a baby sitting service so (my wife) could go upstairs and sleep for three hours. And if was a problem they could go up there and get her. And for liability reasons they don't normally do that. But to help us out, they set up a crew of ladies to come. And those ladies would bring meals on the side and do all of that. That was a surprise to me....

especially the LDS Church. They are so nice. They still call and check on us. (Mike, dad of 32 weeker)

Hospital staff support. Every father commented on the professionalism of the staff. Many commented on the assistance that a primary nurse, one who was assigned consistently to their child, was for them. As one dad explained, "I knew that I couldn't be there all the time and I wanted him to have a nurse there that knew his habits and they were not re-experimenting every time" (Paul, dad of 24 weeker). Another father explained that, "...at the U (University Hospital) it was more like a family and they (the nurses) know you and they trust you and they trust you when you are there and why you are there" (Kris, dad of 24 weeker). They also commented on helpful things that the staff would teach or show the parents about caring for their child:

...I think that we got a lot of pointers from the hospital. You know the people there. We still to this day do (parenting) things that a lot of people have not even heard of that are just ideas that they had given us.... Like, for instance, burping her. They gave us lots of different ideas on how to burp her. One thing that they said to do is do this rolling thing you hold her on your knee and roll her like that.

That works better than anything seriously. (Evan, first time father of 25 weeker)

Other staff members were also seen as helpful:

Ryan, the food guy, is amazing. I can remember him because he brings me really big pieces of cake. Just everybody was so amazing and went out of their way and maybe it is because (my wife) is so nice to people.... It wasn't just being nice or going out of their way. Ryan, if they had extra meals and he knew I was coming in from a trip...He would get dinner for me. It would be sitting in the room. (My

wife) had already eaten and there was an extra meal. I guess when someone checks out they would throw the meals away. He would drop them off so I can actually eat so I would not have to go to the (fast food restaurant in the cafeteria). That (the fast food place) is horrible. (Mike, dad of 32 weeker)

Employer support. Fathers were specifically asked in the interview about impacts to their employment and to what degree employers were supportive. Only two fathers described difficult situations with their employers, and this occurred after the birth of the child. No father described any employer-related difficulty getting away for their child's birth. Most fathers had very little difficulty taking days off when needed. Although they reported some impact to their work performance, especially in jobs where relating to customers was a primary job task, most fathers had no serious or long lasting employment impacts.

The support received from employers took the form of monetary assistance and flexibility with work requirements:

I know that I couldn't have been working for a better company. They paid me for the whole time that I was gone. And any days that I missed after that they still usually paid me. They gave us an extra \$1,000 just to help out. They were real good. They sent us flowers. (Ned, dad of 25 weeker)

Another father described a similar situation:

People at my work are fantastic and very understanding and very helpful in terms of giving us what we need. My boss threw in a couple thousand dollars in my paycheck because he realized financially this is hard for us. So things like that are huge for us. They mean a lot. It has really helped. (Kris, dad of 24 weeker)

The two fathers who reported difficulties were specific about the impacts. One father was in a position that required him to be on-call. This father reported that initially his employer was very understanding. Since his child was home, the support was greatly diminished in his view:

I don't know, my job, sometimes it seems like my job thinks that they are more important than my family life, you know. But it was—I mean I would have liked to have stayed down there longer but unfortunately I had to come back to make money and pay the doctor bills. (Larry)

#### and later:

(They were) fairly understanding (early on). Yeah my boss was pretty good I guess about it. He is not quite so understanding about it any more.

Q. In what way? Say more about that.

When she was in the hospital and stuff he was a lot more convenient and would not call me so much especially when I called him and told him that I have to go down there down to Salt Lake and stuff. He is like, "That is fine go ahead and do what you need to do." Now that we are home he just figures that I can come to work whenever. I don't know.

Q. That is not the case, why? Help people understand why that would be--- why it is still difficult even when the baby is home.

Because the baby, she's on the NG tube (a feeding tube) still, of course. And she sometimes doesn't eat as well as she needs to. A lot of the times she doesn't have bowel movements like she is supposed to and that keeps her from eating so much and her reflux keeps her up at night sometimes and so mom is awake with the

baby at night sometimes and dad has to go to work and she does not get to sleep as much as she needs to. (Larry, father of 29 weeker)

One father quit his job because his employer was out of state; his wife gave birth while they were visiting family in Idaho. He reported these employment difficulties:

The biggest issue was if something happens, it's a matter of minutes and the baby would be delivered, because of infection or anything. I mean there would be no way for me being at any distance away to get back. And so they were saying stay there. So basically I would spend all of my time with her. And they talked a good game about being pretty good about it. When it came right down to it they just -- they sent someone down and came and got the truck.... So then I didn't have anything to do. And then my boss expected me to go back to Oregon to work and just come back if there was a problem. I said, "No, that is 11 hours away. I am not doing that...." And at first he is like, "No problem. Don't worry about it."

And then he decided not to pay me any more. So I found a different job. (Orville, father of 28 weeker)

In summary, the fathers of these preterm infants were impacted by a variety of events and issues. These four themes: the size and appearance of their child; the associated fragility of the infant; becoming attached to the baby; and the support they received from a variety of sources outside of their relationship with the mother of the infant, all point to a context of barriers to bonding with their child, impacts to the typical functioning of the family, and associated feelings of difficulty connecting to their child. Not surprising, these fathers have much to manage in their lives. As fathers described their child's time on the unit, they painted a picture of how they attempted to cope with

the difficulties. This approach became the overarching theme and described the coping process these fathers used to manage the varying pressures of their lives.

### Paternal Role and Developmental Themes

The interview attempted to elicit from fathers the way in which they were able to deal with the preterm birth of their child, and underlying this coping approach was the way in which they attempted to manage a variety of issues. Fathers were specifically asked to describe what they would suggest to other fathers in similar circumstances, particularly about parenting on the unit. None of the fathers described anything specific; however, there was a predominant theme interspersed through the interviews that the investigator noticed while analyzing the transcripts. This theme will be fully developed in the final chapter, but the information that leads to this conclusion will be presented here.

The overall sense of the paternal role, its development, acquisition, and manifestation were described in various areas of the interview. Fathers were asked about their time in the unit, including how they viewed themselves as a parent. They were asked about expectations and about attachment and bonding to the child. While there was no single answer that was given by all of the fathers, what was apparent, and will be conveyed in the subsequent results, were themes and patterns that were consistently drawn out. Although describing a particular approach the themes were broad enough to allow for individual differences, culture, and family arrangements.

The pattern of involvement was both temporally and role specific, meaning that they described events and behaviors that were as bound by the time in the unit (delivery, early interactions, when the child was more stable, etc.), as by specific tasks related to caring for their child (putting on diapers, clothes, comforting the child, etc.). This pattern

was described in five areas that reflect some temporal order. First, fathers were involved with spousal support throughout the process, but particularly close to the delivery of the child. Second, the fathers sought information and were involved in setting up a primary nurse for their child. Third, their level of involvement was indicated in the degree to which they trusted the medical staff to do their jobs and the way in which disagreements were handled. Fourth, the pattern was noted in family issues and their resolution. Finally, the involvement was shown through negotiating and developing the paternal role in relation to the infant, including tasks like visiting and care for the infant, along with financial and employment issues.

## Spousal Support

Pre-delivery and delivery. Initially, fathers described a role that involved maternal support. Each father interviewed, initially provided emotional support, often with him accompanying the mother of the child throughout the labor, delivery, and birth events. Only one father wasn't there for the delivery of the child, but had been in contact with her through his cellular phone prior to her being taken by helicopter to University Hospital. Often the father attempted to calm the mother, seeing this as helpful to the process of delivery and birth. Fathers commented on the nature of the relationship that was being fostered: "The transporting to the U -- all three of us are new at this experience and we are going through this together. That alone kind of brought us together in a way that the first two babies hadn't" (Jorge, dad of 28 weeker). Fathers also acted as a liaison between mother and medical personnel. Their own emotional reaction was described as muted or secondary:

What was important was whether or not they (his wife and child) were going to be alive and safe. And I needed someone there that knew me enough to tell me to calm me down. I needed to be there. And I was not going to get there in this state. I needed to get rid of my emotions, and I don't normally get rid of my emotions in front of anyone. I needed to get rid of them and the only person that I knew to do that was my sister at the time. So I called her and get through those things so that I could come here and deal with what I had to deal with. (Henry, dad of 27 weeker)

Another father described the process in this way:

I just wanted to be positive. I wanted to be up-beat and positive about the whole situation. I just didn't think about that. I didn't want that to -- I didn't let that come into my frame of mind. This was the cards that we were dealt and we have to deal with it. (Burt, dad of 25 weeker)

This support was a part of the very earliest indications of preterm labor. One father described finding out that his wife was heading to the hospital while he was at work:

She called me the day after Christmas. We took her in Christmas night. I don't know if you remember, it was the snowiest day of the year. The day right after Christmas. Oh, my goodness, and I work in Orem (about 40 miles to the south). So she called me at about... I want to say ten and told me that. And just I just don't know how to explain -- it was just you know-- it was the scariest day of my life. You know what I mean? And she didn't really know what was going on. I wasn't there to be with her.... So (my wife) is all by herself. And I am just

helpless. So I just said bye and told everyone (at work), "I have to go." I didn't even tell them what was happening. And I just left work and started heading to the University from Orem. It took a couple of hours.... I was afraid of -- I don't know. I was afraid of I think (my wife) – (she) came first. I told the doctors that too.

