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FATHERS' EXPERIENCES with THEIR PREMATURE INFANTS or UNHEALTHY  
NEONATES

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A Dissertation Submitted to The Graduate School at the University of Missouri– St.

Louis in partial fulfillment of the requirements for the degree

Doctor of Philosophy in Nursing

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### **DEDICATION**

This study is dedicated to the fathers of the premature or unhealthy infants in this study, who graciously agreed to participate and to help other fathers reach their fullest involvement with their premature infants or unhealthy neonates.

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## Chapter One: Introduction

The purpose of this chapter is to provide an overview of this study on fathers' experiences with their premature infants or unhealthy neonates and how these experiences may influence the transition to fatherhood. The significance of the problem, the importance of the study, research questions and aims of the research are presented.

Prematurity has become an increasingly common and devastating experience for parents from all societies around the world. Even the birth of a healthy infant and the transition to parenthood is an intensively emotional experience for both parents, but the birth of a premature or unhealthy neonate can make this transition even harder. Factors influencing this transition include stress, extended hospitalization, possible long-term consequences, and gender ideologies (Misund, Nerdrum & Diseth, 2014; Treyvaud, Lee, Doyle & Anderson, 2014).

The birth of a child and the onset of parenthood can cause stress in the lives of parents, yet the delivery of a premature or unhealthy infant causes increased stress due to the uncertainty about the infant's survival, risk of medical complications and concerns regarding long-term complications (Alkozei, McMahon & Lalav, 2014; Lasiuk, Comeau & Newburn-Cook, 2013; Lefkowitz, Baxt & Evans, 2010; Schenk & Kelley, 2010; Vigod, Villegas, Dennis & Roos, 2010; Watson, 2011). Due to the highly technical environment, NICUs have the potential to increase stress and the alienation of parents from their infants (Busse et al., 2013; Pohlman, 2009, 2005; Miles & Carter, 1983). The technological sights and sounds indigenous to the NICU environment can cause increased fear, stress and feelings of being overwhelmed for parents (Carter et al., 2005; Jotzo & Poets, 2005; Kantrowitz-Gordon, 2013; Pohlman, 2005; Shaw et al., 2006). This

increased stress can delay the father-infant attachment process and have a negative impact on a parents' fulfillment of their parenting role and the premature or unhealthy infant's cognitive development.

Throughout the last decades, research has documented difficulties parents have in parenting their premature or unhealthy neonate, and especially for those whose infants were hospitalized after birth. Separation from an infant and the inability to fulfill parental responsibilities while in the hospital, the unusual appearance of their infant, and the infant's lack of responsiveness can impair parental infant attachment, and decrease parental self-confidence (Boykovas & Kenner, 2012). Due to the extended hospitalization of an infant admitted to a NICU it may alter the normal process of transition to parenthood (Odom & Chandler, 1990).

A premature or unhealthy neonates' developmental outcomes depend on both biological and environmental risk factors. Biological risk factors include spontaneous preterm labor and birth caused by infection or inflammation, medically indicated preterm birth due to preeclampsia and non-medically elective preterm delivery. Environmental risk factors include poverty, air pollution, and life stressors. Due to these risk factors and subsequent admission and prolonged hospitalization in a neonatal intensive care unit (NICU), there can be continued parental separation and diminished father-infant interactions, both of which can lead to lower cognitive and behavioral outcomes of the infant (Lonio et al., 2016; Guillaume et al., 2013).

Most expectant parents look forward to the arrival of a healthy, well-developed baby. A premature birth or the birth of an unhealthy neonate can drastically alter this expectation. The capacity of parents to adjust to the premature birth or an unhealthy

neonate and the potential long-term hospitalization can cause considerable stress for parents. This increased stress can potentially result in a delayed emotional attachment and this delayed attachment may have implications regarding the transition to parenthood namely on parents' representations and caregiving competencies.

Both gender ideology and gender role identity refer to attitudes regarding the appropriate roles, rights, and responsibilities of men and women in society (Bianchi, Robinson, & Milkie, 2006). These constructs reflect views based on specific domains such as economic, familial, legal, political and social areas (Bianchi, Robinson, & Milkie, 2006). Gender ideological constructs range from traditional, conservative, or anti-feminist to egalitarian, liberal or feminist (Bianchi, Robinson, Milkie, 2006). The roles of parents are reflected by such constructs and need to be considered when attempting to understand how parenting can be affected by stress.

Traditional gender ideologies emphasize the value of distinctive roles between men and women. According to traditional gender ideology about family structure men fulfill their family roles through the instrumental or breadwinning role, while women fulfill their roles through nurturing and primary parenting activities (Lundqvist & Jakobsson, 2003). Egalitarian ideologies regarding the family have increased in recent decades, focusing on men and women equally sharing breadwinning and nurturing family roles (Cotter, Hermsen & Vanneman, 2011). With today's variety of gender roles and changes in gender ideologies, studies are needed to understand fathers' involvement with their premature infants.

Paternal factors such as societal, financial and gender role expectations can make the challenges of involvement and attachment between a father and their premature or

unhealthy infant even more difficult (Lundqvist & Jakobsson, 2003; Lee, Lin, Huang, Hsu & Bartlett, 2009; Martel, Milette, Bell, Tribble & Payot, 2016; Pederson, Anderson & Kain, 1980). Research suggests fathers' transition from the traditional financial provider to caretaker has a positive effect on father-infant attachment and the infant's cognitive development (Anderson & Kain, 1980; Fegram, Fagermoen & Helseth, 2008; Lee, Lin, Huang, Hsu & Bartlett, 2009; Lundqvist & Jakobsson, 2003; Pederson, Lundqvist & Jakobsson, 2003). Given the multiple challenges fathers face in the circumstance of a premature or unhealthy birth, it is essential to understand a fathers' unique needs to foster involvement and attachment.

### **Background**

Nationally, the current rate of prematurity in the United States (U.S.) has increased by 36% since the early 1980s (Harrison, Margo & Goldenberg, 2016; March of Dimes, Born Too Soon, 2007; March of Dimes, 2015). Over the past 20 years, neonatal intensive care units (NICUs) have become more sophisticated making it possible for even younger and sicker infants to survive. Roughly, 400,000 to 750,000 newborns are admitted to an NICU each year in the U.S. often for several weeks to months (March of Dimes, 2015). The issues associated with prematurity are multifaceted since prematurity impacts families, healthcare, and society. Globally, approximately one in ten babies (fifteen million) are born prematurely each year (Center for Disease Control and Prevention [CDC], 2014) and approximately 4% of normal births and 85% of low birth weight (LBW) newborns are hospitalized each year in a NICU (Witt, Weiss & Elixhauser, 2006). Subsequently over one million babies die annually from preterm birth complications (World Health Organization [WHO], 2009). Preterm infant birth has been

found to be the leading cause of infant mortality and a significant cause of long-term loss of human potential amongst survivors all around the world (CDC, 2014). Prematurity is a significant direct cause of neonatal mortality, and accounts for 60 to 80% of the 3.1 million deaths a year, second only to pneumonia for children under the age of five (CDC, 2014).

The Institute of Medicine (2006) estimates the annual economic cost of prematurity to the U.S. to be at least \$26.2 billion or \$51,600 per infant born preterm. These expenses include \$16.9 billion for medical care services, \$1.9 billion for maternal delivery costs, \$611 million for early intervention services, \$1.1 billion for special education services and \$5.7 billion for losses in household and labor market productivity. These costs, unfortunately, may be shifted to families already burdened by the birth of a premature infant.

### **Problem Statement**

During the past three decades, researchers have conducted studies investigating mothers and fathers' roles in the involvement of their children's lives (Braharudin et al., 2010; Desimore, 1999; Epstein, 1986; Hoover-Dempsey & Sandler, 1995; Lipscomb, 2011; Strom, 1974; Uddin, 2011). These studies have shown that parental involvement positively influences children's developmental outcomes. Few studies, however, have focused solely on fathers, and even less exclusively on fathers of premature or unhealthy infants. For infants who are at risk for developmental delays paternal involvement and the development of a secure father-infant relationship may be even more critical.

### **Purpose Statement**

The purpose of this study is to provide new insight into the experiences of the vulnerable population of fathers of premature or unhealthy infants since paternal involvement has been underreported and not fully understood. An improved understanding of fathers' experiences may lead to nursing and healthcare interventions that foster paternal involvement.

### **Significance of the Study**

A considerable amount of research has been conducted over the past 20 years to assess and examine the relationship between parents/caregivers and their full-term infant's cognitive developmental outcomes. Significantly less research has been conducted on parents', particularly fathers, experiences with their premature or unhealthy infants. To date, what has been reported is a positive correlation between the quality and quantity of paternal involvement and with their premature infant's favorable developmental infant outcomes (Choi, Pyun & Palmert, 2014; Gilligan, 2017; Howard et al., 2006). Due to the lack of research on ways in which paternal involvement is experienced and understood, further research is needed to understand fathers' needs while in NICU settings, as well as the unique challenges that they may face later in the community setting.

Paternal involvement with premature infants is a notable problem, yet extensive research on factors that influence paternal involvement is lacking (Misund, Nerdrum & Diseth, 2014; Pohlman, 2005; Treyvaud, Lee & Doyle, 2014). Research has shown that the birth of a premature baby exponentially increases parents' stress primarily due to the



abrupt end of the role adjustment period, concern for the health of the infant and the possible subsequent short and long-term consequences. Three general areas have been identified as stressors for fathers of premature infants, including (1) infant factors (2) interpersonal factors and (3) the NICU environment, (Lundqvist et al., 2007; Turan, Basbakkal & Ozbek, 2008). It is reasonable to expect that if healthcare workers understand what fathers perceive as barriers or facilitators to their involvement and attachment, they could help them to adjust to the paternal role and improve their parenting skills. This, in turn, may result in improved growth and development of the premature infant. The focus of this current qualitative research is to explore the experiences of fathers whose premature or unhealthy infants have been hospitalized in a NICU, shedding light on some of the early experiences that may shape their ongoing involvement.

### **Research Questions and Aims**

The research questions addressed in this study were:

RQ 1. What is the meaning of fatherhood for fathers whose infants have been hospitalized in the neonatal intensive care unit (NICU)?

RQ 2. What are the facilitators and barriers to fathers' participation in the care of their premature or unhealthy infant?

RQ 3. How have fathers' perceptions of fatherhood changed due to premature or unhealthy birth?