They told me how at risk she was. What they were doing was holding her off as long as they could and giving the baby -- they gave her steroids so the baby's lungs would develop and be stronger. Knowing that they were putting (my wife's), I guess, life at risk really scared me. And then I was scared for my baby too. I wanted to stay with him too you know.... I was really worried about (whether I was going to get to the hospital) because people were just driving by me. I really thought for sure I was going to get in an accident because of the way that the people were driving and the roads are so slick.... And then not to mention to the "U" which is uphill. I really didn't think "Am I going to get there?" I was just thinking "I GOTTA get there. No matter what, I am going to get there. If I have to walk, I will get there." It was rough. (Burt, first time father of 25 weeker)

#### A father related:

Basically, I was there to support my wife. She was a little bit nervous and so we are nervous that day -- and you know you feel that really you can do the most but I only thinking about her and the baby and pray to our Heavenly Father that everything will be okay. (Carlos, dad of 29 weeker)

Even if the father was separated by distance this supportive role remained important. One father's wife was a couple of hours away when her water broke and he

found out that she would be taken by helicopter to University Hospital. He still attempted to stabilize the situation:

I was real concerned about my wife to make sure that nothing was wrong with her, that she was fine. When they established that she was okay and then the next concern was for the baby to make sure that -- the best thing for the baby to make sure that she was going to be fine. Because you know it is really a hard deal. My wife was having a stress attack anyway.

What I tried to do was to keep her calm. And the calmer she is, the better it is for her. Even though inside I might have been a little worked up. I tried to be as calm as I could and help her through it on the phone as much as I could.... We wanted to keep everything calm. Someone needed to put a calm foot in there to keep things toned down and not make any rash decisions. The calmer she is, the calmer the doctor will be. Easier for him to do his job. (Orville, dad of 28 weeker)

*Post-delivery*. After delivery, there remained a decided concern for the mother's well-being. Fathers attempted to calm the mothers, and described themselves as best suited to the task.

The whole time she was sad because he (his son) was so tiny. She kind of blamed herself for the whole thing.

# Q. How did you respond to that?

Just trying to boost her morale and make her happy and be supportive. Tell her that there is nothing to be sad about. He is in there kicking and crying and screaming and doing what babies are supposed to do. Just playing the role of support. That was the thing that I was trying to do.

Q. The reason that you felt that you had to be in that support role was? She just needed someone. Kind of like when your friend needs someone. And (my wife) is my best friend and my wife. And that is the reason why. We have nobody here. We don't have family. We have friends obviously. You don't have the support network that you would have if your parents and grandparents all lived in the same city. (Mike, first time father of 32 weeker)

Right after birth, fathers stayed with the mothers and never reported a desire to leave her until the infant was stabilized. They expressed concern about their child, but described feeling that the mother needed them more than the child:

I knew that she (his daughter) was in good hands and there was nothing I could do. I mean she's where she needs to be, let's focus here (with his wife) and make sure that everything is ok, and really there wasn't even a second thought about where I needed to be. (Alan, father of 29 weeker)

Even after seeing their child initially, fathers described going back to the mothers:

I really had to get back and find out how my wife was doing to make sure that she was okay. When I walked out I knew that she (the daughter) was fine. I needed to get back to my wife. Her blood pressure was still high. She was still quite groggy and her headaches were still there when I had left her. (Ivan, dad of 31 weeker)

As seen in the preceding statement, fathers also described placing a great deal of trust in the medical professionals. This was regardless of how often they were able to visit their child. Fathers often described their role as a supporter, a stabilizer, and a facilitator. Fathers described helping the mother as a primary caregiver to the child.

We are making a difference in holding her and getting her in a different environment. (My wife is) breastfeeding and I'm supporting her. I always felt more like an ancillary support than a direct support. (Alan, dad of 29 weeker)

As one father described it: "Like I said, when we were there, we were with the caregivers, that is our baby. It is like we were the coordinating influence between the shift changes with the nurses..." (Francis, dad of 23 weeker)

Time in Unit—Information Seeking

The time around labor and delivery can be chaotic. The infant can be born and hustled away for stabilization, the mother's situation can be critical, and the bustle of staff, the actual status of the child may be unknown for a considerable time.

Understandably, fathers reported wanting to obtain information.

I tried to stay cool and made sure that I got all of the information that I needed. I knew that my wife didn't have the level of understanding (because she was medicated) of what was going on to understand what had to happen. I made sure that my mother-in-law and mom had both come in the room to listen to all of the nurses and the doctors so that if I had to make a decision life or death at this point I had someone to talk to that had both sides of the situation in mind to where it was. (Ivan, father of 31 weeker)

A first time father reported something similar:

That was the hard part for me. And that is-- I don't know--- what the truth to this is. I wanted information. I wanted just somebody to tell me what the probabilities are. I don't think of myself as a numbers person. I understand that you don't know what is going to happen. And you don't want to give me some kind of false hope

or you don't want to say fine and something happens.... Just nothing specific; just give me some odds, you know? This week, this statistic is this and this. And you have 20 percent chance of this to happen and this to happen. You know, and I had nothing. I don't know what that would have done for me. Maybe it would have made me feel better, maybe it would have made me feel worse. (Henry, first time father of 27 weeker)

For some fathers, the information gathering provided a grounding during the chaotic time.

The only time that I felt like things were surreal was probably when I first got the call and her water broke and she could be in preterm labor. That first little while I was like this is weird. It is like you are watching the movie, but it is you. And after that what helps me not get in that situation is information, which is why I ask so many questions. Because then it brings it home to you. It helps you evaluate in your own mind. (Orville, father of 28 weeker)

There was one father, who was particularly reserved in the interviews, who had a more difficult time with the information he received. For him, the information seemed to overwhelm him:

Q. What was going through your mind when all of the doctors are talking about what is going on?

They are crazy. They go in there and they tell you a bunch of horror stories and they are always give you that worst case. Then they come in a half hour later and say that they are taking the baby and only give him a 20 percent chance. I thought,

"Oh, you are nuts. We have to figure out some other way. There has to be something else." (Ned, first time father of 25 weeker)

This statement was given early in his description of the preterm birth of his child. Later in the interview, this same father described the immense respect he had for the physicians and nurses, stating in no uncertain terms that they saved his child's life and that he trusted them a great deal. Consequently, his comments convey more of being overwhelmed by the immediate situation.

Not surprisingly, the source of much of this information was the hospital staff. As indicated in the previous quote, every one of the fathers expressed his admiration for the staff and the work they do. No fathers in this study expressed problems turning the care of their child over to the staff.

To me it was just they knew exactly--- well, they're professionals and they knew exactly what they were doing and they knew exactly how to handle it. That's when I panic is when people are unsure what to do. Everybody took -- if they didn't they sold it pretty well. Everybody knew exactly what to do. (Henry, first time father of 27 weeker)

#### Primary nurse

The policy at University Hospital was to arrange for a primary nurse care for the child during each shift. The assignment of a primary nurse allowed for continuity of care with the new infant. Since all children are different, the primary nurse allowed for a hospital staff member to know the child's particular patterns, difficulties, as well as what interventions have worked and which have not. The parents chose this individual with approval from the staff, so that staff members were not overwhelmed. The importance of

this decision was conveyed representatively by one father, "We choose her primary nurse because we were comfortable with her. We were comfortable especially with the way that she was taking care of our daughter and have confidence in that. And when we were with her it was easy." (Evan, first time father of 28 weeker)

### Child Ownership/Care Direction

The trust that was placed in the staff and the primary nurse did not appear to keep fathers from questioning the care when they had concerns. Two fathers reported specific disagreements with the physicians about the care of their child. Francis, father of a 23 week gestational age child, had a discussion about a potential shunt to be placed in his child for "hydrocephalus" concerns. The child had been transferred to Primary Children's Hospital for this surgical procedure. Before they performed the surgery, the father and his wife asked if the doctors were going to do some blood work first. When they found "something they didn't like," a course of antibiotics was ordered. He stated that "in the meantime, the hydrocephalus started to resolve and started going down and she ended up not needing anything and they eventually sent her back."

Paul, father of a 24 weeker, reported his summary of the interaction with the staff regarding a surgical procedure commonly performed for reflux:

We were trying to figure out this reflux. The only thing that worried us really bad was at the end when they started the Nissen. That was at the very end. (My fiancé) and I decided that no we don't want to do that. That doesn't make sense to me. I called my daughter's pediatrician and called everybody to get a second opinion. Some of them told me yeah. Some of them said there's a good chance it will work out on its own, think of the long term effects. That was the biggest one there. And

just like I said that was the only thing that worried us at the end. Even some of the nurses told us that you need to do this for him. This is the only option. If you do it he will be home. And we just kind of said no. It was almost like they got frustrated with us. The staff got frustrated with us for not doing it. And then we didn't need to do it any way. I can't remember the name of the one that we did. But it was a simple operation. The two little bandages on his stomach. He was home four days later.

#### Family Issues

Fathers also described impacts to the various families. Given that each family was quite different in its makeup, there wasn't agreement amongst the fathers, but there were predominant themes. Those fathers who resided the furthest away from the unit had their wives stay near the hospital nearly the entire time the child was hospitalized. One father took up a recreational vehicle for his wife to stay in, others resided at nearby family or at the nearby Ronald McDonald house. The fathers described the impact to the entire family:

We are going through the prolonged hospital stay and the commuting back and forth. And a whole different -- I mean changing your lifestyle for two months of how your normal household functions. I mean it is just nothing like it was. I mean the kids ate at every fast food place there is out there. It was just difficult. And they had activities. All three kids are on baseball games, different times and different places. Work pressure, you just feel like you are stretched 1,000 different ways and try to accommodate everybody. (Alan, father of 29 weeker)

No fathers reported issues due to the preterm birth of the child that had devastated their relationship. Every father described their marriage or relationship as stronger because of what they had gone through. One father related that the preterm birth had both positive and negative effects on the marriage when he stated, "I think that it was affected our marriage in a positive way for the most part. It is also been stressful on a marriage. But I think if anything it has brought us closer in the long run." (Burt, first time father of 25 weeker)

Another first time father related that the commute was a good time to communicate:

...it brought us more closer together than I think we you know spent more time traveling together to go and see him at the hospital several times a day. Just talking about what we need to do to prepare for us coming home. It made us communicate more about what we needed to do as a family. So I think that that was a good thing. (George, father of 32 weeker)

One father had been experiencing difficulty in the marital relationship prior to the birth of the child. His description of the impacts of the preterm birth were interesting because he described it as a completely positive, relationship-changing experience early in the interview but later described some problems, particularly related to finances, that appeared to be re-emerging:

Our marriage is stronger. The little nitpicky things are gone. We are talking again. Instead of just me making decisions financially, I am discussing them with her before I make any choices. Before this, I was not sleeping in the same bed as her. We are now back in the same bed. We are doing things together, going places. We

are a couple or a family again. My kids are not asking why I am not in certain places or all of that has gone away. They used to ask questions like, "Why is dad down stairs sleeping. Why isn't he here upstairs? Or going with us to go here or there?"

- Q. If the baby had gone full term do you think the outcome of the marriage would have been different?
- A. No, it would have been the same.... I do not think that if it had come normally that things would have changed much. There was no -- part of what changed both of us was the fear of both of them dying. That I could have lost this one or even my wife was important enough to say "Is that really important to worry about? Is this argument about where the finances goes or who makes the decision really as important as their lives?" Had she gone normal, I think that I would be leaving and gone and I would be sleeping in a different room. I think that is what changed it. For whatever reason she had to come early to make that kind of a change.

Later he described difficulties are perhaps reemerging:

- Q. Anything that has gotten in the way?
- A. Stubbornness.
- Q. In what way has that gotten in the way?
- A. Oh, to some extent it is making arrangements and plans. I am not always of the opinion of leaving the children and doing something. I am more of the let's take them all and my wife wants to find a baby sitter and leave them at home and go by herself. We have been in the middle of trying to get that room ready for this

one. Her own room.... I just didn't have the money to finish what I needed to move my computer back in there and reoccupy the room and now it is my son's room and mom wants it now at a certain point and I have to stand my ground to some extent to do it a certain way or spend the money that we may not really have to put the shelves in the room or the clothing bar in the room to get it done. And some other things to that extent.... (Ivan, dad of 31 weeker)

One of the Hispanic fathers related the difficulty he had with the amount of time that his wife wanted to spend on the unit. The degree to which this may be a cultural view was unclear, but, in his view, this was having negative impacts on the two young daughters who were at home:

Just because we kept on arguing about (taking turns visiting the hospital) — my wife wanted to spend all of the time at the hospital. And that did bother me — it didn't bother me if (our daughter) was the only girl. I don't mind if she was not with me at all. But she being away from the other two daughters, that is what bothered me. We had arguments about that. I said to my wife, "You know, you have to spend the same time that you spend with (our daughter) at the hospital you have to spend with your other two daughters. I don't care if you spend four hours at the hospital, but you spend the same time with the other two daughters that is fine." She said, "But she is just a tiny baby and everything." And I said, "Yeah, but the other two need you too. They are older and they totally understand. They need you to be here. If you want to spend ten hours during the nighttime when they are sleeping that is fine with me. I don't care if you leave at 7 pm and come back at 8 am the next morning. I am fine with that. But don't

spend too much time over there when the other two are awake and they are asking about you." Yes, that was hard taking turns. And I usually — to prove a point I will try to go very early during the day or late at night so I can be here for my two other daughters kind of to make a point to my wife. I guess she didn't take it very well. (Jorge, father of 28 weeker)

Another father described the near death of his child as altering the family:

We have been to the battle. We have been to the front lines. And so the stuff that you see on a day-to-day level is less important to us. And the relationships that we have with our children, and the time that we spend and the way that we communicate is more important. I would say so. Having been that far to see your own child die. We emotionally prepared ourselves for his death. Anything else is sort of cake. Anything else is easier than that. But I don't know that we could do that without having gone there and back. And maybe I am not describing it well. But we have talked about how having had that experience changes us, our perception of ourselves as parents. It brings our family closer together and helps with the amount of love and cooperation that we have in the home. I am not sure that I see it. But we feel it. (Kris, dad of 24 weeker)

#### Paternal Identity Acquisition

As indicated earlier, the acquisition and development of the paternal identity occurred, at least as the fathers perceived it, as the child approached discharge. Fathers described their perception of the paternal role, along with their ability to carry it out. Initially, and with some connection to the father's trust in the staff, father reported their role in the following way:

I think that I see myself more in a role of... yeah of a parent. But more of a care giver at that point (early in his child's time in the unit). You have all of these medical conditions, like I said, providing the baby a good environment by touching, holding, feeling and talking. It was hard for me. I think that toward the end of our stay we felt a little bit differently.... At this point we know what works for (our child) and what does not. We were pretty vocal after that. And initially I think that the nurse would say "Oh, I don't think that you should hold her. She is a little bit agitated. She's a little bit tired." And when they say that, you think, "But this is my child. Why are you directing the care and not me?" As it progressed we took that role of you know she is fine. You need to do this. We wouldn't say, "Can we hold her?" We would hold her. If you didn't like it, then tough.... I think that we made that transition, but initially you feel almost like an outsider like it is not your child. She is under all of the supervisions and under all of the routines. Here is when she gets her medications and here's when she gets her feedings and you don't have any role over that. (Alan, father of 29 weeker)

The paternal role changed over time as one father reported:

I didn't really feel like one (a parent) because I was busy working and trying to keep everything afloat. And going in there when I could. There were times that I was just too tired and didn't want to go in there and deal with the stress. I wanted to see her but not in the hospital. So I didn't... I feel like a dad when I was there and changing her diaper and feeding her and learning how to do that.... I didn't really feel like a dad until later on when we could hold her a lot and stuff it kind of sunk in. At first it seemed kind of surreal. (Evan, father of 28 weeker)

Still fathers repeatedly described the staff as encouraging their involvement:

I fully trusted them. Even when (my daughter) went in there the first time I had full confidence. The more time she spent there the more confident I got. And they were very "We are not the parent; you are the parent and we want you to do what you can do." But to keep the ball rolling. When I would go in as a parent they would let me do what I can do and I was happy to do it. It's kind of tough to let them... I mean, I didn't look at them as them being the parent. Because they are not the parent they are just talking care of -- just the care giver, not the parent. And the baby knows who the parents are. They could tell. And you have to keep that in mind too. The baby knows who their parents are and who is really going to take care of them ultimately. And the nurses do the medical stuff. (Orville, father of 28 weeker)

A first time father reported the way in which the staff helped him learn the caretaking activities of the paternal role:

Yeah in the beginning I was like, "Holy cow, how am I going to handle this?"

Just (my son) and... it is kind of scary enough to be a first-time dad and have a normal child and then we have this preemie who will have special needs.... We kind of felt -- this is kind of weird I guess -- but I felt kind of lucky that he was in the hospital for so long because we had a coach. We had someone to hold our hand and said "No, you don't do the diaper this way because it will irritate the scab on his belly button. You fold it down like this." You always had someone holding your hand. So for the first six or seven weeks he was in the hospital we

had someone watching us and teaching us along the way, like CPR and all of that....

They hold your hand and slowly introduce you to everything. The basics as to how to hold the bottle. I remember this nurse... a nice guy he was showing us tricks on how to get (my son) to eat. When I would hold him he wouldn't eat. And then (the male nurse) would pick him up and he'd suck the bottle down in 2 seconds. I didn't even know how to feed the baby. (Mike, first time father of 32 weeker)

The child's discharge was reported by fathers as further moderating their view of themselves as a parent:

Especially having her home we feel a lot more like a parent. You know, just being able to take care of her and comfort her when she is crying. Feed her a bottle, just all of these things that to me that parents do that we just didn't get to do. So we have this baby, we just were not there to take care of her.... We went every single day like I said and we were there for a couple of hours. But you know just when you think about a couple of hours in a day with your kid it is just — you know. I think that is what I mean by — I didn't feel as much like a parent as I think I would have had the baby been home. (Burt, father of 25 weeker)

The father of the most critically ill child in the sample described his overall experience and the way he viewed the paternal role. This included the typical role of breadwinner, but also included sacrifice, housework, and caring for all the children:

Actually, it was during my wife's bed rest and during when (my son) was in the hospital is when I felt the best about being a dad that I ever had. Because a) we

were able to keep our family alive. I was continuing to work to some degree. You know the money was still coming in. Our children were -- I think we were all growing closer as a result of the sacrifices that we were making. I was personally making more sacrifices for my family than I ever had. When (my wife) was on bed rest I did everything, the housework and putting the kids to bed and working and grocery shopping and you name it and taking care of her. When she was out of the hospital she was able to do some things around the house. But still the traveling back and forth to see (my son) and seeing the other kids and spending time with the other kids when (my wife) was at the hospital, it I think helped me as a father more than anything else. I felt better as a father than maybe I even do now, just because of the amount of sacrifice that it required. Sacrifice. You know commitment, time, whatever. (Kris, father of 24 weeker)

Fathers also described the paternal role in terms of what activities they could perform. Given the nature of the NICU, opportunities for actual caregiving are limited, and fathers viewed their opportunities as even more limited given the mother's role:

It is hard for the dad of make a connection with the child because you are just the dad. There's a barrier (referring to the incubator). It is not like you are breastfeeding them or providing milk for them to feed.... They would let mom hold her but I could hold her for a second but not very long. That did not bother me at all. I was like, "Whatever it takes. I have plenty of time to hold her." That is going to help mom feel like she was doing something for her. (Orville, father of 28 weeker)

#### Visitation

Not surprisingly, some fathers had difficulty being on the unit. For two of the fathers, this arose from already existing difficulties with hospitals and they sometimes found themselves lightheaded in the NICU. For other fathers there remained other concerns:

Actually if wasn't hard for me at first. I looked forward to going up there until I went up there and the first time I went up there -- the IVs were hard for me to handle when they were in his hand. And then I went up there the one night after work and he had one put in his head and I just couldn't stand that. That just drove me up the wall. That's when I kind of started slacking off. I would always call in on the phone to check on him, but the desire for me to actually go up there fades away because I don't want to see it.