### **Aims of the Study**

The aims of this study were to:

- 1 Generate an interpretation of the meaning of fatherhood for fathers who have had premature or unhealthy infants hospitalized in a NICU.
- 2 Uncover how a father's expression of self, family, and fatherhood manifest in their practices, habits, perceptions, and skills.
- 3 Reveal the challenges and barriers to parenting experienced by fathers of premature infants or unhealthy infant who have been hospitalized in a NICU.
- 4 Understand fathers' everyday practices regarding their interactions with their premature or unhealthy infants.
- 5 To better understand the phenomenon of fathering in the unique setting of the NICU and what influences the NICU experience has on the start of fatherhood and the life of the child

### **Definition of Terms**

The following acronyms and definitions will be used in this study

Prematurity/Preterm	Less than 37 completed weeks of pregnancy
Term	Between 37-42 completed weeks of pregnancy
LBW	2500 grams or less at birth
VLBW	Less than 1500 grams at birth
ELBW	Less than 1000 grams at birth
Perinatal period	Period from 24 weeks of gestation (168 days) to 7 days of postnatal age, irrespective of birth weight and gestation at delivery

Neonatal period	First 28 days of life, irrespective of the gestation at delivery
Infant	A baby born from the moment of birth to his/her first birthday (365 days), irrespective of the gestation at birth
Neonatal mortality rate	Number of deaths occurring in the first 28 days of birth per expressed per live births
Infant mortality rate	Number of babies who die in the first year of life (0-365 days) expressed per 1000 live births
BPD	Respiratory sequelae in an infant requiring oxygen at more than 28 days after birth (Shennan, 1998)
IVH	Escape of blood from within the brain's ventricles. Four classifications: Grade 1 – isolated germinal matrix hemorrhage Grade 2 – rupture of the hemorrhage into the ventricle but without ventricular dilation Grade 3 - rupture of the hemorrhage into the ventricle with ventricular dilation Grade 4 – IVH with additional parenchymal hemorrhage

ROP	Changes in the developing retinal vasculature resulting in the development of new abnormal blood vessels, which may heal or progress to a chronic phase of scarring, retinal detachment and visual loss
Neonate	A newborn infant; especially an infant less than a month old

#### **List of Abbreviations**

NICU	Neonatal intensive care unit
SGA	Small for gestational age
LBW	Low birth weight
VLBW	Very low birth weight
ELBW	Extremely low birth weight
IVH	Intraventricular hemorrhage
BPD	Bronchopulmonary dysplasia
ROP	Retinopathy of prematurity

#### **Researcher's Assumptions**

This section describes my interest in the study and the background from which I approached the research questions. Many of my assumptions come from my 32 years of clinical practice. I believe that fathers want to be present and more involved in the care of their premature or unhealthy infants but, due to historical and societal gender

ideologies, this may not be possible. Gender ideologies (breadwinner vs. primary caregiver) placed on fathers by society, the father themselves, or NICU nurses have potential to influence fathers' involvement and attachment. Therefore, I wanted to explore the different perspectives of the fathers to understand their personal experiences better. I believe that to do this well I needed to form a relationship of familiarity between the participants and myself to "understand what they had to say" (Creswell, 2007, p. 18). As I conducted the interviews with these fathers, I assumed they would speak freely. A comfortable interaction between the participants and myself would provide a richer and more meaningful description of their experiences. Finally, the questions answered were dependent upon on the descriptions obtained from the fathers; therefore, changes to the interview guide and research questions occurred as needed, based on the experiences disclosed during the interviews.

### **Delimitations**

This study was limited to fathers who had experienced the phenomenon under investigation and who agreed to share their stories and agreed to be audio-recorded. The study excluded fathers of infants born with an identified congenital disability or infants diagnosed with a Grade III or IV intraventricular hemorrhage as these infants suffer increased mortality and morbidity rates as well as additional special needs (Bakewell, Ewald & Wallin, 2011).

### **Nature of the Study**

The purpose of this hermeneutic study was to understand and interpret the experiences of fathers whose premature or unhealthy infants were hospitalized in a

NICU. Hermeneutic phenomenology was the chosen methodology for this research as described by Diekelman and Ironside (2011) because this research was aimed at producing an interpretation of the phenomenon of fatherhood in the circumstance of prematurity or complicated birth. The use of hermeneutic phenomenology enabled the exploration of participants' experiences to be interpreted by the researcher based on the researcher's theoretical and personal knowledge (Ajjawi, 2007). In short, phenomenology seeks for an understanding of how a phenomenon manifests itself and the meaning of that phenomenon. Asking about specific experiences, punctuated by the experience of the NICU, helped fathers disclose the meaning of the phenomenon of fatherhood and fathering a premature or unhealthy infant. "The spoken word allows the participant to give considerable input into their experience and perceptions of the event" (Benner, p. 110, 1994).

Using this methodological approach, I attempted to interpret the practical acts of fatherhood through the analysis of narrative texts of interviews with fathers of premature or unhealthy infants who were hospitalized in a NICU. The intention is not to re-examine my understanding or assumptions but to interpret and understand fatherhood in the unique setting of the NICU and beyond.

Data was collected using interviews, field notes, and iterative interpretive summaries. Fathers with varying demographics and differing gestational age infants were recruited, offering different perspectives on the phenomenon. Interviews were analyzed using hermeneutic philosophy focusing on finding common patterns across texts to better understand their world of fatherhood. The interpretations of these patterns occurred through an inductive and interpretive lens, and were not based on hypotheses

(Creswell, 2007). The study concluded by interpreting and describing the patterns that developed from the experiences of fathers whose premature or unhealthy infants were hospitalized in a NICU.

### **Summary**

The focus of this hermeneutic phenomenological research was to explore the experiences of fathers whose premature or unhealthy infants were hospitalized in a NICU. This study is significant because gender-specific interventions that focus on the unique needs of fathers have been under-reported in the literature. Fathers of premature or unhealthy infants are a vulnerable population and their influence on the well-being of their premature or unhealthy infants can be significant.

Focusing on these experiences and understanding fathers' needs may lead to potential benefits to future fathers who will face the challenges associated with fathering a premature or unhealthy infant. Furthermore, an empirical contribution focused on fathers' experiences of being involved with their premature ill infants and their perceptions related to competence, autonomy, and relatedness in rearing a premature or ill infant could be made.

## **Chapter 2: Review of Literature**

This chapter situates the phenomenon of interest within the body of science as it relates to prematurity and the role of fathers in the care of premature or unhealthy infants. It includes a review of studies related to prematurity, its prevalence, costs, and complications. Age-related development after preterm birth, theories related to attachment, paternal stress and coping and the influence gender have on parenting are included in this discussion.

### **Literature Search and Information Sources**

Extensive literature was searched in the PubMed, Scopus and Ovid databases. Medical Subject Heading (MeSH) terms were used to refine the searches. Only sources in English were included. Essential keywords and MeSH terms identified as a result of the initial search included fathers, fatherhood, fathering, premature infant, neonatal intensive care, premie, and unhealthy neonate. Additional searches were conducted using combinations of these keywords and MeSH terms. A hermeneutic research study calls for an approach to the literature, which distinctively engages the reader and the text in a manner congruent to the philosophy of Gadamer and Heidegger. According to Gadamer, literature is a complex array of meanings, all of which will be thought-provoking. Heidegger believed the critical purpose of a literature review is to provoke thinking and believed texts other than subject-related literature are of value also. He postulated that a scholarly hermeneutic literature review collectively brings about new ideas about existing information (Smythe & Spence, 2012).



## **The Problem of Prematurity**

Prematurity is a regional and global problem affecting one in ten babies each year or fifteen million (Center for Disease Control and Prevention [CDC], 2014). Fifteen million babies worldwide are born each year prematurely, impacting a multitude of infants and families. The rate of premature birth in the United States (US) has increased by 36% since the early 1980s (Born Too Soon, 2007; Harrison, Margo & Goldenberg, 2016). Preterm birth is the leading cause of death and a significant cause of long-term loss of human potential amongst survivors around the world. Neurologic deficits are some of the most significant morbidities resulting from the conditions requiring NICU admission even when admitted for a short period of time (Stensvold et al., 2017; Stoll et al., 2010, 2015). Prematurity is the most significant direct cause of neonatal mortality, responsible for 60 to 80% of the 3.1 million deaths per year in infants born without congenital malformations (Morrison, 2017). Changes in the care of premature or unhealthy infants have allowed many infants to survive who would not have done so previously. These changes have placed the field of premature care including the infant and family in full view.

Premature babies are surviving at younger gestational ages due to advances in medical technology. It is now possible for infants born as young as 22 weeks gestation to survive due to the advances in technology and technique (Guillen et al., 2013). With advances in technology comes a considerably higher risk of mortality and morbidity in the fragile neonatal period. Premature infants are more susceptible to neonatal infections, perinatal and postnatal respiratory depression and poor feeding [CDC], 2014). These morbidities then place them at a higher risk of delayed neurodevelopment such as

cerebral palsy and death. This risk is inversely related to gestational age and is highest in extremely low birth weight (ELBW) infants. ELBW infants have an 8-10% increased risk of cerebral palsy (Clark & Hawkins, 2003; Huusom et al., 2011). Ill or premature neonates often require a long length of stay in the NICU, which is an environment that many times is chaotic and painful. Healthy sensory and social interaction may be inhibited and exacerbate neurological deficits.

The last decade of the 20<sup>th</sup>-century has seen a decrease in mortality associated with prematurity, but also a rise in the overall numbers of babies born prematurely to approximately 11% of all births (Blencowe et al., 2012; Martin et al., 2000). Explanations exist for the increase in prematurity including maternity care has improved, mothers at risk and adolescents have a reduced pay rate for prenatal care, and there has been an increase in multiple births (twins, triplets) as a result of fertility treatments (Cavoretta et al., 2017; Schindehette, 1997). Due to the changes in the care of premature infants over the course of the 20<sup>th</sup>-century survival viability has dramatically improved setting parameters of viability at approximately 22 to 23 weeks. For babies born before this time, parents and healthcare professionals must choose to either initiate resuscitation efforts, taking into consideration the possibility of debilitating consequences or let the baby expire. Parents in the neonatal intensive care unit (NICU) face difficult choices making the NICU a highly volatile and emotional place for their parenthood journey begin (Guillen et al., 2006).

The potential for complicated outcomes is also on the rise with infants surviving at younger ages. Approximately 77% of low birth weight infants born in the United States (US) will require admission to a neonatal intensive care unit, sometimes for several

months (CDC, 2015). Due to these admissions and potentially lengthy hospitalizations, many aspects of the infants and parents' lives are disrupted, including attachment, adjustment to the parenting role, the concern of the cost, and the immediate and long-term consequences.

### **Costs of Prematurity**

Complications of prematurity do not only affect the infant themselves but, with increasing survival rates, the associated expenses are also growing. These costs impact healthcare, society, and families, and are staggering. The Institute of Medicine in 2007 reported that the costs associated with preterm births in the US were \$26.2 billion each year. The March of Dimes (2015) breaks these costs down as follows:

- \$16.9 billion in medical and healthcare costs for the baby
- \$1.5 billion in labor and delivery costs for the mother
- \$611 million for early intervention services, including programs for children from birth through age 21 with developmental and learning disabilities: (These services help with physical, cognitive, communication, social, and self-help skills.)
- \$1.1 billion for special education services, including specially designed programs for children age three through age 21 with developmental and learning disabilities: (These services can be delivered at school, home or hospital.)
- \$5.7 billion in lost work and pay for people born prematurely due to their chronic health conditions

The average cost of medical care for a premature infant in the first year of life is approximately \$49,000 compared to \$4551 for that of a full-term infant (Landau, 2009). Although healthcare plans cover most of these costs, the out-of-pocket expenses have also risen. The cost of premature and low birth weight babies is also higher because of the combined medical costs for the mother and child. The average price of high-risk delivery is \$64,713 compared to \$15,047 for an uncomplicated birth (March of Dimes, 2015). The cost of a NICU stay is approximately \$10,000 per day, with an average length of stay in the United States (U.S.) being 20 days, or a price ranging from \$40,000 to \$80,000 in commercial health care plan for infants born less than 32 weeks and who spend greater than four days in the NICU (March of Dimes, 2015). The associated costs that correlate with gestational age are displayed in Table 1.

Table 1.

*Average Inpatient Costs by Gestational Age and Year of Life, United States*

Gestational Age (wk)	Birth Year	Year 2	Year 3-4	Year 5-7
< 28	181,111	2,893	691	123
28-31	85,171	3,519	766	76
32-36	10,855	344	123	66
37-40	1,895	266	129	64

The data is based on the 1998 2010: heart covered under the IHC Health Plans. The birth your costs is adjusted for national rates of infant mortality by gestational age (infant deaths were assigned to the first month of life for those born less than 28 weeks gestation and to the end of the neonatal period for those born at 28 to 36 weeks gestation). Costs were adjusted geographically to the nation by using Medicare inpatient adjustment

factors and were adjusted for inflation between 1998 and 2010 based on Medicare Prospective Payment System Hospital Cost Index

Societal costs associated with prematurity are broken down into direct and indirect expenditures. Direct costs include the value of resources used to treat the condition, such as medical care, special education, and developmental services. Indirect costs include revenue lost to society, such as reduced labor market and household productivity due to the heightened morbidity and mortality (Behrman & Butler, 2007; Black, Hulseley, Lee, Parks & Ebeling, 2014).