## And later he explained:

I felt a little guilty because I didn't want to be up there as much. It caused a little friction between her and I. Even she would get on my case and she had to poke and prod to get me to go. It wasn't that I didn't want to see him, I just didn't like the environment. Not that it was a bad environment. It's just not some place I want to spend time. It drove me crazy. And I knew he was being taken care of. I knew that his mom was seeing him. And I knew when I was up there was nothing that I could do any way. It was more frustrating for me. That's the best way to explain it. (Paul, father of 24 weeker)

Fathers also reported being very fatigued by the time work was over, and that visiting frequency was related to this:

I would come home from work at 9 or 10 and she would say, "Let's go." And I would be like, "No. I am not going." She would be like, "You don't even want to see your baby and blah blah," because she was eager to go. The last thing I want to do is go to a hospital where there are a bunch of sick people to see my baby not home and to deal with nurses and it just wasn't the thing that I wanted to do. I wanted to be there and I wanted to have my baby but I didn't want to go to the hospital and do it. (Evan, first time father of 28 weeker)

Visiting the child in the unit was easy for some fathers, and more difficult for others. There was no correlation to any of the demographic information that would help explain this difficulty. Fathers reported visiting frequency was a matter of two issues besides comfort level: time and finances. Those with other children at home described more difficulty visiting and it required outside support or a diminished experience to visit.

I figure 45 minutes up and two hours there and 45 minutes back. You are talking about four hours for one trip. Doing that more than once or twice during a weekday was difficult for me. Sunday was a real nice day, just my wife and I to catch up and sit there and spend the whole day with her." (Alan, father of 29 weeker)

Understandably, the greater the distance from the hospital the more difficult it became. The fathers who lived outside of the Salt Lake area described finances as affecting their visiting. A first time father stated that it cost over \$600 in gas during one month of his son's stay to commute to Salt Lake City to visit his son, while another described his experience this way:

You know monetarily it was almost impossible to afford to drive down there. Even on the weekends. There were a couple of weekends where we just didn't have the money to pay for gas. Plain and simple. It would cost me sixty to seventy dollars. It would get you down and back with food or whatever. Sometimes I have to suck it up and stay. Not that I didn't want to be there, I just couldn't. (Orville, dad of 28 weeker)

The father whose work required him to be on-call at times also described the difficulties in going down:

I went down every couple of weeks and I would stay for a weekend usually.... A lot of times I would go down and we would go out to eat and stuff too because (my wife) was under a lot of stress while she was down there. It was nice to take her out every once in a while. (Larry, dad of 29 weeker)

To distinguish whether visiting was a desired event, even if it was more feasible financially or due to time, fathers interviewed during the later part of data collection were specifically queried about how much they visited, and whether they would have wanted to visit more often. A father who visited once a week was asked:

# Q. Would you have wanted to visit more often?

That is a good question. Yes and no. Sometimes like (my wife) was there every day. She works up Immigration Canyon so it was kind of pretty convenient for her. So yeah, she just — she is like one of the nurses she knew a lot of everything. That is one of the questions — (a male nurse) asked, "So how many times were you here?" Obviously not enough. So part of me wanted to be there but also it was very uncomfortable when I was there too.

Q. What was uncomfortable about it for you?

Because I put myself in you know his shoes basically, I empathized with (my son). It has to be hard for a baby... (Henry, first time father of 27 weeker)

Sibling Issues

Fathers with other children at home also described difficulties visiting. Very young children were not allowed on the unit, particularly during winter months, and when allowed, were only able to visit for a short time. This was typically due to concerns about disease, particularly Respiratory Syncytial Virus (RSV). Taking siblings to the unit was described by one father in this way:

...each weekend we would go with Grandma. We would have Grandma stay out in the hall with them and when they were done, we let grandma go back and spend the time with mom.... (W)e could barely manage once (a week) with all three of them with school and everything else. Trying to get them up there that is a two-hour ordeal. Just in the hospital itself. Trying to get them in and out, back in there, cleaning their hands, getting them back to mom and the baby. So it was quite hard. (Ivan, father of 31 weeker)

Another father from further away, described the results of taking his children down to see their mother and then returning:

My kids knew and they are old enough to know that things were wrong and weren't normal. There were people in the family, our oldest son, he is eight. We were coming back from Salt Lake one weekend and as we pulled in our subdivision here I could hear him sobbing in the backseat. I said, "Are you okay?" And I said "What is wrong?" "I miss Mom already." And (our daughter) really

never had any emotional out-break. Hers was more of why she was on a sugar high regression. Yeah, she was potty trained but she was peeing her pants all of the time. Just couldn't get her to settle down. You know it was like someone stuck an IV of solid sugar in her vein and she was bouncing off of the walls all of the time and she would just crash. So we try to keep some kind of normalcy but thing things are never normal when mom's not home. My son is in karate and I would take him and I would let him go and do things that they would normally do when they were home. (Daniel, father of 28 weeker)

Fathers often expressed the hope that once the infant was home things would be different. They described homecoming as a time when their ability to care for the infant, hold them, as well as leave behind the commuting, visiting hours, and worry about the child's health.

I kept on thinking, "Well, when she comes home it will be different because I would have her right there. Whenever I want to see her I will be able to see her. It will not be a 40-minute drive to be there for a half hour or an hour or something." Even if I spend a lot of time there was this barrier, this isolette thing. I couldn't take her out. I wasn't able to be touching her and stuff. She would be asleep and there was this plastic barrier for me. It was very uncomfortable. It was kind of bothering me that lack of connection but I knew when she came home it would change.

And it did?

It did, yes. (Jorge, father of 28 weeker)

## Employment issues

Finally, many fathers described their involvement with employment. One father (Daniel, father of 28 weeker) described the need to work as the need to maintain the financial stability of the family. He stated:

My wife is a registered nurse and it takes both of our incomes together to make ends meet around here. And I knew that it was going to be a long time before she went back to work and whether financially we were going to be able to handle it. We had money set aside for having a baby, but not a premature baby....

And later he stated that although they had insurance, "But the insurance does not cover your mortgage and your lost income when you are not working. It covers medical and even then, most insurances any more try and find a way of not paying for everything."

But fathers also described employment as providing other perceived benefits: I would have been up there as much as I could. But I also think that one of the reasons that I was able to deal with things a lot easier because I have that outlet. I go to work and I am on the clock and I have to concentrate on what I am doing for the most part. So I think that it gives me a release. And it gives me a break from all of the burden or heaviness of it. And then I can go back and be there. Whereas my wife she is 24/7. I think that it is a healthy thing to get away and come back. (Francis, father of 23 weeker)

While another father described the benefits of going to work as:

I liked when there was someone here to help (my wife) like a mother-in-law or something. (My wife's) mom. So that I <u>could</u> go to work and not have to worry

about her coping with the issues. Because it is hard. It is hard to do -- you know we are better at it now than we were then. But when she had to drive to the hospital and pump eight times a day and all of these things. It was so hard on her that it was hard for me to let go. If someone was here to help, I quite enjoyed going to work and talking with the guys and telling them the latest with (my son) and they'd tell me what the latest thing was. And there were a couple of days where we would sneak away at lunch and play golf. So we go at lunch and play nine holes of golf. To me, that was just fantastic. I needed that. I think that there was one or two occasions during the summer where I would take like a Saturday morning or maybe even an afternoon of a workday and play 18 holes with these guys. For me it is fantastic sort of refreshing and a rejuvenating experience compared to this life that we have been living. I look forward to that. There is that anxiety about I am not doing a good job at work so I don't really want to go there and show my face.... It is nice to go to work and pick up the phone and hear how things are going and not have to deal with them directly. I don't think that I'm slacker like I am trying to escape the responsibility. But as long as things are covered, you know my sister is here or someone is here to help. I like to be able to focus on something else for a while. I even tried to give (my wife) that opportunity but she is not good at taking it. She has a hard time getting outside of this set up that this is my life. Just go to a movie or something, but she won't. (Kris, father of 24 weeker)

#### Summary

Within the context of preterm labor and delivery, the roller-coaster of life in the

NICU, and the preparations for the parenting role and taking care of a formerly critically ill child at home, fathers of preterm infants navigate through a variety of stressors. The size and appearance of the infant was always described as meaningful, and fathers saw their child as understandably fragile, with some sense that their child's fighting for life signified some strength. Holding the infant and their child responding were meaningful in the father's time with their child, and they received support from a variety of sources outside their marriage.

They supported the mother in her efforts both pre- and post-delivery, often attempting to be a calming and stabilizing force. Fathers sought out information, initially as conduit between the mother and child before she could see the infant. They also involved themselves with decisions regarding the care of the child, including choosing a primary nurse for the child, and greatly trusted the medical staff.

Attempts at parenting were understandably frustrating, and were affected by visitation, employment and financial concerns, and the available tasks to be performed on the unit. Each of the fathers interviewed described themselves as emerging well from the stressors of the unit and able to continue in the paternal role despite some typical concerns about their child's health and later development. All described their marriage as stronger, even when the stresses of the unit caused some minor conflict in the relationship. The implication of these findings is discussed in the subsequent chapter.

### CHAPTER 5

### Discussion

The sixteen fathers interviewed in this study provide a significant look at fathering or as a father a preterm infant. The average gestational age and birthweight of the infants in this sample are smaller than other groups. In Bacon's (2000) study, the average gestational age of infants was 28.7 weeks and the infants had a mean birthweight of 2 pounds 8 ounces. The children in that study were hospitalized an average of 55 days with a range of 10 to 156 days. The current sample averaged 87 days in the hospital ranging from 38 to 169 days. The children of the sixteen fathers interviewed had a mean gestational age of 27 weeks 4 days and an average birthweight of 2 pounds 3 ounces. This current sample had a tighter range of both gestational age and birthweight.

An additional strength of this sample is that all the fathers were interviewed shortly after the singleton birth of their child, with no more than about six months, and an average of two months, passing between time of discharge and the actual interview. For Bacon's (2000) study some of the participants were several years post-discharge, and forty percent of her sample had multiple preterm infants at birth, some of whom had passed away. Additionally, there was every indication, both from the investigator's experience and the fathers' own report, that these infants had a relatively easy course in the NICU given their gestational age and birthweight.

In some sense, these fathers had the "best-case-scenario" of preterm fatherhood with infants born so young. This is not to say that they had it easy. Preterm birth and parenting infants at this gestational age is very difficult. The status of their children and the relative ease of their NICU course indicates that given the circumstances that these fathers were in, which was better than some with children of similar gestational age, they still reported a difficult time having their child in the NICU and experienced an upheaval to their lives and that those with a more typical situation could have even more disruptions than those described here.

As noted in the previous chapter, the participants interviewed had four experiences and themes that were common amongst all sixteen fathers. There was noted a particular coping process, something that could be termed a paternal identity, that was described by all the fathers and found expression in a variety of ways, depending on the particular circumstance of the family. This paternal identity is perhaps the most notable finding of these interviews because it relates to paternal role development and indicates that the way fathers approach preterm birth may be quite different from mothers.

While the other four themes allow for direct comparison to previously cited literature, the paternal identity of preterm fathers also allows for expression and discussion. If for no other reason, the results of this study described what Gaiter and Johnson (1983) were looking for,— "...the kind of contact fathers have on first meeting their preterm baby in the nursery." (p. 387) This may, in fact, be a very significant part of preterm fathers' paternal identity.

In this chapter the paternal identity will be defined and introduced, linking it to descriptions delineated in the previous chapter. This identity and approach and the other

four themes described will be shown through the chronological process of having a preterm infant. Additionally, as prior literature speaks of a particular time in the identity development or relates to a particular theme that this sample of fathers described, it will also be discussed. Finally, other findings of interest, the application of these findings for clinicians and medical personnel, along with the limitations and future areas of research interest will be discussed.

# Paternal Identity and Team Approach

The paternal identity is defined simply in this sample as the stance that these fathers shared to manage the impacts of having a preterm infant. It involves using a team approach to the birth and care of their child. Since the care for the child requires such a great deal of effort medically, psychologically, financially, etc., it appeared that early in the course of their child's birth, the fathers searched for a way to do all that was required within their perceived paternal identity for their child's well-being. They took the image of being a father they had created or felt was consistent with expectations and attempted to find a way to make that a reality. They worked to create a team that would handle the facets of care and they participated in activities that would manifest the paternal identity through a paternal role, or in other words through specific tasks.

Pre-delivery activities. Fathers have been seen by previous researchers as building a network to support the mother-child bond (Diamond, 1995; Dollahite & Hawkins, 1998; Parke, 1981). This network has included keeping the breadwinner role. Fathers were not specifically asked about their involvement in the relationship and identity prior to the preterm birth of their child. There was every indication, however, given that the preterm birth was such a chaotic event, that a role and identity had been established

regarding their place in the family. Researchers have noted that paternal development occurs before the actual birth of the child, sometimes before the individual is considering conceiving children and that this continues into the childbearing relationship. Fathers worked quite quickly to ascertain what was needed in the system, a way in which it could be consistent with their view of being a father, and worked to meet those needs within that framework. As was shown, fathers worked quickly to support the mother, calm the situation, and assisted in decision that would have direct impact on the mother and child. Their needs often were secondary to the mother-child dyad. Later on in the child's hospitalization, as will be shown later, fathers worked to continue this network building.

May (1982c) described a three-part paternal development for full-term fathers including *announcement*, *moratorium*, and *focusing* phases. Many of the fathers in this study would have been placed chronologically in the moratorium or focusing phases given the gestational age of the child at birth. However, no direct querying was done about where the fathers were, given that the focus was on their birth and post-delivery experience.

May (1980) also described three different styles of involvement in the relationship with the mother that encapsulate ways in which fathers' structure and implement the relationship. These three styles: *observer*, *expressive*, and *instrumental* did appear to be present in the sample. Three of the fathers appeared to be more observer-like, especially later in the child's course, wherein they were supportive and happy, but avoided more active involvement. This lack of active involvement was typically related to difficulty being on the NICU, sometimes for preexisting phobic-like responses to hospitals. It also appeared to be present in fathers who had a more difficult time seeing their child attached

to more aggressive medical technology such as the oscillating ventilator which causes the child to shake in seizure-like movements or to having an IV in their head.

The expressive style, characterized by a strong emotional response, was not seen to the degree described by May, wherein psychosomatic symptoms may be present. Two fathers described a very strong emotional reaction to the preterm birth of their infant, but this tended to subside over the course of the hospitalization.

The remaining eleven fathers seemed to have a more instrumental style which is characterized by a task oriented, productive and supportive manifestation. In fact, every father had some characteristics of this style and gives credence to the way a paternal identity was developed and manifest. Fathers talked about tasks around the home, at work, or on the unit that they were involved in or needed to be resolved. These were seen as part of their role within the family system and served to either support the maternal-child bond, sometimes at the expense of their own time with the infant, or to stabilize the system. The degree to which May's paternal styles changed or were adopted as a result of the preterm birth remains an area of future study and may also be in response to maternal expectation. A study with a matched mother and father who may be followed from before preterm labor to the discharge of the infant would help tease this information out. The difficulty with such a study is the need to follow large numbers of people, since preterm labor is unpredictable.

Preterm birth and delivery. Oehler (1981a) and the qualitative pieces from mothers of preterm infants in the literature review describe labor and delivery as a chaotic time. Fathers of preterm infants also described this chaos and they viewed their initial

role as one of support of the child's mother. This involved serving in a support and calming role with the mother before and during delivery.

It was also clear that fathers had no difficulty in choosing where to be shortly after birth. Freud (1995) indicated that the choice between staying with the mother or with the child was a particularly difficult decision given that both were likely very ill. The fathers in this sample reported no such difficulty and always stayed with the mother. They may leave briefly to check on the child and act as an umbilical, but they always came back to the mother and spent the majority of the time with her. This may have been due to the environment of the unit which understandably required that the parents wait until the child was stabilized, but there was a clear indication that the fathers had no concerns about the staff's commitment to do their very best for the child.

Shortly after birth, and consistent with Freud's (1995) view, fathers acted as an "umbilical" or a conveyer of information between the medical professionals and the mother. This information gathering activity continued through the child's time in the unit. Fathers described actively seeking information through going to or calling the unit to gauge their child's well-being. Even the choice of the primary nurse had overtones of picking someone who would be on the unit consistently who would know their child's behaviors, and in some sense act as a pseudo-parent and one with whom they could exchange information. Freud (1995) felt that some fathers may avoid the unit or interaction with their child. There may be some who would then see the interaction with a primary nurse as a behavior motivated by a desire to avoid contact with the infant or their status.

These fathers' interviews did not seem to support this idea of paternal visitation avoidance due to having a primary nurse. The fathers knew that certain medical procedures would necessarily be given, and having someone that wouldn't, in the words of one father, "re-experiment" on the child was important. Further, many fathers reported wanting to participate in the care of their child and were willing to participate, sometimes despite concerns about the fragility of their child and the degree to which they might hurt the infant if they assisted in his/her care.

While Herzog (1982) and Hynan (1991) described anger, stress, grief, and powerlessness as common reactions of fathers as they prepare for and deal with the preterm delivery, the fathers in this sample did not describe these reactions to that depth and degree. While fathers described being worried, frustrated, sad, and somewhat lost given the chaotic and new environment of this type of birth, anger was only described by one father, who found the information he was given overwhelming. Additionally, these authors often described these reactions as hindering the father from engaging with their child. None of the fathers appeared to be unable to engage in tasks consistent with the paternal role. The reasons why this reaction was not present in this sample is unclear as none of the fathers described these reactions in others and gave no sense that their reactions were anything but typical or expected.

Neonatal period. Fathers first meet their child or are experiencing the first long term contact since delivery in this period. It is at this point that fathers described the appearance and fragility of their child and this was noted as two of the themes consistent with all sixteen fathers. Klaus and Kennell (1979) have noted that the appearance of the child makes adjustment to the infant more difficult as have other researchers (Hughes,

McCollum, Sheftel, & Sanchez, 1994; Miles, 1989; Shields-Poë & Pinelli, 1997; Zaichkin, 1996). This is perhaps the most consistent and prevalent theme in the literature of preterm parents.

Stainton (1985) described the "fantasy child," or psychologically created perfect infant image, that many parents have in mind pre-birth. While none of the fathers volunteered exactly what this would look like for them, they were all clearly affected by the size and appearance of their child, and that this view of their child was something new, unexpected, and foreign for them. The observation that parents may wait to name their child because of their compromised health and appearance (Kaplan & Mason, 1960; Hynan, 1991) was not reported by any of the fathers. They all named their child within hours of the child being born. Many reported, even before the onset of preterm labor, that a name had been chosen and would continue to be given to the child regardless of their medical condition.

Some fathers touched their child at the first meeting, as this was encouraged, but most did not linger very long with the child, due to nursery pressures and the father's desire to be with the mother, for whom he was worried. All were struck with the fragile nature of their child's existence. The hallmark of these fathers' paternal identity, support of the mother, continued at this point as they established initial contact with the infant, determined the status of the child and then returned to the mother.

McGettigan, et al. (1994) stated that many parents experience depression and distress as they wait to see their child. None of the fathers in this study reported a clinical depressive syndrome waiting to see their child. They typically stayed with the mother of the child, supported her, and waited to go meet the child. Many reported being hopeful

and anxious to meet their infant, and even after meeting their child, sadness and shock were the strongest descriptors of their reactions. While fathers had some depressive symptoms, they all described the birth as relatively exciting, and most were very excited about the new child. Only one father, Ned, a father of a 25 weeker, reported being very sad about his initial time in the unit. MeGettigan, et al (1994) described a much more severe reaction than what these fathers reported.

Kaplan and Mason's (1960) view that parents must prepare for the potential loss of the child, acknowledge their failure to bring a healthy infant into the world, reassume the parenting relationship, and understand the child's new needs and patterns was seen partly in these fathers. The noticed fragility of the child certainly speaks to the potential for the child to die, and each of the fathers attempted to assume a parenting relationship, but there also appeared to be some consolidation initially of what their paternal identity was and what roles and tasks would be needed at this point. There was no specific acknowledgement from these fathers of failure on their or the mothers' part. In fact, the majority of fathers reported feeling that the mother had done everything expected. The fathers reported a number of the mothers as feeling guilty, but this was never a view shared by the fathers.