The costs of prematurity are not only restricted to those costs that affect infants but also includes maternal, caregiver and family. For instance, parental expenses include the cost of prenatal care and delivery services, the cost of any extended care associated with maternal morbidity arising from the pregnancy, and the potential cost of subsequent precautionary pregnancies (Behrman & Butler, 2007). Caregiver costs can include travel expenses for the extended care of the premature or unhealthy infant and time devoted to caring for them. Fathers are particularly attuned to the costs of their premature infant's care contributing to the personal issues for which this study is concerned (March of Dimes, 2015; Pohlman, 2005).

### **Definition of Prematurity**

Prematurity before 1960 was defined as the birth of an infant weighing 2,500 grams or less (Southgate & Pittard, 2001). This definition was the most useful and reliable measurement at that time for identifying newborns that were at risk of mortality and morbidity, such as mental retardation, cerebral palsy and death (Lumley, 1987). The

American Academy of Pediatrics (AAP) by the end of the 1960s recommended that infants should not be classified by birth weight alone but by birth weight, gestational age and intrauterine growth (Silverman, 1967). This classification separated premature and term infants at 38 weeks gestation. The World Health Organization (WHO) in 1977 again changed their definition of a premature infant as one born before 37 completed weeks gestation or less than 259 days since the last day of the last menstrual period of the mother.

The 1977 WHO definition was adopted because according to the AAP infants born before 37 weeks gestation are at increased risk of complications. The final weeks in the womb are critical for healthy weight gain and full development of various vital organs, including the brain and lungs. Infants born before 37 weeks of gestation or premature have an increased risk of medical problems which may require an extended hospital stay. These infants have also been associated with long-term health issues such as learning and physical disabilities, ranging from neuro-development and behavioral to social-emotional difficulties (AAP, 1977; Bhutto & Kelley, 2006; Cleves, Casey, Cradock & Anand, 2002; Esbjorn, Hansen, Greisen, & Mortensen, 2006; Feldman, Ploof, Hofkosh & Goehring, 1993; Gyurke & Aylward, 1992; Kerkering & Blackman, 1992; Palfrey et al., 1991).

### **The NICU Environment**

The United States Committee on Perinatal Health in 1976 published a seminal document titled *Toward Improving the Outcome of Pregnancy* describing a concept of regional reorganization of perinatal services and the development of three levels of NICU

care (The National Foundation-March of Dimes, 1976). Hospitals identified as Level I would provide care to uncomplicated maternity and newborn cases. Level II hospitals would provide care to both uncomplicated and moderately complicated obstetrical and neonatal care. Level III hospitals, usually departments of significant regional centers, would provide leadership in education and research and care for high-risk infants. As the care of premature infants has advanced, an additional level of NICU categorization emerged. Level IV NICUs are designated to care for infants requiring: sustained assisted ventilation, either mechanical or continuous positive airway pressure, need for cardio-respiratory monitoring for recurrent apnea or seizures, cases of extreme illness, (e.g., sepsis, need for parenteral nutrition, need for long-term oxygenation) and extracorporeal membrane oxygenation (Rashidan et al., 2015). Outcomes for premature newborn have improved with the regionalization of perinatal and neonatal care, and neonatal survival rates have increased (Rashidan et al., 2015).

The highly technological environment of the NICU supports the survival of young infants but is also an intense and often frightening environment for families. The intensive care required for premature or ill neonate often creates an environment that can provoke negative feelings for parents. This phenomenon underscores the need for staff working in the NICU to understand the needs of parents. Staff in the NICU can play a vital role in promoting opportunities for physical and emotional contact between parents and their infants. The NICU itself can influence parental involvement, including both physical, social, and emotional engagement. Today's highly technological NICU environment can create barriers to parenting, including the equipment and terminology used by the staff. Technical aspects of the NICU may increase parents' anxieties and

fears, delaying their interactions with their infants (Lee, Lin, Huang, Hsu & Bartlett, 2009; Lundqvist & Jakobsson, 2003; Pohlman, 2005).

### **Causes of Premature Labor**

The cause of premature delivery is equally distributed between the causes of spontaneous early onset of labor and early elective labor including elective cesarean sections resulting in 1.3 million premature babies per year (CDC, 2015; Zhang et al., 2010). The etiology of premature labor is multifaceted but is classified under four main headings: (1) complications of pregnancy, (2) socio-demographic factors, (3) iatrogenic factors, and (4) unknown causes (Cain, Bornick & Whitman, 2013; Freda et al., 1991; Lipshitz et al., 1993). Women known to have cervical insufficiency tend to deliver between 20 to 24 weeks while placenta previa and abruption both frequently result in preterm labor and delivery any time after the 20<sup>th</sup>-week gestation to 32 weeks gestation (Harlow & Spencer, 1999; Kelnar & Harvey, 1987).

Multiple gestations have increased in incidence for several reasons, including natural causes and fertility treatments. Twin deliveries before 37 weeks now account for 58% of all early births and 11.9% before 34 weeks of gestation (Joseph, Allen, Dodds, Vincer & Armson, 2001). All infants born before 32 weeks account for only one to two percent of the overall deliveries but makeup 50% of all long-term neurological morbidities and 60% of the neonatal mortality. Maternal co-morbidities including hypertension, diabetes, cardiac defects and renal disease may also result in premature delivery. These co-morbidities are a result of either spontaneous labor or obstetrical interventions such as induction of labor due to the increased risk the illness poses to the



mother (Anath, & Vintzileos, 2006; Brackley & Rubin, 1999; Goldenberg, Culhane, Iams & Romero, 2008).

Socio-demographic risk factors such as lower socioeconomic status, poor maternal nutrition, inadequate prenatal care, and pregnancy at younger and older ages all can play a part in preterm birth. Maternal age of 16 years or less has a twofold higher risk of preterm delivery compared to women 18 to 29 years of age (Branum & Achoendorf, 2005). Women over the age of 35 are also at an increased risk of preterm birth, although the exact reasons are unknown (Chattingius, Forman, Berendes & Isotalo, 1992; National Center of Health Statistics [NCHS], 2000).

Other epidemiological causes of premature birth include cigarette smoking, a history of preterm delivery, maternal drug use, and racial disparities. Cigarette smoking during pregnancy is a significant risk factor for premature birth and may contribute to 20 to 30% of all known cases (Center for Disease Control [CDC], 2015). Fetal birth weight has been directly correlated with the number of cigarettes smoked (Lieberman et al., 1994). A woman who has had a previous preterm birth has a 15% greater risk of having a subsequent early delivery and the risk of prematurity increases with each additional pregnancy (World Health Organization [WHO], 2012).

There has been an increase in maternal drug use in the last ten years with estimates of five percent of all pregnant women use one or more addictive substances (Parazzini et al., 2003; Thadani et al., 2004; Wendell, 2015). There are approximately 750,000 cocaine-exposed pregnancies each year, which are associated with premature rupture of membranes, abruption, placenta previa, preterm labor, and complicated deliveries (Cain, Bornick & Whitman, 2013; Strathearn & Mayes, 2010; Wendell, 2015).

It is difficult to fully estimate the extent of the consequences of maternal drug use and the specific hazards to the unborn child because of multiple factors including the amount and the number of all drugs used (prescribed and illicit) and the unknown purity or potency of the illegal drugs (Chattingius, 2004; Thadani et al., 2004; Albertsen et al., 2003; Kesmodel et al., 2000; Kline et al., 1997; Savitz & Pastore, 1999, 2002a). Having a premature or unhealthy infant often increases parents' feelings of incompetence and insecurity. These insecurities are primarily due to the stressful and traumatic aspect of preterm birth or unhealthy infant and its psychological impact on parents many times negatively interfere with the process of attachment (Pisoni, Garofoli, Baiardini, Tzialla, & Stronati, 2014).

Factors leading to premature birth affect parents in various ways. The effects of the premature or complicated birth itself and the experiences during the prenatal period may influence the response of fathers in unknown ways. How fathers perceive and respond to premature or unhealthy birth and its aftermath could affect the lifetime of an infant.

### **Racial Influences in Premature Birth**

Racial disparities in premature birth have persisted for decades, although there are not confirmed precise reasons (Cradock & Anard, 2002). Racial inequalities are of great concern to many because preterm birth can strongly predict infant mortality and adverse health and developmental outcomes in childhood (Behrman & Butler, 2007; Bhutta, Cleves, Casey, Cradock & Anard, 2002; MacDorman, 2011; Saigal & Doyle, 2008). The reported rate of premature births among African American women is approximately

13.2%, almost five percent higher than the rate among white women, which are roughly nine percent (Saigal & Doyle, 2008).

Several explanations for racial disparities in premature birth have been proposed, including ethnic differences in socioeconomic factors including income, wealth and education, maternal behavior, stress, infections, and genetics (Hogue & Vasquez, 2002; Rich-Edwards, Kleinman, Harlow & Gillman, 2001; Rodney, 1994, 2001). The latest emerging literature on racism and preterm delivery suggest that racism may be a potent stressor throughout the lifetime of African- American women. These stressors contribute to physiological changes and disparities in the rate of both preterm and low birth weight infants (Alhusen, Bower, Epstein & Sharps, 2016; Bolin, Grineski & Collins, 2000, 2004; Braveman, et al., 2015, 2017; Loggins, Shondra, Flavia & Drumond, 2015; Lorch & Enlow, 2016; Mendez, Dara, Hogan, Vijaya & Culhane, 2014; McKinnon et al., 2016; Prussing, 2014; Rodney, Norman, Clark & Williams, 1993; Wallace, Nazroo & Becaress, 2016). Racial and geographic disparities in preterm birth continue to exist, offering potential opportunities to better understand these population-based risk factors for preterm delivery and its impact. The current levels of preterm birth in the US represent a significant healthcare concern. Best estimates suggest that preterm birthrates will continue to increase due to the previously mentioned risk factors (Lee et al., 1980).

### **Relevant Theories**

The phenomenon of prematurity and fatherhood has yet to produce a theory of its own although there are several relevant theories that add insight into this area, including

Magnusson's Stress Theory, Bowlby Attachment Theory, Leininger's Sunrise Model, Hegemonic Masculinity and Identity theory.

### **Magnusson's Stress Theory**

Magnusson's stress theory has been identified as a relevant theory when studying child development and stress in parents of premature infants. Magnusson (1982) defined stress as an individual's reaction to demands that approach or exceed the limits of coping resources. Stressors are the physical and psychosocial elements of a situation that impose requirements on individuals that can lead to stress reactions. When parents have an infant in the NICU, they bring their own unique characteristics and circumstances all that can influence how they perceive, live and experience through the NICU journey.

Parents are faced with situational conditions while in the NICU that can increase their stress. Stressors include the severity of their infant's diagnosis, the infant's appearance, level of functioning, and possible prolonged hospitalization. Environmental factors that can contribute to their stress levels can include difficulty fulfilling their parental role, the medical equipment, communication, and behaviors of the staff (Miles & Carter, 1983). Parenting stress is a significant risk factor, as it may interfere with the father-infant relationship during a NICU admission and consequently increase the risk of uncertain long-term outcomes.

### **Bowlby's Attachment Theory**

John Bowlby introduced attachment theory in 1982 and described attachment as an intense and enduring emotional bond that is rooted in the protection of their infants from danger, which profoundly influences later development. Attachment is a sophisticated human experience that requires early physical contact, and this contact

forms a fundamental emotional connection between the caregiver and the infant (McLeod, 2007). The quality of the attachment between a parent and their infant contributes significantly to the development of the infant. The immediate contact between a parent and their infant is a crucial factor in the development of a secure attachment (Thomas, 2008; Klaus et al., 1972). Myers (1984) and Solomon & George, (1996) claim that a secure attachment process continues throughout the first year and that attachment between a father and their infant is a precursor to the fathers' parenting skills, growth, and the development of the infant, as well as the establishment of involvement bonds.

The significance of attachment theory to long-term development is illustrated by a longitudinal study conducted that tracked child outcomes related to different early attachment categories (Grossman et al., 2005; Sroufe, 2005). The results showed the importance of early attachment, and the development of this could continue into adulthood. These results also showed that mothers and fathers have unique influences on child development that emerge at different developmental stages (Grossman et al., 2005; Paquette & Bigras, 2010).

Children who develop a secure attachment tend to have fewer extreme reactions to stress, are more willing to try new things, explore their environments more independently, are better problem solvers, and form better relationships with others. Children who develop an insecure attachment may refuse to interact with others, have exaggerated distress, exhibit anger, anxiety, and fear (Bradley & Roggman, 2007). A positive child-parent attachment has a positive impact on parental identity and a child's developmental outcomes (Bowlby, 1997).

### **Leininger's Sunrise Model**

Leininger's Sunrise Model has been used many times as a theoretical framework for research on attachment between parents, their infants, and the cultural and social aspects of care (Leininger, 1991). The formation of attachment between a parent and their child may begin before the birth although a premature birth may create unique problems due to the sudden and unexpected birth (Moehn, & Rossetti, 1996; Bloom, 1998; Harlow, 1995). The Sunrise Model was developed in 1991 as a seminal text and represented the essential parts of Leininger's Trans-cultural Care Theory (Leininger, 1991). Leininger postulated that care and health are embedded in the worldview (social context), values, and practices of the people within a culture. This theory incorporates observation of care, participation in care, and reflection. Using this theory of attachment in the NICU could be delayed due to the health status of the infant, environmental circumstances, and the quality of nursing care.

### **Critical Studies of Men and Masculinities (CSM)**

Historically, Critical studies of men and masculinities (CSM) have focused on the 'role' of the father and the impact of their involvement has on child development (Cabrera et al., 2000; Lewis & Lamb, 2007). Socio-cultural, and interpersonal processes affect fathers' identities (Barclay & Lupton, 1999; Dermott, 2008; Featherstone, 2009; Hobson, 2003; Henwood & Procter, 2003; LaRossa, 1997; Lewis & O'Brien, 1987; Lupton & Barclay, 1997; Miller, 2011). The concept of hegemonic masculinity is central to not only exploring men's experiences, but how these experiences form the gendered caring responsibilities with their partners, babies and healthcare staff in the unique context of the NICU.

Hegemonic masculinity represents a fathers' gender identity to be strong and a protector. When a father has an infant admitted to the NICU, men struggle to fulfill their dual roles of provider and sustaining a physical presence in the NICU. Men are products of gender in terms of employment responsibilities during times of stress (Pohlman, 2005, 2009). Many times, the hegemonic gender roles of the 'involved father' and 'family provider' are also affected by social structures. Hegemonic masculinity adds insights on how a father struggle to articulate a parenting role in the NICU (Denny, Lohan, Spence & Parkes, 2012),

### **Identity Theory**

Identity theory, according to (Larossa & Reitzes 1993), is useful as it places an individual in the context of social structure, roles, and how a person interacts with others in each situation (Thoits & Virshup, 1997). Identity theory has been used by many to explain a fathers' involvement with his children and the fathering role (Pasley, Futris, & Skinner, 2002; Maurer, Pleck & Rane, 2001, 2003; Rane & McBride, 2000). The theory does not just say individual identity is important, but also states that how identity is determined is essential and how this determines paternal involvement. It speaks to how a fathers' status is related to a man's overall perspective of self and 'who the father is' and 'who he is as a father' (Pleck, 1997 pg. 84). Paternal identity can be viewed as an integration of the individual's developmental history, personality characteristics, and beliefs related to fathering.

While there has been evolving knowledge about men undergoing the transition to fatherhood, there is minimal research exploring the involvement of fathers with their

premature or unhealthy infants. This lack of research and understanding requires further attention.

Neonatal intensive care unit nurses know that how premature or unhealthy infants receive care is integrally related to the social context in which fathers reside. This study will closely explore and analyze fathers' needs.

## **Complications of Prematurity**

### **Complications to the Premature Infant**

Complications of prematurity or unhealthy birth include the short and long-term complications to the infant, increased stress levels in the parents, alterations in involvement, and attachment. Infants born prematurely may experience significant difficulties due to their low birth weight and the immaturity of their body systems. Investigations have shown a direct correlation between the degree of immaturity and the severity of adverse sequelae (Allin, Rooney & Cuddy, 2006; Marlow, Wolke & Bracewell, 2005). Some of the most common challenges premature infants' faces are: 1) hypothermia, 2) respiratory problems, 3) Apnea of prematurity, 4) Intraventricular hemorrhage (IVH), Retinopathy of prematurity (ROP). Descriptions of these challenges are presented in text box below.



**Hypothermia.** Preterm infants are more prone to hyperthermia for a number of reasons including (1) a greater surface-area-to-weight-ratio (2) low brown fat stores (3) less subcutaneous tissue and (4) their flaccid posture which increases the exposed body surface to the environment (Lemon & Bradburn, 1988; Mayo Foundation for Medical Education and Research, [MFMER], 2015).

**Respiratory problems.** Respiratory distress syndrome (RDS) is the most common cause of distress in premature infants and can affect up to ten percent of infants born between 22- and 30-weeks' gestation. RDS occurs because infants born at this age have a deficit in pulmonary surfactant, an agent that prevents alveolar collapse at the end of the expiratory phase (CDC, 2015).

**Apnea of prematurity.** Apnea is the cessation of breathing for greater than 20 seconds. It may be caused by the immaturity of the premature infant's central nervous system and the respiratory control center in the brain (AAP Clinical Report, 2015).

**Intraventricular hemorrhage (IVH).** A condition in which immature and fragile blood vessels within the brain burst and bleed into the ventricles, generally filled with cerebrospinal fluid. The severity of IVHs are graded on a scale of one to four. Grade one being clean and confined to a small area around the burst blood vessels and four being an extensive collection of blood not only in ventricles but in the tissue of the brain itself. The more severe IVHs can result in hydrocephalus. Hydrocephalus is a potentially fatal condition in which too much fluid collects in the ventricles causing increased intracranial pressure on the brain. The increased pressure may lead to severe handicaps. Grade three IVHs have been associated with a 36% handicap rate. Grade four IVHs have a 76% chance of a significant disability leading premature infants to a higher risk for both learning and behavioral difficulties. Magnetic resonance imaging (MRI) studies have shown that premature infants also have reduced brain volume when compared with full-term infants. Smaller brain volume is associated with lower cognitive scores and a higher incidence of attention deficit disorder (ADD) and attention hyperactivity disorder (ADHD) (March of Dimes, 2015).

**Retinopathy of prematurity (ROP).** A condition in which abnormal blood vessels and scar tissue grow over the retina, causing visual disturbances that may result in blindness. ROP continues to this day to be a significant cause of blindness throughout the world. Some infants will overcome these problems while others will go on to long-lasting physical or developmental deficits (McCrary & McCutcheon, 2016).

Long-term complications of prematurity are challenging to predict. In some cases, it may not become apparent until the child is school-aged. The risk of severe, long-lasting complications depends on many factors, including gestational age of the infant at birth, birth weight, and the presence or absence of breathing problems. With the advances in neonatal care, premature infants are surviving at younger ages, many of whom go on to develop disabilities and chronic medical conditions that may require frequent readmissions. Premature infants, because of their immature immune systems, are more susceptible to infections placing them at increased risk for later disorders, and readmissions to the hospital (March of Dimes, 2015). Very low birth weight infants have the highest readmission rates during the first year of life for the care of chronic health problems such as bronchopulmonary dysplasia (BPD), cardiac abnormalities, gastrointestinal issues, and neurodevelopment deficits (March of Dimes, 2015). There is progress in the number of the risk factors and etiologic pathways for preterm birth subsequently much more needs to be done to enhance attachment and reduce possible adverse infant outcomes.

### **Stress**

Stress according to Magnusson is a relationship between a person and the environment that exceeds the person's resources and threatens his or her well-being. Stress reactions can be both physical and/or psychosocial.

The birth of a child and the onset of parenthood can cause stress in the lives of parents of both term and preterm. The delivery of a premature or unhealthy infant causes increased stress due to the uncertainty about the infant's survival, risk of medical

complications and concerns regarding long-term consequences (Alkozei, McMahon & Lalav, 2014; Lasiuk, Comeau & Newburn-Cook, 2013; Lefkowitz, Baxt & Evans, 2010; Schenk & Kelley, 2010; Vigod, Villegas, Dennis & Roos, 2010; Watson, 2011). Parents of infants admitted to a NICU experience heightened stress due to poor preparation for the unexpected birth and the uncertainty of the survival and outcome of their infant (Arockiasamy, Holsti & Albersheim, 2008; Carter, Mulder, Bartram & Darlow, 2005; Gonulal, Yalaz, Altun-Koroglu & Kultursay, 2014; Heidari, Hasanpour, & Fooladi, 2013). In addition to the customary stress of the transition to parenthood, parents of premature or unhealthy infants experience the physical and emotional separation from their infant, lack of control and fear associated with having a sick baby. Mothers are often reported to experience more stress than fathers possibly due to the bonding process during pregnancy (Arockiasamy, Holsti & Albersheim, 2008; Ekstrom, Widstrom & Nissan, 2003; Lindberg, Alelsson & Ohrling, 2007; Lundqvist et al., 2007; Pohlman, 2005). Few studies have reported fathers experience more stress than mothers (Feldman et al., 2003) while others found no gender differences (Trombin, Surcinelli, Piccioni, Alessandroni & Faldella, 2008; Feldman et al., 2008).

The increased stress fathers experience could be because fathers have more significant difficulties understanding infant behaviors and experience stress from different sources (Trombin, Surcinelli, Piccioni, Alessandroni & Faldella, 2008; Feldman et al., 2010). Consequently, fathers move through the fathering process slower than mothers and have a higher perception of lack of control due to the uncertainty of an infant's diagnosis and treatment (Arockiasamy, Holsti, Albersheim & 2008; Lundqvist et al., 2007; Cobiella, Mabe & Forehand, 1990; Crnic, et al., 1983; Grunau et al., 2009;

Halpern, Brand, & Malone, 2001; Harrison, & Magill-Evans, 1996; Singer, Davillier, Bruening, Hawkins & Yamashita, 1996).

Studies regarding preterm birth commonly characterize the birth of a preterm or ill infant and subsequent admission to the NICU as a stressful event for parents. Factors affecting this stress include parental age, previous experiences with children, role adjustment, coping skills, the unexpected birth of a premature infant, and environmental problems (Lee & Doyle, 2014; Misund, Nerdrum & Diseth, 2014). Fathers of premature or unhealthy infants experience specific stressors that are identified as: (1) infant factors (size, health status, and infant feedback, (2) interpersonal factors (rewards, attitudes, and beliefs regarding fatherhood, family dynamics, previous experiences) and (3) NICU environment (physical and social) (Aagaard & Hall, 2008; Feeley, Gottlieb & Zerkowitz, 2007; Holditch-Davis et al., 2009; Jackson, Ternstedt & Schollin, 2003; Lefkowitz, Baxt & Evans, 2010; Lundqvist et al., 2007; Turan, Basbakkal & Ozbek, 2008).

Parents' stress increases exponentially with the birth of a premature or sick baby due to the abrupt end of the role adjustment period and the concern for the health of the infant and possible subsequent short and long-term complications (Carter et al., 2005; Jotzo & Poets, 2005; Kantrowitz-Gordon, 2013; Shaw et al., 2006). Increased parental stress can potentially influence parenting behaviors as well as produce long-term emotional problems such as post-traumatic stress disorder (PTSD) (Busse et al., 2013). Stress, anxiety, depression, and fatigue can alter a parents' perception of their competence, parent-infant interactions and ultimately the infant's cognitive, emotional and health outcomes (Dudek-Shriber, 2004; Franck et al., 2005; Miles, Funk & Carlson, 1993; Schenk & Kelley, 2010). Fathers compared to mothers, are more reluctant to

interact physically with their premature infants due to the infant's perceived fragility and fewer social interactions (Fegran, Helseth, Fagermoen, 2008). Due to the perceived fragility fathers often engage in fewer intimate and proximate behaviors with their infants (Lindberg, Axelsson, Ohrling, 2007; Thurman, & Korteland, 1989).