The fathers appeared to use the information seeking aspect of the paternal identity to ascertain not only their child's needs, but also the family's. Their own needs to stabilize the family, to have some sense of normalcy and proximity to pre-hospitalization routine could readily explain their return to work, the amount of visiting they engaged in, and the support they offered the mother of their child. The choice of the primary nurse also seemed related to this. As fathers reported, this person represented a vital link to a

continuity of care for the infant that was comforting to the parents. After discharge, many of the fathers reported that they were waiting on follow-up visits to ascertain the future needs of the child. The work of knowing the child's future needs seemed to be ongoing, and may be beyond the time constraints of this study to accurately measure.

Holding the infant. No prior study has described the experiences of fathers when they have first held their child. In this study, holding the child was perceived by fathers as a two-fold event. Fathers typically held their child the first time simply by holding them above the bedding of the incubator or warming bed to allow for the changing of linen. This event seemed to confirm for the fathers the tremendous difference between what they had expected their child to be like and what they actually were like in weight and appearance.

The second, more meaningful, holding that more closely approximated their expectations was seen as a very important event. Holding the infant close, which often required that the child be off the ventilator, indicated a milestone had been reached in the child's proximity to discharge. Further, fathers described it as a time when they could engage in more typical paternal tasks including changing diapers, bathing and clothing the infant, as well as just sit and enjoy being with the child.

Other impacts until discharge. Once the mother has been discharged from the hospital and a more typical routine of visiting the infant has been established, the chronological nature of the paternal identity changes. In a very real sense, the paternal identity has been solidified and the paternal role activities serve to express this identity in the family. Fathers returned to work, if they had not already done so, and while supporting the mother continues, it is more likely to be a function of assisting her in the

maternal role. At this point, the father is part of a team that is caring for the child. The paternal identity includes being part of this team, and at times appeared to manage it.

This gave a quality of power and control to the situation that is different from the way others have described preterm fathers.

Hynan (1991) described impotence as one of the emotions for new preterm fathers. None of the fathers interviewed described this reaction in either the sexual impotence that can occur in stressful situations or in sense of feeling powerless. In fact, fathers appeared to find powerfulness in the establishing of the paternal identity and in their activities. Routine was established in the home, the child was being cared for by trusted medical professionals, the mother was being supported in her role and identity, and allowances were made for possible changes to the system. Fathers did not describe this time from stabilization to discharge as one of ease and comfort; there was still considerable stress in their lives. There appeared to be a new set of expectations that needed to be met and fathers were trying to continue a team approach within the paternal identity to manage them.

W. E. Freud's (1989) views that parents feel like guests on the unit and that the preterm birth was a blow to male virility, were only partially realized. The guest view was spoken of by a few fathers, and did not last very long. The powerlessness and outsider issues seemed to be mitigated by team approach, and by the family-friendly nature of the unit (Nystrom & Axelsson, 2002; O'Donnell, 1990). In fact, fathers may have been working within the unit to find their niche, to create a working relationship, and be an active participant in the child's care. The attempts to gain information, which also serve to normalize the situation, facilitate this participation.

The support that was obtained or offered from sources outside the parenting relationship seems to have allowed for some of this transition to occur. Meals brought in by neighbors, arranged babysitting, family help, employer support and other assistance seems to have lessened the areas that the father, or the mother, had to attend. This allowed for more energy to be focused on the child and the stability of family relationships.

As the fathers' experience related to their role and the main theme of paternal identity, the positive communication with staff noted by Hughes, McCollum, Sheftel and Sanchez (1994), as a particularly paternal thing to do, did hold true. The information seeking activities along with the overall approach led to numerous interactions with the medical staff. These authors also noted that fathers used a problem-solving approach more often than mothers, and this can easily be seen as part of the paternal identity and approach used by these fathers. Many fathers described waiting to deal with problems until they presented themselves, focusing on the here-and-now, with specific problems and issues, and appeared to avoid wondering about what might be, which is how their spouses were often described.

The paternal identity and role taking did not occur within a vacuum. Adjustments were made not only within areas the father was directly, or solely, involved with but also in the family system. Some of the role alteration within the parents' relationship, as described by Miles (1989), also occurred. Fathers took care of home and family responsibilities, especially early in the preterm infant's course, but this appeared to be somewhat short-lived as fathers attempted to define roles, establish a routine, and prepare for the child's discharge, which then led to involvement that may have more closely

approximated a pre-birth status. The mothers' discharge and re-entry into the home also seemed to affect the amount of involvement fathers had in new home responsibilities.

Discharge. As parents approached the discharge of their infant, other researchers' findings become salient. Cohen's (1982) finding that parents often felt like the child is not theirs until discharge was somewhat true, but each father felt like the infant was actually theirs. Further, while the child was not seen as completely theirs, there was distress involved in this realization. Fathers were perfectly comfortable giving the medical care to those highly qualified to offer it. The child was seen in better hands for now, and everyone, including staff, looked forward to discharge. Fathers all described looking forward to having the child to themselves and to care for the child in a more typical and expected way. They expressed concern about their ability to do all that the hospital had done once the child was discharge, but looked forward to the benefits of having the child out of the hospital.

While on the unit, there were obstacles to feeling particularly close to the child, but as with Affonso, et al.'s (1992) work, as the length of child hospitalization increased, the concerns about separation decreased, and perceived competence about how to take care of the child increased. Each of the fathers attempted, and reported succeeding, in acquiring a sense of the paternal identity and role by the time the interviews had taken place. They all reported that the time in the unit made this acquisition more difficult, and many had hoped for the child's eventual discharge as a way to make this transition complete. The team approach also seemed to be a marker of the paternal role.

Employment issues. Employment was also an important theme seen in Freud's (1995) work, and these fathers did see their work role as important. What also became apparent was the moderating influence employment activities could have for fathers. Getting too far behind, feeling unable to meet financial demands, or recognizing the costs of the commuting, care, and support for the mother were difficult for fathers to deal with, but the break from constantly thinking about their child, especially when the child was being cared for by professionals whom the father trusted, was a welcome respite. This may be an indicator of the father's need to get their mind off the unit and their child's condition.

Fathers saw their paternal role involving managing the various stressors on themselves and their families. Being on the unit was necessary because they desired to be with their child and set themselves apart from the medical staff. Continuing to work partly involved a paternal role of breadwinner, and it is possible that this stance is some indication of the protector role that Shapiro (1993) found was the most ingrained and influential role for fathers.

The employment activity of the fathers may be difficult to completely analyze without more focus and may be an area of further study. There may have been many reasons why fathers returned to work. The financial security that May (1982a) speaks as an important factor in readiness for the paternal role could explain the return and importance of their work, but returning to work may also be explained by simple economic need. The medical care for a premature infant is very expensive, with fathers in this sample reporting bills or medical costs approaching \$100,000. These pressures combined with the continuing financial needs of insurance, mortgages, rent, etc., are

profound and ongoing while the child is in the hospital. The statements by the fathers indicate that there are benefits to returning to work, including support, a stress release, and something to relieve the constant reminder of having a sick infant. These could be further explored by focused research.

Other issues. Tracey (2000) states:

...the father's role changes considerably. If the premature baby is in a different hospital from the mother, the father will be the one to keep close and direct contact with the baby. He has the burden of supporting and emotionally carrying his wife. He has the discussions with doctors and hospital staff. He has the preoccupation with the survival of his infant. During this crisis, there can be an intense sense of ownership, of bonding by the father. The mother may be too terrified to bond with an infant who may die, or she may experience the infant as also having failed her. The father has to be available for her feelings to the sacrifice of his own. (p. 43)

This description only partly described these fathers. The information seeking and medical care coordination were all noted, as was the emotional reservation described by fathers. However, none of the fathers seemed preoccupied with the survival of the infant. It was quite clear from the descriptive words and summaries of the fathers that the events and experiences of having a critically ill baby were significant and had come with great impact, but none of them described the mother, or themselves, as too terrified to bond. In fact, as some of the statements from the results indicated, some fathers had to encourage the mother to meet the needs of other children at home. Three fathers did note that they rarely shared their emotional reactions with others, and if shared with anyone, it was the

spouse or very close family member. The family-friendly nature of the unit may have affected this to some degree as will be noted later.

Freud's (1995) statements regarding the impotence, loss of a dream, and the ostracizing by other males was not seen or reported in any of the fathers. In fact, when discussing their interactions with others, many described the great interest other coworkers, neighbors, and others had in their experience and the child's health. In fact, some fathers commented on how others were very interested in their child's progress. However, his allusions to a "halo of manliness" (p. 237) that may encourage others to underestimate the degree to which men are affected did appear to be present in the interviews. The fathers were open about discussing how their child was doing, but did not speak about the personal impacts except as noted above.

The most recent other study on fathers of preterm infants, Fidler's (2002) study, indicated that fathers sometimes felt overlooked. None of these fathers reported that type of experience. Given that Fidler looked at fathers very shortly after birth and this study made contact after discharge, there could be a change that occurs throughout the course that needs further exploration. Fathers in this study reported focusing on the mothers' needs and this was often at the exclusion of their own needs. Any ignoring of the fathers initially could be a part of the process of taking care of the family and may be more transitory. Fidler's fathers had not typically had the time that this study's fathers had to stabilize the family routine and manage the system, and this also may have led to some differences.

#### NICU Environment

The degree to which the unit's approach assisted fathers in their transition cannot be discounted or overlooked. University Hospital created numerous opportunities for parents to feel welcome. The general setup of the unit, with tours of the unit prior to delivery, nursing and pumping mothers, internet access, and parent support groups may affect one's feeling about their time in the unit. None of the fathers had experienced preterm hospitalization at another facility and therefore had nothing to compare their own experience to. A unit's environment may help to mitigate certain impacts to the acquisition of the paternal identity and role and a parent's ability to be with their child comfortably. Nevertheless, no matter how welcoming the unit may be, sibling issues, commuting, and financial impacts were apparent in this sample and others, and may be more universal to the experience of having a child in a NICU (Affonso, et al., 1992). *Implications for clinicians and medical personnel* 

One of the main purposes of this project was to describe the experiences of fathers in a way that had not been done previously, which can limit confirmation of other findings but gives a deeper appreciation for the experiences of those who are often overlooked in research studies on families of preterm infants. Nevertheless, there are observations that may be helpful to those who work with these families and fathers in particular.