Environmental factors that can contribute to parents' stress levels can include difficulty fulfilling their parental role, the unfamiliar medical equipment, and the communication and behaviors of the staff (Miles & Carter, 1983). According to Mercer (1981) the development of role adjustment for parents is a process that requires a period of one year. During this time, parents develop individual attitudes and expectations of how their new baby will look and act as well as how they will care for them. Thus, parenting stress is a significant risk factor, as it may interfere with the father-infant relationship during a NICU admission and consequently increase the risk of uncertain long-term outcomes.

Parental depression, anxiety, and PTSD symptoms elevate while their infants are in the NICU, but generally decrease in the first year after discharge, although these symptoms can continue for years after the preterm or unhealthy birth (Holdtich-Davis et al., 2009). Many times, infants discharged from a NICU are perceived to be different by their parents in their social abilities. Many parents often expect behavioral and emotional problems in their child (Huhtala et al., 2012; Treyvaun et al., 2014; Silverstein et al., 2008).

Vulnerability is established early in an infant's life due to the NICU environment. The infant's vulnerability may continue after discharging due to the need for follow up visits after discharge (TalIndini et al., 2015). Parents feel distressed from the

incongruence between their anticipated identities as a parent of the perfect child to that of a parent of a child who may struggle their entire life (Kantrowitz-Gordon, Altman & Vandermause, 2011). Gender differences may contribute to the differences between mothers and fathers and their stress levels associated with preterm or unhealthy birth.

Coping strategies change with the birth of a premature or sick infant. Fathers who felt in control before the unexpected birth now report feelings of helplessness, anxiety, fear, sadness, and out-of-control (Pohlman, 2005; Valizadeh, Zamanzadeh & Rahiminia, 2012). Others have stated feelings of distance or of being an outsider and excluded (Casteel, 1990; Fortinash & Holodayworret, 2008; Kenner & Lott, 2007; Lindberg et al., 2008; Lundqvist, Westas & Hallstrom, 2007; Pohlman, 2005; Simon, 2008). A primary coping strategy many fathers exhibit is that of hiding their emotions increasing the potential of increased stress and possibly precipitating PTSD (Arockiasamy, Holsti & Albersheim, 2008; Helth & Jarden, 2012; Hugill et al., 2013; Pohlman, 2005). Identifying and considering risk factors that can contribute to fathers' stress enable healthcare professionals to facilitate fathers' adaption and coping skills. Newly established coping skills may lead to optimal father-infant relationships and infant outcomes.

### **Involvement**

Involvement is defined as a parents' sense of responsibility towards their infants and capacity to engage with them (Martell & Addis, 2001).

Both empirical and theoretical literature on fathers found that a father's role is complex and changes throughout the lifespan including the transition to fatherhood

(Berman & Pedersen, 2001; Cowan, 1987; Lamb, 1987, 2010; Lewis, 2007; Michaels & Goldberg, 1988; Parke, 2000; Strauss & Goldberg, 1997). Paternal involvement constructs include (1) engagement; (direct interaction with the child in the form of play, caregiving, and other activities) (2) accessibility (availability to the child), and (3) responsibility; (making sure to provide care for the child).

A fathers' involvement has also been shown to have a life-long impact on the father-infant attachment process (Clotney & Dillard, 2013; Martell & Addis, 2001; Sansavini & Faldella, 2013). Many studies have found that a father's involvement has a positive effect on the behavior, social and cognitive development of their young children (Belsky, 2012; Bowlby & Anisworth, 1991; Cabrera et al., 2000; Frank & Paris, 1981; Lamb & Lewis, 2010; Monteiro et al., 2008; Olsson, Erikson & Anderzen-Carlsson, 2017; Panter-Brick, et al., 2014; Porat-Zyman, Taubman-Ben-Ari & Spielman, 2001; Rubin, Bukowski & Parker, 1998; Sarkadi, Kristiansson, Oberklaid & Bremberg, 2008; Tamis-LeMonda, 1999; Voigt, Macias & Myer, 2011) including increasing the chances of academic success and reducing the chances of delinquency and future substance abuse including drinking among adolescents (Barnes, 1984; Coombs & Landsverk, 1998; Flouri & Buchanan, 2002a; Harris et al., 1998; Howard et al., 2006; King & Sobolewski, 2006; Mosley & Thompson, 2002; Zimmerman et al., 1995).

Infants of highly involved fathers, with involvement measured as the amount of interaction, higher levels of play, and caregiving activities, are more cognitively competent at six months and score higher on the Bailey Scales of Infant Development (Pedersen, Rubinstein & Yarrow, 1979; Pedersen, Anderson & Kain, 1980). By one year, they continue to have a higher cognitive functioning and are better problem solvers

as toddlers and have higher IQs by age 3 (Easterbrook & Goldberg, 1984; Nugent, 1991; Yogman, Kindlan & Earles, 1995). Fathers also benefit from involvement with their children. When fathers build a strong relationship with their children, it helps them to enjoy a more secure attachment, develop better coping skills in stressful events, feel more confident in their parenting skills, and are more understanding and accepting of their children (Fogarty & Evans, 2009; Pleck & Masiadrelli, 2004; Almeida & Galambos 1991; Russell, 1999).

Determinates of paternal involvement can be influenced by individual paternal characteristics, characteristics of the parental relationship, and child characteristics. When a father views participation as a positive attribute, higher levels of engagement are found (Aitchison Russell & Pedersen, 1990 cited in Cowan & Cowan, 1987; Dickie, 1987; Grossman, 1987; Levy-Shiff & Israelashvili, 1998; Russell et al., 1999). The closer the father's perceived paternal role is to that of reality, the higher the father's involvement. Despite the growing research showing the importance of father involvement on an infant's and child's cognitive development, the role of the father in a premature or sick infant's life has been less researched.

In studies focusing on NICU experiences, fathers described the birth of their premature infant as shocking and an unexpected event for which they were not prepared (Fegran et al., 2008; Heineman et al., 2013; Hugill et al., 2013; Lindberg et al., 2008). Unexpected incidents in the infants' progress can place fathers in a frightening position, including shock, fear, anxiety, guilt, and disappointment as well as feelings of lack of control (Arockiasamy, 2008; Benfield, 1995; Boxwell, 2000; Nystrom & Axelsson, 2002; Pohlman, 2005). At the time of delivery, the father's initial concerns were with their



partner's well-being. After receiving reassurance about their partner's well-being, their fear was replaced by concern over the health status of the infant (Cummings, 2017; Fegran & Helseth, 2009; Guillaume et al., 2013; Koppel & Krauser, 2001).

From the birth through the initial stay in the NICU, fathers have fears about their infant's perceived fragility and their abilities to care for their fragile infant. Many fathers prefer not to touch the infant but instead talk to them because of the infant's fragile appearance (Guillaume et al., 2013). Fathers tend to increase their involvement as the health status of the infant improves, which from a father's perspective, many times is indicated by weight gain (Lee et al., 2009). The uncertainty about the infant's outcome can compromise their interactions with them or even lead to a delay or withdrawal in the parental psychological investment (Arnold et al., 2013; DeMier et al., 2000; Fegran et al., 2008; Fegran & Helseth, 2009).

The environment of the NICU, both physically and socially, can directly affect the father-infant dyad. When the staff tells fathers that their infant is too sick to be touched this may lead to fathers' prolonged anxiety and fear. Fathers who are encouraged by the staff to touch and interact with their infants may result in a father's feelings of being proud and a contributor to the care of their infant (Helth & Jarden, 2013). The highly technological physical environment or barriers to involvement may include the equipment used and terminology used by the staff about their infant's medical condition. Many times, the father's lack of understanding can increase the father's anxieties and fears, which also can also delay their interactions with their infants (Lee, Lin, Huang, Hsu & Bartlett, 2009; Pohlman, 2009, 2005; Lundqvist & Jakobsson, 2003). Being a

contributor to their infant's care can be an essential building block to lifelong positive outcomes for both the father and the infant.

### **Attachment**

Attachment according to Bowlby is built on our first relationships that are dynamic and enduring and that can profoundly influence later development.

Attachment requires early physical contact. The NICU environment, where the focus is on the care of the infant, highly technological equipment, unfamiliar sights, and sounds, and the infant's diagnosis may cause a delay in the attachment between a father and their infant. Fathers of premature or sick infants state various difficulties and challenges in the process of attachment. These challenges may start with the timing of the birth, the prolonged hospital stay, behaviors, and possible cognitive development of the infant (Goldberg & DiVitto, 2002). Parent-infant separation is inevitable in the NICU. This separation can cause pain and increase a father's anxieties and fears. During the initial NICU journey, parents must learn new terminology, establish a trusting relationship with people they don't know and accept their new roles. When parents struggle with these in the NICU they may display a variety of verbal and non-verbal cues ranging from frustration to lack of questions.

Premature infants have an increased chance of neurological impairments that may further delay the attachment process (Wolke, Eryigit-Madzwamuse & Gutbrod, 2014). Much of the research on the cognitive development of premature infants focus on infants born between 23 to 28 weeks gestation and VLBW (<1,500 grams) or extremely low birth weight ELBW (< 1,000 grams). However, even infants admitted to a NICU for only

short periods may still be at risk for neurological development delays. Altered attachment due to neurological abnormalities has been reported present in about 35% of infants admitted to a NICU at some level (Van IJzendoorn, 1993).

Premature or sick infants who develop a secure parental attachment have a reduced chance of experiencing cognitive delays, have better weight gain, and improved social and adaptive development at 18 months of age (Fogarty & Evans, 2009; Levy-Shiff et al., 1989, 1990). Children are more able to handle strange situations and are more resilient in times of stress with secure attachment (Kotelchuck, 1976; Mischel, Shoda & Peake, 1988; Parke & Swain, 1975). A positive attachment between a father and their child positively correlates with a child's overall life satisfaction and fathers experience less depression (Dubowitz et al., 2001; Field et al., 1995; Flouri & Buchanan, 2003; Formoso et al., 2007; Furstenberg & Harris, 1993; Zimmerman, Salem & Maton, 1995).

Attachment is a profound and complex experience that requires physical contact and early interaction (Oakley, 1998). Higher levels of paternal sensitivity are associated with better infant-father attachment and this can be a predictor for positive developmental outcomes of the child (Lucassen, VanIJzendoorn, Volling, Tharner, Bakemans-Kranenburg & Verhult, 2011). Due to a NICU's complex and highly technological environment, the infant many times is separated from their parent. It is necessary to determine its effects on parents and particularly fathers. This study focused on fathers' perceptions of the quality of attachment and the need to improve it.

### **Move Over: Premies Need Dads Too**

Father involvement and attachment can be inadvertently impeded by others, including mothers and healthcare providers. There have been changes over the last several years in women's domestic and childcare roles, although mothers still tend to exhibit maternal gatekeeping tendencies while in the NICU. Maternal gatekeeping is defined as a mothers' preference and attempts to inhibit fathers' participation (Allen & Hawkins, 1999; Fagan & Barnett, 2003). Maternal gatekeeping is an essential variable that can inhibit a father's involvement (Coltrane, 1996; Hochschild, 1989; Lamb, 1987). Many times, maternal gatekeeping behaviors are not intentional, and mothers are unaware of how their gatekeeping practices affect father involvement (Walker & McGraw, 2000).

There are three dimensions of maternal gatekeeping; (1) standards and responsibilities, which refers to a mother's resistance to relinquishing her responsibility and managing the father's participation; (2) maternal identity confirmation, which refers to a mother's desire for external validation of the maternal role; reaffirming their roles as the primary caregiver possible restricting a fathers' involvement (Higham & Davis, 2013; Waitzer & Boisvert, 2013) and (3) differentiated family roles, which refers to a mother's expectation of a clear set of gender roles for men and women (Allen & Hawkins, 1999). Sharing childcare responsibilities with the father may compromise the power attached to the maternal role. A study by Gaunt (2008) found a correlation between a mother's self-esteem and gender identity with maternal gatekeeping. The lower the mother's self-esteem and the higher the mother's feminine gender identity, the stronger her tendencies

are for gatekeeping. Maternal gatekeeping has been correlated in all three measurements of involvement in childcare.