First, fathers are not a homogenous group where a single practice or policy will always be successful. No two of the sixteen fathers or infants were exactly alike. First-time fathers did appear to be more hesitant to approach their child and this typically stemmed from not knowing how or if it was even allowed or if they would hurt the infant.

Facilitating the first meeting between the father and infant, especially with specific guidance around how to interact may be very influential in the father's sense of paternal identity and comfortableness in associated tasks.

Second, assessment of the fathers, particularly as a way of getting to know them and their needs would be helpful. Knowing if they have any particular questions initially, or even what things are typically helpful for fathers of preterm infants to know, could potentially ease that transition. Information can be a very powerful tool for fathers. Finding out what information may be helpful for the new father can be instrumental in two ways: first, helping them to vocalize their areas of concern; and, second, allaying worries they may have about their child, which could facilitate a move to care giving and parenting. It may also make parent support groups more male friendly. Since these fathers appeared to want a significant amount of information, groups that focus more on how one is feeling may not meet the father's need. More information-focused meetings, or at making information more a part of the meeting may encourage father participation.

Third, most fathers were willing to care for their child when asked to, but typically took a more passive approach. In some broad sense, the more staff can encourage a relationship with the father and between father and child, the more the father appears to be willing to interact, as well as trust that the child is being taken care of adequately. Encouraging fathers to participate in the child's bathing, weighing, etc., may encourage paternal identity and role development. In this study, this type of relationship where there was more paternal involvement tended to lead to more stability within the family unit, allowing the father of concentrate on other needed areas and may have far reaching effects outside of what is seen in the unit.

These last two ideas of encouraging paternal interaction and information seeking could also lead to assisting fathers recognize those events that these fathers reported as important. Staff's recognition of good holding or care behaviors, or when the infant appeared to recognize the parent, or when a particular milestone may have been reached could encourage the father's interaction. This recognition may also facilitate the paternal identity and role taking.

Fourth, simply because a father isn't present in the unit does not necessarily mean that the father is disinterested. From the interviews, it was quite apparent that they were all very informed, interested, and invested in their child's well-being. For some, the pressures of finances, time, and other children led some fathers to not be present on the unit for the overall good of the family.

Fifth, parent support groups didn't appeal a great deal to fathers. There appeared to be two reasons for this. First, they felt that the limited time they had on the unit was better spent with their child. Second, they reported little helpful information gained when they went for more than a few times. They did report that it appeared helpful to the mother of the infant, but also noted that mostly women were at the meetings.

In the location studied, two of the weeks the group sessions were devoted to practical matters like insurance and discharge, while one week had a quick meal available. It was noticed by the principal investigator that there were no fathers as leaders of the group, and this may have set an expectation or perhaps even a barrier regarding male interaction. This could also lead to fathers perceiving the meetings as a support for the mothers of the children, and thus served a purpose that they didn't require. If part of the paternal identity is to gather information, many of the meetings may have not

provided what they were looking for. Finally, if the mother's support is important to the father, encouraging her participation in the groups as they are currently facilitated would be seen as helping the mother, and provide very little for the father and his needs.

Possible methods of meeting the aforementioned areas could include having fathers lead out parent support group meetings, or at least be present with the female leaders. Shared time between them could lead to the meetings being more meaningful to fathers. Additionally, having information ready for fathers could be helpful. Since fathers tended to not be present on the unit as often as mothers, perhaps putting a video of common needs of fathers would be helpful. This could be comprised of vignettes of various fathers, covering the spectrum of experiences and conveying the types of information that is common amongst preterm infants. It could explain the unit, policies, helpful information, sources of support, how to obtain a primary nurse and other information that assists parents in transitioning to life in a NICU.

Another area of potential support could be a system similar to support given to mothers on bedrest. There are groups that coordinate support for mothers by providing them with someone who has been through the experience and can give encouragement and answer questions. These individuals require minimal training, but can provide a great deal of support. A similar contact for fathers may allow them to get some of their needs met, while allowing them to either initiate the contact, or for it to be provided by someone that may make the conversation easier, like another preterm father or leader of one of the support groups.

## *Limitations of the Study*

As with any study, there are limitations to what was studied, who was recruited and the way data collection and analysis was performed, and these areas have an effect on the overall effect and scope of the study. These fathers were obtained through a volunteer process, which may have allowed for those with different experiences to be missed. The sample also comes from one hospital setting. This means that at least three things are possible.

A hospital with a different setting dynamic could produce very different paternal experience and identity development. The setting for this study has a limited collection area (the Intermountain West) which may be quite different in the potential types of fathers available in other areas. A more inner-city setting, or one that does not appear to be quite as family centered could yield different results.

The vast majority of the fathers were married Caucasians. A more diverse sample or a concentrated effort to explore the experiences of minorities may provide a very different dynamic. One of the Hispanic fathers had more difficulty with English in expressing his thoughts and feelings and a bilingual or native speaker of Spanish may have allowed for a more comprehensive telling of his experience. He did have an interpreter that assisted him with information on the unit. Although there did not appear to be significant differences between the Caucasian and Hispanic fathers, it is something that needs direct attention.

The literature on preterm parenting is limited. The literature on minorities and their experiences is nearly non-existent. Additionally, only one of the fathers was not married to the mother of the child, and none of the participants was younger than 22, and

only two were younger than 25 years of age. A more focused look at unmarried, younger participants could detect differences in the paternal identity development and in a sense of readiness for parenting a critically ill infant.

While catching fathers post-discharge allowed for different observations than what Fidler (2002) found, it remains a possibility that these participants were obtained too early to see significant impacts to marital relationships and the child's future well-being on paternal identity. The preterm infants were too young to have serious developmental delays or have difficulties emerge. The potential for this to affect the paternal identity, the way the father may cope with this and its impact to the family system were outside the scope of this study.

Third, the nature of this hospital was such that parents of those who required more intense surgery were not part of the potential sample. There is no way to know what effect this would have on the paternal experience from what was learned through these fathers. One could suppose that the more critically ill the child is the more difficult the paternal experience, but a more concentrated study in this area would be more helpful.

Finally, the interview might possibly have yielded some more helpful information if the semi-structured nature had been relinquished for a more unstructured approach. It became apparent through the interviews that focusing on some of the interview questions were not as helpful in eliciting information as others. The overall describing of the story, areas of support, employment issues, and staff interactions were extremely helpful. More information about the relationship with the spouse, direct inquiry about emotional reactions, and the way(s) in which the family is coping and dealing with post-discharge issues could be more helpful in preparing individuals for life in the NICU and at home.

## Dealing with Death

While each preterm infant is at a higher risk for dying compared to full-term infants, there are some gradations within preterm infants. Within the sample of infants there was always the chance for some medical emergency to appear that could change the child's condition from reasonable stability to imminent death. There was only one father who had to realistically grapple with the possibility that his child was within hours of dying. His description of those few days are very informative and give a sense of just how different this type of experience could be and why a study of an entire group of fathers with a similar experience could yield valuable information:

...when (my son) was not quite two weeks old, he was born on a Tuesday, and he had gotten to where he was considerably more sick over the first few days. You know he got to the U and they got him on nitric and they got him on the different ventilator and he was fine for the first few weeks. After the first week he started to go down. He started to get worse and worse, and he got to where he was retaining fluid which affected his breathing and they were at 100 percent oxygen and 17 whatever the measurement is for pressure, whatever it is. I have it written down somewhere else. They got to where they had to increase his pressure (on the ventilator). And it was sort of a downward spiral. And they started to prepare us that (he) would not survive. And on a Sunday I went in the morning to see him. And when I got there, the social worker said we want to see you. And so I went to (his) bedside and about eight people came and got around me and started having a talk with me about being honest and open. And so I could tell what they were up to and the group included the attending, the resident, the nurse, you know the

respiratory therapist and the social worker. And there were quite a few people there. (A doctor) told me that (my son) was not doing well. He said, "I give him one percent chance to live." That was because of the conditions that he was under, he would not survive the day. That was hard to hear. Not because it was unexpected.

- Q. Your wife was not with you at this time?
- A. She wasn't. I was there by myself. The first thing I did after I had this conference was I told them I need to talk to my wife before we make any decisions about what care we do or don't give. That was part of the conference. They wanted me basically to decide how much they were going to do before they called it quits with (my son). (My wife) and I are not of the sort that we wanted to unnecessarily prolong his life if he was going to die.... We understood the facts. We knew since day one that this baby was at risk. That was before he was born. I told them that I cannot make any decisions about how much we do without (my wife). I called her and she came up.... So that was they took a few hours a couple of hours for her to get there. And I sat next to (my son) and just thought about the things that they had said. When (my wife) got there the same group sat around us and some extra people and gave the same story to (my wife). Although it seems when (she) was there and they told the story it was even more bleak.

(The doctor) was painting a very dim picture for (my son). He was basically not wanting us to get any sort of false hope. He didn't want us to come away with — well there is a one percent chance. So he was really trying to

squelch any fires of hope that we had. And we know that they do that sort of thing. That is what they do.

So we talked to him about the condition that (our son) was in and what that means. (The doctor) actually recommended four different things that we would set limits on. How high we would set the pressures. What we would do if he had a cardiac arrest. What we would do if he blew a lung. I can't not even think of the term that they use for that. That is strange because I used to be able to say this stuff as if I was a doctor. And the last thing was having to do with the levels of medications that they were giving to him to help him with the removal of fluids; Lasix and some others that had to do the blood pressure. That's the part of the story I left out. The second week he had serious issues with his blood pressure. It was going down and down and down, and the more they gave him to help him in terms of volume was affecting his lungs. We were walking a fine line. So the Sunday things were so critical — His blood pressure was 17 and his lungs were maxed out. And there was no more that they could give him to get his blood pressure back up. So the problem was his blood pressure would continue to climb until he was in cardiac arrest and he would die. And we agreed with the doctor to set the limits that he recommended. Which was 20 mils per hour of this medicine and 20 of this one and such and such on the ventilator and no resuscitation if he had cardiac arrest or any other problem. We watched (our son) through the day. They left us alone and we cried alot, (my wife) cried a lot during that conference. I called family. I left the room and called (my wife's) mom and dad and my mom and dad and my brother-in-law and sister who live in Provo. And told him what

was going on. They offered to come up and be with us. They started on their way. I went back to talk to (my wife) about (our son) and her overwhelming sensation at that point was if he is going to die, let him die. Don't make him suffer. He was obviously in pretty bad shape. So she kept saying that to me and as she prayed, let him die if he is going to die. And it got to where I felt like as a priesthood holder — can I talk about LDS items.