Because a gatekeeper can close and open a gate, maternal gatekeeping beliefs and behaviors can affect a fathers' involvement (Fagan & Barnett, 2003; Schoppe-Sullivan et al., 2008). Maternal gatekeeping practices may also moderate a fathers' belief about their roles and their involvement with their children. When mothers believe in more traditional gender roles fathers are more facilitators to the mothers' intimacy with the baby. For these fathers when they have the chance to visit without the mother they may interact more and feel most self-efficient (Thomas, et al., 2008). When mothers believe in more non-traditional beliefs about gender roles, increased father involvement is possible.

Mothers are not the only ones that can act as gatekeepers to a father's involvement. At times nurses in the NICU may do the same (Corlett & Twycross, 2006; Cummings, 2017; Wigert et al., 2008). Fathers' internal fears of the equipment can influence a father's ability to exercise parental autonomy while for others it was a result of their interactions with caregivers or nursing gatekeepers (Cummings, 2017; Lindberg, Axelsson & Ohrling, 2007; Swift & Scholten, 2009). Some nurses may tell fathers not to touch the infant while others tell fathers they should. These mixed messages can create a reluctance to be involved until staff invites them. When nurses act as "coaches" or "mentors" to fathers and give fathers information in a timely manner their involvement in areas of decision-making and parental autonomy becomes easier (Cummings, 2017; Lee et al., 2009; Reis et al., 2010; Thomas et al., 2008; Wigert et al., 2008). Parental autonomy relates to fathers recognizing they have the right to care for, hold, and make decisions about their newborns' care.

Other influencing factors on a father's involvement include previous delivery, hospital experiences, and life experiences. Busse, Stromgren, Thorngate & Thomas, (2013) found that even when a father has had previous children, they still saw the NICU as unfamiliar, which could hinder involvement and attachment. When fathers had experience with prior hospitalizations of an older child or family member, they saw it as a positive due to their familiarity with the hospital setting and terminology. This familiarity often left them somewhat less overwhelmed and more able to focus on their infants (Busse, Stromgren, Thorngate, Thomas, 2013).

Influencing factors on a fathers' involvement have shown that fathers have different beliefs regarding their influences on their infants. Fathers who believe their presence had a positive effect on their infants visited and interacted as much as possible. Fathers who thought a mother's involvement was of greater importance, spent more time in the background (Jia & Schopp-Sullivan, 2011; Nugent, 2007).

Feedback from the infant either positive or negative, can also influence a father's involvement. As infants become more responsive, fathers stayed longer and attempted to elicit more infant responses (Feldman et al., 2010; Goodman, 2005). When fathers see their interactions with their infant in a more positive light, they are more willing to share these experiences with friends and relatives outside the hospital (Hugill et al., 2013). Positive social interactions aid the father in making the transition to fatherhood more manageable (Skene et al., 2012). Despite the growing research showing the importance of father involvement on an infant's and children's cognitive development, the role of the father in a premature or sick infant's life has been less researched.

### **Prematurity and the Transition to Parenthood**

Transition to parenthood is a unique experience with a profound impact on both women and men. During the last decade research on the transition to parenthood has begun focusing on social patterns and social processes within a socio-historical context, but many issues have barely been explored, including gender and the transition to the fatherhood of a premature infant.

The transition to parenthood is a critical time in which both economic and cultural forces reinforce gender inequalities. These factors are generated in part by the social construct of mothers as primary caregivers and fathers as relatively peripheral in the care of their infants (Walzer, 1998). Gender theories that focus on interaction may be useful when looking at the increasing differentiation during the transition to parenthood, due to the strong connection between gender and mothering and fathering. Scholars suggest that people who “do” parenthood in the same way that people “do” gender, is defined through social interaction (Garey 1999; Walzer, 1998; Doucet, 2006).

### **Gender Differences in the Transition to Parenthood**

Father: Derived from the word pater: a man who has engendered a child, a male parent, or a person who takes responsibility (Solnit, 2003).

One can trace the idea of fatherhood historically from the seventeenth century. In many Western countries, such as England, France, and the United States (US) fathers were all-powerful and served as the family’s ruler (Lamb, 1987). Men oversaw the moral, spiritual and disciplines of their children. This early father-child relationship was described as distant and authoritarian. This type of fathering in the U.S. continued until

the mid-eighteenth century. Feminist thought in the 1980s began to influence the research field, and the assumptions about the fathers' role expanded to include multiple aspects of parenting. Scholars began to categorize "types" of father involvement as engaged, responsible, and accessible and how these types influence children. At the same time, social movements began to call into question two assumptions of underlying fatherhood research:

- (1) That what fathers do as parents is different from what mothers do
- (2) That father involvement is essential for child well-being

During the nineteenth and twentieth century the rise of industrialization helped spread the ideals of the modern fatherhood roles. Changing gender roles was reflected in several studies on perspectives of fathers in the NICU (Hollywood & Hollywood, 2011; Fergran, 2008; Hugill, 2013). Masculinity includes cultural ideals, values and expectations that form social norms related to men. These social norms of masculinity are changeable, varying by culture, ethnicity, time, age, and life stage.

Norms regarding masculinity were traditionally characterized by the father's ability to earn a living and protect their families, and this skill seems to be the case. Many men suppress their feelings because showing emotions is culturally perceived as a sign of weakness. If men receive too much compassion, they tend to feel vulnerable (Noergaard, Ammentorp, Fenger-Gron, Kofoed & Johannessen, 2017).

Gender ideology can often explain cultural and family practices. Ridgeway & Correll (2004, p. 511) defined gender beliefs as the "cultural rules or schema for enacting gender." Some of the significant changes that have occurred with the transition to



parenthood are a combination of influences such as maternal employment, feminist ideology, and egalitarianism.

Hegemonic masculinity has become a profound and pervasive theoretical framework for understanding men and masculinities (Coles, 2009). The premise of differences in gendered power, and that masculinities and gender practices are not generated in isolation forms the basis of this theory (Connell, 2005). There is no one single pattern or form of hegemonic masculinities. Each type of hegemonic masculinity is context dependent (Noone & Stephens, 2008).

The ideals of hegemonic masculinity may shift as men's position in the life course changes (Robertson, 2006). Initially, they have positive feelings about being able to 'father' a child (Dolan & Coe, 2011). After the birth of their child, fathers move to the role of taking control and being the primary provider (Dolan & Coe, 2011; Robertson, 2006). Masculinity can influence how healthcare professionals interact with men and many times healthcare professionals often fail to incorporate the full range of masculine identities into account when dealing with fathers (Dolan & Coe, 2011).

The complexities of today's society, as well as the many different lifestyles that make up today's family have moved the description of the term parenthood from the traditional definition. By traditional definition, a parent is a person who is responsible biologically for giving life to a baby. There are many kinds of individuals called parents (e.g., adoptive parents, foster parents, nonbiological parents) in current society. Increasingly, same-sex parents are also recognized as having full parental rights and responsibilities. With these changes, today's father is no longer always the traditional

married breadwinner and disciplinarian. Fathers can be single, externally employed, stay-at-home, gay or straight, adoptive or stepparents.

The term father traditionally meant being heterosexual, virile, dominant and competent (Coltrane, 1996; Lamb, 1987; LaRossa, 1997). Having a family home established a man's heterosexuality and masculinity. Focusing on work rather than spending time caregiving signaled economic dominance at home and established a man as a dedicated and reliable worker (Kantrowitz-Gordon, Altman, & Vandermause, 2016; Pohlman, 2005). Work defined what a “good husband and good father” were. Men who care for their children often fail to meet gender ideals set by society. Men who deviate from these social norms were often met with negative social judgment.

Appropriate gender actions define masculinity. Fathers enjoy the fatherhood benefits in the workplace because they conform to traditional notions of masculinity. Fathers who actively care for their children can be viewed as insufficiently masculine and be less likely to enjoy the status perks that fatherhood affords men (Berdahl & Moon, 2013). Men who violate cultural expectations many times are sanctioned more harshly than women.

Gender inequalities can go far beyond biology. Power comes with masculinity, but not without a price for fathers who care for their children. Society may cause resistance to child-rearing activities (Kovach, 2015). Other males may ridicule fathers for staying at home, leading to feelings of loneliness or being an outsider. These feelings can further lead to thoughts of failure by fathers who stay-at-home and care for their children (Connell, 2005). Men who practice outside traditional breadwinning stereotypes suffered more mistreatment and harassment at work than conventional fathers (Berdal & Moon,

2013). Working men with children who spend a relatively large amount of time caring for their children violate stereotypical ideals for men. These men are often seen as frail or wimps, or those who are not dominant at home. Insults such as being *henpecked* or being told that *your wife wears the pants in the family* may be heard. Comedies like *Daddy Daycare* (Carr, 2003) and books like *What to Expect When You're Expecting* (Murkoff & Mazel, 2012) make fun of men who serve as the primary caregiver for their children (Prentice & Carranza, 2002; Ranson, 2012). The legacy of the patriarchal manhood and power cannot be erased from men's history or experiences, including male pride and breadwinner (Berdahl & Moon, 2013). The perception of fatherhood is linked to and influenced by men's view of the male role within the family and in broader society.

Fathers' participation in child-care has long been a feminist issue. Today's stay-at-home dads don't want to be 'helper dads to mom'; they want to be seen not as *mothering*, but as *parenting* (Petroski & Edley, 2006). Terms like "domesticating patriarchy," "hegemonic masculinity," "marketplace masculinity," and "domesticating masculinity" emphasize that "stay-at-home" fatherhood is a complex construct for males grounded in history, race, class and the U.S. economy (Gavanas, 2004; Kimmel, 1996; Vavrus, 2002).

Feminists in the 1980s began to influence the research field relating to parenting. Assumptions about roles expanded to include the multiple aspects of parenting. For fathers, there were two opposing trends, father-absent, and father-involvement (Rotundo, 1993). Fathering roles since the 1900s has fluctuated between fathers as providers (instrumental role) and fathers as nurturers (expressive role). The new culture of fatherhood expects men to be more involved in the home, and with their children. This

new culture expects men to be an equal partner to their significant other, as well as continuing their status in the workplace (Gerson, 2015).

Work-family balance includes two central discourses for fathers that are heterosexual, including the conflict between being the breadwinner or the involved caretaker (Deutsch, 1999; Este & Tachable, 2009). The culture of the *new father* includes fathers seeing themselves as sharing both domestic and breadwinning tasks equally with their partner (Cooper, 2000; Mannix, Jackson & Wilkes, 2010). Many times, men's hegemonic identities remain bound in the breadwinning ideology, while caretaking practices are still considered feminine (Deusen, Humbred & Harrington, 2011). Fathers want to be more involved but fear humiliation and loneliness due to the asymmetry of masculine and feminist cultural norms.

A man who engages in a highly feminized activity such as caring for his children may be disrespected or teased for being insufficiently masculine (Jackson et al., 2003). Along with gender relations, fatherhood is embedded in a system of power, emotions, and symbols ranging from personal feelings and interpersonal relationships to economic pressures between work and family balance, culture and state policies (Dorfler & Kaindl, 2007; Dribe & Stanford, 2009; Lammi-Taskula, 2008; Merla, 2008). There has been a positive change in the belief that a nurturing father is essential and an integral part of the father-child relationship and child development.

Modern fatherhood lies somewhere between these two opposing poles. The feminist movement and more women entering the workforce have forced gender roles to undergo reshaping and shifting to a higher overlap in men and women's roles (Connell, 2005; Kimmel & Aronson, 2004). As part of the feminist movement, fathers have

become more active participants in the care of their children and are expected to be more equal partners in parenting. As equal partners in parenting, fathers are spending more time nurturing their children and performing both interactive and physical caregiving activities but social discourses for fathers are still enforced by the breadwinning identity (Davis & Ward, 2012; Este & Tachable, 2009).

Transition to fatherhood entails a negotiation between their gendered responsibilities. The process of mediation not only include their partner, but also includes social expectations, male peer groups, and one's own father (Bradinter, 2010; Hofner, Schadler & Richter, 2005). Despite the considerable social change in recent decades and how fathers' parent, tensions exist for fathers as they try to navigate the parenting role, gender and breadwinning roles (Daly & Palkovitz, 2004). Being able to care for their children in the 'new fatherhood role' continues to conflict with the traditional good worker and breadwinner stereotype (McLaughlin & Muldoon, 2002). The historical and ritualistic practices of fathers need reviewing with emphasis placed on the family unit and in the context of the problem of prematurity and sick neonates.

Gender ideals placed on fathers by themselves, by society or the NICU environment can have an impact on a father's stress levels. When fathers do not have paternity leave, many return to work to provide for their families (Pohlman, 2005). When fathers return to work, they visit less frequently and for shorter periods decreasing their opportunities to interact and making attachment with their infant more difficult (DaCosta, Cuhna et al., 2013; Feeley et al., 2012; Garten et al., 2013; Helth & Jarden, 2013). Fathers must choose between being close to their infants or providing for their

families, forcing them into a push/pull paradox of provider or nurturer (Cummings, 2017; Pohlman, 2005).

Open visitation policies can help reduce a father's stress by allowing them to visit when conducive to them. Fathers tend to interact more when visiting alone (without the mother), possibly due to their perceptions of the mother as the primary caregiver (Busse et al., 2013). Fathers who are overwhelmed by the physical or social NICU environment, may return to work to regain control over their lives and restore their self-confidence by being the family provider (Franck & Spencer, 2003; Helth & Jarden, 2013; Hollywood & Hollywood, 2011; Jackson et al., 2003; Lundqvist et al., 2007; Pohlman, 2005).

Family responsibilities for fathers above and beyond work can increase their stress due to the pressure of dual roles. With mothers being hospitalized prior to or after the birth of a premature or sick infant, or when mothers decide to stay at the hospital with their premature or unhealthy infants, fathers must juggle home life. The father's responsibilities now include housework, caring for other children at home, and being the person who relays information to extended family and friends about the infant's condition (Cummings, 2017; Brown, et. al., 2011; Lundqvist & Jakobsson, 2003). While the infant is hospitalized, fathers are faced with new demands on their time, including emotionally supporting their wife, performing household chores, caring for other children while continuing to support the family financially all of which can create increased stress levels and interfere with the bonding process (Cummings, 2017; Fontoura, Fontenele, Cardoso & Sherlock, 2016; Feeley, Waitzer, Sherrard, Boisvert, & Zelkowitz, 2012; Higham & Davies, 2013; Bruce, Lilja & Sundin, 2014). This increased stress can make fathers

vulnerable to mental health issues such as PTSD and anticipatory grief (Valizadeh, Zamanzadeh & Rahiminia, 2012).

Anticipatory grief (AG) is a state in which parents prepare for the potential loss of the premature or ill newborn, while they still hope for the infant's survival. AG occurs before the actual loss, causing a mixture of symptoms, including psychological, cognitive, behavioral and physical which has been reported by both mothers and fathers (Bennett, Dutcher & Snyders, 2011; Bowden, & Greenberg, 2010; Fortinash & Holodayworret, 2008; Kenner & Lott, 2007; Reynolds & Botha, 2012; Verklan & Walden, 2010 ). Most fathers' reactions to AG are exhibited by preoccupation or dreaming about their baby. Feelings of sadness, anger, and guilt were also seen (Valizadeh, Zamanzadeh, Rahiminia, 2012). Fathers often tend not to express their feelings or suppress them, perhaps due to their feelings of needing to support and protect their partners (Armstrong, 2001; Kerstin & Kerstin, 2004; Lee, Miles & Holditch-Davis, 2006; Murohy, 1998; O'Leary & Thorwick, 2005).

### **Fathers and Child Development**

Child development includes the physical, social and emotional changes in a child. Each child develops at his or her rate but develops in a predictable order from simple to more complex. Children may grow predictably, but many factors can influence this growth and development. Factors influencing childhood growth and development include heredity, family, and community and many of these early experiences can affect them now and, in the future, (Janzen & Kelly, 2012).

As social structures changed (women entering the workforce, different family dynamics, and structures) the number of fathers staying at home and assuming childcare and domestic responsibilities have increased. As these social structures became more apparent, researchers in the 1970s and 80s began to focus on fathers as nurturers, and how they affected their developing children (Weiss, 2016; Hallberg et al., 2005).

A fathers' role in child development has changed over the last generation. The role has changed from fathers being the primary provider and disciplinarian and someone who would interact with his children when time allowed, to a more committed partner. Studies have shown nonresidential fathers were directly associated with children's behavior. Children of fathers who did not spend time with them, had higher incidences of substance abuse, drinking, and lower academic achievement (Choi, Pyun & Palmert, 2014).

Fathers have a distinct style of communication that can be distinguished by an infant as early as eight weeks of age. Two prominent books published, one by Lamb, (1981) and one by Pruett (1987), reported consistent findings that fathers are not mothers. Fathers' modes of interacting, caring for, playing with, disciplining, and talking to their children are distinctly different from mothers. In play, men tend to be more physical and rough house more than women. Women use verbal interaction, direction or make-believe, and modify their language when speaking with children, while men do not.

Fathers do not modify their language, helping children to expand their vocabulary and linguistic skills, which are important building blocks to their academic success. Men usually ask questions that are more "what" and "where" questions which require children to assume more communicative responsibilities in the interaction. This questioning style



encourages toddlers to talk more, use more diverse vocabulary, and produce longer utterances when interacting with others (Rowe, Crocker & Pan, 2004). Men tend to structure their play around a task, game or project. The effects of this play have been shown to have a long-range impact on the cognitive, social development, problem-solving skills, and encouragement for children to broaden their environments (Lamb, 1981; Pruett, 1987).

Parents interacting with their children differently foster opportunities for children to build an attachment with each parent distinctly. Preschool-age children had increased cognitive competence, increased empathy, increased self-control and a decrease in gender-related stereotyping when fathers were involved. Father-child involvement is associated with better socio-emotional, academic functioning, and children had fewer behavioral problems and scored higher on reading achievements (Howard et al., 2006; Pruett, 1987; Lamb, 1981).

Fathers discipline differently than mothers and stress justice, fairness, and duty (Gilligan, 2017). They tend to observe and enforce rules systematically and sternly, which teaches children that there are consequences of their actions. Fathers also project to their children that their attitudes and behaviors can have positive or negative effects.

Girls with involved fathers are more likely to have a healthier relationship with the opposite sex because they have learned what types of practices that are appropriate for males. Boys who have grown up with involved fathers learn to channel their masculinity in positive ways leading to less violence and delinquent behavior (Popenoe, 1996). The quality of a relationship between a father and his infant contributes significantly to the development of the infant and father involvement has proven to

enhance their children's short and long-term outcomes (Thompson, 2008). Focusing on how to improve the quality of father involvement in the NICU can only improve the father-infant dyad and potentially impact the cognitive health of the premature or unhealthy infant.

### **Interventions with Fathers**

Approximately 85% or nearly 4 million newborns are hospitalized in the highly technical environment of the NICU (Weber & Harrison, 2019; Witt, Weiss & Elixhauser, 2006). Providing support to parents will help them identify their parenting roles. Programs for fathers should be tailored to meet their specific needs and be adaptable to fit different populations. Early intervention programs for fathers need to focus on fathers' abilities to cope and their changing needs during their infant's time in the NICU. A fathers' ability to cope can affect his potential to embrace their changing paternal roles, emotions, and the relationship between themselves and their premature or ill infant. Expecting a healthy neonate, but then being confronted with a premature or sick neonate, and the subsequent admission to the NICU requires fathers to reexamine and adapt to a new and unfamiliar situation and parenting role. They are now faced with intense and confusing emotions. These include the unexpected delivery, concern about the survival of the neonate, life-long physical and/or developmental outcomes, admission to the NICU, possible transport of neonate to a different hospital, appearance of the premature or ill infant, grief from the loss of the perfect birth and child, and communication with many unknown healthcare providers who many times use unfamiliar terminology. Feelings of

guilt, shock, fear and stress can also be seen (Dreyer, 2004; Shellabarger & Thompson, 1993).

Parents are often in a state of shock when they first enter the NICU requiring the information to be repeated and may require information to be given in creative visual form (Reichman, Miller, Gordon & Hendricks-Munoz, 2009). Premature birth or the birth of a sick neonate is a crisis for fathers, forcing them to redefine their paternal roles and requires psychological adjustments. The birth of a premature or sick infant often causes feelings of shock, self-blame, anticipation of what may happen next, despair, pain, increased levels of depression as well as uncertainty about the infant's short and long-term physical and developmental outcomes (Trowell & Bowers, 1995). Interventions for fathers need to consider the differences in the specific needs between mothers and fathers, and that fathers needs may change throughout the NICU stay. Evidence on the usefulness of interventions to support fathers, reducing their stress and increasing their involvement are mixed: from reports of few or no effects (Matricardi et al., 2013) to measurable positive effects (Lee et al., 2003).

Interventions that support fathers of preterm or sick infants can have several beneficial effects. The benefits include decreased stress levels, increased knowledge of their infant's condition, and strengthened their parenting confidence (Matricardi, Fedeli, & Montiroso, 2013). Psychosocial parental support programs may reduce the length of stay in the NICU and possible readmissions to the hospital (Melnyk et al., 2006; Nearing et al., 2012). Parents who have undergone parental training have also been shown to be associated with improved cerebral white matter in the preterm infant (Milgrom et al., 2010). The following are few examples of interventions for fathers who have infants

admitted to the NICU are 1) Family centered care, 2) Primary caregivers, 3) Two-person technique, The COPE NICU Program, 5) HUG Your Baby Program and 6) Skin-to-Skin.

These interventions will be briefly explained below.

### **Family-Centered Care**

Parents of premature infants before the 1970s were thought to be carriers of germs. Parents were allowed only limited access to their infants to reduce the possibility of passing these germs on to their premature infants, which resulted in a decrease in parental involvement (Bornstein, 1995). In the mid-1970s researchers from Stanford University Medical Center compared infection rates of premature infants at two different time intervals. When comparing the periods when parents were not allowed visitation in the NICU and when parents could visit, no differences were found in the rate of infection rates (Burnett et al., 1970; Kennell et al., 1975). As a result of these studies, many NICU visitation policies shifted towards open visitation and family-centered care.

Family-centered care (FCC) is a holistic form of care for the infant and their families. FCC emphasizes family participation, sharing knowledge, and reciprocal communication between the healthcare providers and family (Ramezan, Hadian, Schirazi, Sabet, Sarvenstani & Moattari, 2014). Parenting is a developmental process where parents must learn how to care for their infants. FCC sees parents as an essential part of the NICU team and helps parents learn to care for their infant which leads to empowerment. However, despite the use of FCC and free access allowed for parents of premature infants in the NICUs, many still experience high levels of stress.

### **Primary Caregivers**

Parents see primary nurses as a positive attribute. Parents feel having consistent caregivers allow them to build relationships which leads to a higher comfort level when *present* or *absence* at the hospital. Primary nurses can be teachers, encouraging and supporting parents. According to the National Encyclopedia (2014) communication is the conveying or sharing of information between people. Communication between parents and staff can drastically decrease their stress levels (Kowalski, Mackley & Spear, 2006; Kuo, Houtrow, Arango, Kuhlthau, Simmons & Neff, 2012; Turner, Chur-Hansen & Winefield, 2014; Wiget & Dellenmark, 2013). Information can be provided by both *what* is said verbally and *how* the message is communicated non-verbally (Watzlawick, Beavin & Jackson, 1967).