- Q. Sure.
- Α. I felt like as a priesthood holder I should take the opportunity to release him and therefore end his suffering. I called my brother-in-law and they were on their way and asked him if he would join me and they were delayed in coming. They were basically an hour away. So I said, ok, I'll wait. I sat with (my wife) and she was crying and talking again about why won't he go. And I felt sort of a pressure of — I need to help this kid. And so I separately prayed and came back and released him with a priesthood blessing. I released him from this life, expecting of course that he would die. So I called my brother-in-law and said that I have already done the release blessing and they arrived probably a half hour later. He is a (leader of a congregation) and the first thing that he said was and it stuck me and it has stuck in me ever since, "Yeah, it is so easy to trust in the arm of flesh" and at the time I thought what a strange comment to say. Here my kid is dying and the doctors are telling me that he is dying and I could see the numbers that he is dying. Why would I not believe that? It was almost like surprise, like what is the other option? So we ended up having a great conversation.

After I released him with this blessing, I had a levity come over us. We were joking with (our son) and sitting at his bed side and we played Yahtzee on my PalmPilot, sort of a different feeling of gratitude and during the shift change we went down to the lobby and sat with my brother-in-law and my sister and talked about them with life and death and the priesthood and all of those things and it was comforting to us. We would worry that (our son) would expire while we were talking, while we were on the shift change. It was good to sort of talk through the issues with them. We went back up after the shift change and they said — one more piece of information, we have these limits that we had set with the doctors. He had reached each of them. He was maxed out medicine, maxed out on the blood pressure stuff, maxed out on the ventilator. Exactly that we had defined, to the number. And after the shift change, they said he had a huge diaper. He filled a diaper with 80 grams or something, that was out of this world sort of diaper and as a result they were able to reduce some of his medication and a little bit on the ventilator. I thought that is interesting, I wonder when he is going to die. That is still what I am thinking. (Kris, dad of 24 weeker)

# *Areas of Further Study*

Some of the areas of future interest relate to the limitations of the study. The aforementioned parents of more critically ill children is one area that deserves more attention. Since these results reflect the experiences of a "best-case" scenario, a closer look at individuals dealing with more difficulty would broaden the scope of knowledge across the spectrum of difficulties.

A more diverse sample or a focus on minorities would yield information not yet obtained to any significant degree. Given that many minorities actually have higher preterm birth rates, the study of their experience is a significant area that has been heretofore untouched. No studies have looked at the degree to which maternal or paternal age is related to the parenting experience and could also be interesting in assessing potential differences amongst parents.

A combination of the recent studies by Fidler (2001) and Bacon (2000) exploring maternal and paternal reactions would also be helpful. The types of interviews that Bacon (2000) and this study conducted could yield very interesting results if done with the mother and father of the same infant. The ability to then gauge the perception of one partner's experience, along with eliciting what they perceived the other partner to have experienced could be quite beneficial to understanding parenting from a more system approach.

Quantitative studies could now be structured to look at specific areas of interest. As has been noted elsewhere, a replication of studies that have look at mothers through a quantitative structure could now be constructed in a fashion to look at fathers reactions in comparison, or in concert, with mothers. It became apparent throughout the interviews that the mothers of these infants have some similarities and differences in their emotional response to the birth of their infant. There also seemed to be a different sense of how the family relationship was being impacted. Measures of family functioning, depression, anxiety, coping mechanisms, and agreement about parenting roles all exist and could be used with fathers and their reactions.

Follow-up with this group of fathers or a similar cohort of parents and infants over a number of years would be something that has yet to be described in the literature. An interview at roughly a year post-discharge, as well as at two years of age, near the entry to elementary school, middle school, and high school could allow a perspective of parent, child, and family impacts. This would allow for developmental delays to appear, if present, as well as looking at what helps families cope best in the long run with a group that becomes far more familiar to the investigator.

The degree to which the NICU environment affected these fathers is really an unknown quantity. A study that explored how similar parents and children deal with the birth of a preemie within two or more different NICU's could yield very important information. There are numerous studies that have explored at least the short term effects of developmentally supportive environments on the infant. These may also have an effect, either directly or indirectly, on the parents. Newborn Individualized Developmental Care and Assessment Program (NIDCAP) training sites have the potential to explore this.

# Summary

This study has provided the body of literature on preterm infants and parenting with a rare look at fathers of preterm infants. The group that was interviewed was comprised of a group of infants at the very cusp of viability. The fathers all seemed to be dealing reasonably well with the birth, hospitalization, and discharge of their infant.

Areas remain to strengthen, broaden, and deepen the information about the coping of fathers of preterm infants. A more diverse group could be studied, more specific interventions with fathers could be constructed and implemented, and follow-up and

investigation of the entire family over a extended period of time would allow those who work with parents of preterm infants, and fathers in particular, to better serve them and meet their needs.

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#### Appendix A

#### Semi-Structured Interview

- 1) Tell me about the pregnancy, early labor, and the delivery of your baby.... In a sense tell me the story of what happened.
  - What were you most afraid of?
  - What sorts of things did you do?
  - Describe the first time you saw your baby
    - What did he/she look like to you?
    - o First thought?
- 2) Tell me about what it was like to be separated from your baby after delivery.
  - If the baby was transported elsewhere--- what was that like?
  - Talk about your discharge and homecoming.
- 3) Tell me about the first time you held your baby
  - What was it like?
  - What do you remember most about that event?
  - How did your baby respond?
    - When did you first feel that your baby knew you? How did you know?
    - When did you feel that your presence affected the baby? How did you know?
- 4) Tell me about your baby's NICU course.
  - Length of time in the hospital?
  - Crucial events?
  - Predominant emotions? (Anger? Guilt? A failure?)
  - Do you ever still feel the ways you did then?
  - What were you most afraid of? Other fears or worries?
  - Were you ever faced with difficult decisions regarding aggressive medical intervention?
    - o What did you do?
    - o How did it feel?
- 5) During your child's hospitalization, how did you see or feel about yourself as a parent?
  - Was this different that your expectations?
    - o If so, what was that like? How was it different?
  - Did your view of yourself as a parent change over the course of your child's stay? How?

- What, if any, NICU policies or staff influenced how you felt about yourself as a parent?
  - o Please describe...
- What would you change about how the hospital handled things (if anything)?
- Do you think your parenting style has been affected by your baby's premature birth? How?
- 6) Talk about the process of becoming connected to your baby.
  - Were there moments when it occurred to you that this was a "real" baby?
  - Were there moments that helped you to realize that this was YOUR baby?
    - o Moments when it felt like this wasn't YOUR baby?
  - When did you name your baby?
  - How did you choose the name?
- 7) How did the premature birth affect your employment?
  - How understanding were supervisors? Co-workers?
  - Were there any long-term impacts to your employment situation?
  - Did employment affect visiting your child? How?
- 8) Describe your baby's discharge and homecoming?
  - What was this like for you? Any fears? Hopes? Special wishes?
  - Any special needs post-discharge?
  - How did you manage?
  - Does your child still have ongoing special needs?
- 9) How has this experience affected other important relationships?
  - Your marriage?
  - Friendships?
  - Social and church affiliations?
- Have you considered or attempted another pregnancy? What was this decision been like?
- 11) Describe the feelings you have nowadays about the premature birth of your baby.
  - These days, how often do you think about the fact that your baby was born prematurely?
  - Do you remember sights, smells, sounds, etc. of the NICU?
  - Do you have any photos, keepsakes, items that you've kept from this time?
  - Do you still have crying spells or other reactions when you think about this?
  - Do you still worry about things? If yes, what kinds of things?
- 12) Did you attend a parent support group where you talked to other preemie parents?
  - If so, describe what this was like.
    - What sort of impact did it have on you?

- If not, do you think it would have been helpful to you to talk to other parents?
   Why
- Have you attended any NICU reunions? Why or why not?
  - o If yes, what was this like for you?
- How well do you think you are coming through the ordeal of having a premature baby?
  - What has been especially difficult for you?
  - What do you think made it possible for you to survive and cope?
  - Is there anything about yourself that you think has helped you to get through this?
  - Have you recognized or made anything positive come of this experience?
- 14) Anything else you would like to mention or talk about?

# Appendix B

Today's Date:	
Name of Parent:	Age: _
Highest Level of Education:	
Occupation:	
Married? Y N # of years together?	
Name of premature baby?	
Date of Birth:	
Weight (at birth):	
Gestational Age:	
Date of hospital discharge:	
Dates of re-hospitalization (if any):	

## Appendix C

Flyer Irreproducible in PDF format

## Appendix D

Consent form page 1 irreproducible in PDF format

## Appendix D

Consent form page 2 irreproducible in PDF format

## Appendix D

Consent form page 3 irreproducible in PDF format

Appendix E Summary List of Fathers and Infants

Name	Age	Infant's Gestational <u>Age</u>	Birthweight (ounces)	Days in Hospital	
Alan	35	29	48	57	
Burt	24	25	23	91	
Carlos	33	29	34	75	
Daniel	34	28	45	101	
Evan	22	28	41	100	
Francis	40	23	18	129	
George	33	32	46	38	
Henry	37	27	41	76	
Ivan	36	31	50	60	
Jorge	34	28	19	77	
Kris	31	24	22	169	
Larry	26	29	49	93	
Mike	36	32	33	51	
Ned	25	25	28	113	
Orville	25	28	42	52	
Paul	31	24	26	123	