Fathers feel the unspoken or non-verbal expectations by staff including how much time they should spend in the NICU, and how much they should participate in and take responsibility for the care of their child. Excellent communication creates a trusting relationship that gives parents peace of mind and the ability to orient themselves to their chaotic situation. When communication is absent, fathers feel isolated, which can amplify their concerns about their infant. Fathers report communication is a critical factor in their perception of healthcare providers empathy and compassion (Weiss, Goldlust & Vaucher, 2010).

### **Two-person Technique**

The two-person technique is a form of care where when there is interaction with the infant by the nurse, the family member acts as the calming variable. Whenever possible parents should be part of the two-person technique promoting bonding and

encouraging care. Interactions like this would be a time for fathers to be involved, learn their infant's cues and build their confidence.

### **The Creating Opportunities for Parents Empowerment Program (COPE NICU Program)**

The COPE NICU program enables parents to cope effectively with the premature birth. COPE teaches parents what to expect from their premature infant during the NICU stay and for nine months after discharge. Through this program, parents learn how to identify their infant's characteristics, developmental cues, and milestones. It teaches parents how to interact with their premature or sick infant that enhances growth and development.

With the COPE program, infants have improved outcomes including 66-day shorter length of stay (LOS) for infants < 27 weeks, decreased readmission rate within 30 days after discharge for infants < 27 weeks, and 4-day shorter LOS for infants 26-34 weeks. Improved parent outcomes include decreased stress, stronger belief in their confidence in their ability to care for their premature or ill infant. Parents are more capable of understanding their infant's cues, experience less depression, and anxiety during the NICU stay, have greater parental satisfaction, and greater readiness for discharge (Melnyk & Feinstein, 2006; Melnyk, Crean, Feinstein, Fairbanks & Alpert-Gillis, 2006).

### **HUG Your Baby program**

Another early intervention care program for fathers of neonates include the

### **(HUG) Your Baby program**

Fathers of premature or unhealthy neonates that are admitted to the NICU are under stress. The HUG Your Baby program is a family-friendly education program that increases a fathers' knowledge about infant behavior. The program can enhance a fathers' confidence in their involvement and promote the father-infant bonding process.

Complicated birth, the birth of a premature infant, and the admittance to the NICU all can increase parental stress (Shield-Poe & Pinelli, 1997; Singer et al., 1996) which can alter the expected parental role and may create feelings of separation leading to a delayed attachment process (Bialoskurski, Cox & Hayes, 1999; Sullivan, 1999). The HUG program is designed to help parents understand newborn behavior, and prevent and solve problems around a newborn's eating, sleeping, crying and attachment. All these components of the program promote more effective fathering.

### **Skin-to-Skin**

Fathers express that being able to perform skin-to-skin contact with their infant relieved their anxieties, increased their confidence and self-esteem. Fathers often see skin-to-skin contact as having a positive impact and helps them to get to know their infant, which possibly leads to a more positive attachment.

### **Conclusion**

Parents with neonates admitted to an NICU have fluctuating emotional distress and needs. The infant's clinical instability and the dependence on the NICU staff and equipment requires an adjustment to their parenting role and lives. If parents are well informed, empowered to fulfil their parental roles and they feel included in the care of their infant, the NICU experience can also be a great experience. Healthcare providers should never forget that a parent of a baby that is admitted to the NICU is under stress

and each may cope with this stress differently. Nurses should focus on finding ways to help these parents express and acclimate to these stressors, making the transition to parenthood easier.

This review of the literature suggests that today's fathers have a multitude of challenges that can constrain their involvement with their premature or sick infants. Father involvement is essential for the infant's developmental outcomes. Since, it is not fully understood how fathers assimilate to their experiences in the NICU, conducting more in-depth research can increase the quality of father-infant involvement and attachment, leading to improved development outcomes of the premature or unhealthy infant. To a certain extent, the quality of the father-infant dyad can diminish the impact of premature or sick infant's medical risks cognitively, socially and emotionally.

Premature infants who exhibit cognitive deficits and behavioral problems can cause physical, emotional, and financial burdens to their families. They may lack cognitive and social skills requiring additional educational and social services. These complications may add extra stress to an already burdened family. Identifying fathers' experiences in more profound and more intimate ways will help identify areas in the NICU journey that can be modified to enhance fathers' parenting skills. Barriers, coupled with the stressors of prematurity or unhealthy neonate and the NICU experience, have not been thoroughly explored. The decreased age of survival and increased acuity of care for premature or ill infants have added to an emergent problem that requires immediate attention.



### **Chapter 3: Methodology and Methods**

The purpose of this chapter is to describe the methodology and methods used in this study. The study's philosophical foundations, purpose, design, operational definitions, setting, sample, data analysis and management, are presented. The research plan was designed to explore and provide new insights into fathers' experiences with their premature or unhealthy infants. A hermeneutical phenomenological design guided this study.

#### **Historical Development of Hermeneutic Phenomenology**

Hermeneutics was “derived from the Greek verb, *hermeneuin*, generally translated as “interpret” or “understand” (Crotty, 1989; Palmer, 1969). The phenomenological movement began in the 1800-1900's with continental philosophers like Franz Brentano, Carl Stumpf, Edmund Husserl, Martin Heidegger, Gabriel Marcel, Jean-Paul Sartre and Maurice Merleau-Ponty. For them, phenomenology meant the study of a phenomenon with the aim of highlighting features of that phenomenon, allowing it to “show itself” (Heidegger, 1995, p. 51). Showing itself occurs by being sensitive to language, its undertones, and allowing phenomena to speak for itself. The text is the tool used to expose and discover and permits one to see the more profound significance the phenomena have for others. With this deeper understanding, it allows the users to add to previous knowledge and raises new questions about the phenomenon of interest.

Users of phenomenology currently view it as either a disciplinary field of philosophy or a movement in the history of philosophy. As a discipline, phenomenology is the study of experience and personal consciousness (Stanford, 2013). It examines

phenomenon as they appear in human experience and the meanings they signify. It is holistic in that it seeks to study the whole person in the situation, rather than finding discrete variables. In the field of philosophy, phenomenology is related to ontology (the study of being or what is), epistemology (the study of knowledge), logic (the study of valid reasoning), and ethics (the study of right and wrong actions) (Stanford, 2013).

Phenomenology began in the first half of the 20<sup>th</sup> century with philosophers Edmund Husserl, Martin Heidegger, Maurice Merleau-Ponty, and Jean-Paul Sartre. Edmund Husserl introduced phenomenology at the beginning of the twentieth century establishing his phenomenological approach as a philosophy to challenge the Cartesian empirical and positivist perspective (Barnacle & Barnacle, 2001).

Husserl founded his perspective of phenomenology as a way of reaching true meaning by digging deeper into reality (Barnacle and Barnacle, 2001). He believed in the importance of discovering the truth by understanding the human lived experience and developed a methodology for social sciences that would clarify how objects are experienced and present themselves to the human consciousness (Spinelli, 2005). One critical aspect of Husserl's work was the identification of what he called the 'life-world' (Langdrige 2007; Smith et al. 2009). He postulated that learning about a phenomenon may be applied to a global view. Understanding the experiences of one member of a group often are understood as shared experiences of other groups. A critical part of the experience is the way that objects are presented or intended, as well as the way we see, conceive or think about those objects, and the meaning of the experience is core to what Husserl called noem.

Martin Heidegger (1889-1976) was a student of Husserl, who wanted to expand on Husserl's perspective of phenomenology. He embarked on his philosophical expansion which he called existential phenomenology (Spinelli, 2005) or hermeneutic phenomenology (Smith et al. 2009). Hermeneutic phenomenology is a philosophy based on the premise that interpretation is the means of understanding one's lived experience (Vandermause & Fleming, 2011).

Heidegger believed that hermeneutics could provide a framework for investigating the meaning of individuals' experiences within the context of their lives (Johnson, 2000). Focusing on the experiences of an individual or a group, reveals the world through a person's life story. "It is a research methodology aimed at producing textual descriptions of an experience or selected phenomena in the life world of individuals that can connect with the experience of all of us collectively" (Smith 1997, p. 80).

An intentional focus on experiences leads to a deeper understanding of the meaning of that experience and determining meaning occurs through reflecting on the use of language in an individuals' or group's told stories. Heidegger believed that humans are always engaged in the world, and as hermeneutic researchers, we are seeking the *as* of the human experience. The hermeneutic *as* is the interpretation or means to understand an expression or representation of the phenomenon under investigation. The *as* will come into its own through the spoken meanings of language. As phenomenological researchers we want to co-create the *as* of the phenomena between the participant and researcher, moving past the immediate response.

By co-creating, the *as*, the interviewer and participants will be the instruments used in the study. Heidegger (1927) stated in *Being and Time* that all activities are always in the world. Personal being is being-in-the-world, (Dreyfus, 1991) and by looking at the relationship things have in that world, one can interpret one's activities and the meaning these things have for them (Smith, 2016).

The study of phenomenology ranges from perception, thought, memory, imagination, emotion, and the desire of human awareness embodied action, and social activity, including language (Heidegger, 1995). Phenomenology is a scholarly approach that provides a research method that strives to interpret the meaning of experience (Diekelman & Magnussen, 2011; Ironside, 2006; Healy, 2011; Smythe, 2011). The structure of phenomenological forms is the directedness of experience towards things in the world (Stanford, 2013). The use of language and the interpretation of a person's meaning-making are central to Heideggerian phenomenology (Smith et al. 2009). Hermeneutic phenomenology does not require researchers to bracket their pre-assumptions or theories (Johnson, 2000; Lowes & Prowse, 2001), rather the researcher and research team consider the significance of the present world and its meaning (Merleau-Ponty, 1962; Richardson, Rogers, & McCarroll, 1998; Taylor, 1989). The team will acknowledge to the best of their ability any assumptions that could both influence the investigator's conduct of the interviews and observations.

Heidegger termed the word "Dasein" to describe the connection between the phenomena and interpretation. Dasein means that a person is unable to separate themselves from the world in which they live and the preconceptions they bring to everyday life (Heidegger, 1927). Key assumptions from Heidegger's work are that

background and the understanding of an experience are understood through language and that one's history and the world influences all knowledge (Lopez & Willis, 2006; Munhall, 2011; Vandermause & Fleming, 2011; Wertz et al., 2011).

Hans-Georg Gadamer (1900-2002) followed Husserl and Heidegger. Gadamer's goal was to expand on Heidegger's work and developed what is now called interpretative phenomenology. Gadamer postulated that language reveals *being* and understanding of all things can only happen through language (Rapport in Holloway, 2005).

Gadamer believed a person who is trying to understand a text is always projecting. He/she projects a meaning of the text as soon as some initial meaning emerges from the text. This Initial meaning emerges because he/she is reading the text with an expectation regarding a certain meaning. He believed that the goal of interpretative research is to find truth through searching for the understanding of experience in its context. Immersing ourselves in the phenomena, bringing our knowledge, and our past experiences to a situation, understanding can occur.

Gadamer (1976) further expanded on Heidegger's concept of time and being and developed what he called the *fusion of horizons* or the *zone of meaning in which a person operates* (Abbey, 2010). *Fusion of horizons* means that every transmission of meaning is the result of the interpreter's horizon transforming their view of the past from a passive object of investigation into multiple options for meaning (Gadamer, 1976). This fusion of the known interactions results in an understanding of time, situation, context, and language from the first-person point of view of the participant and the phenomenon under investigation (Vandermause, 2008).

Some modern philosophers believe that phenomenology is restricted to a person's senses, while other phenomenologists, such as Max van Manen believe our experiences are much more than our surface senses. van Manen developed a research approach that he referred to as hermeneutic phenomenology. It includes the meaning things have in our experience, the significance of objects, or events, the flow of time, the self and others, and all these things are experienced in our "life-world" (Stanford, 2013 p.2). He postulated that language reveals 'being' from a historical and cultural context and is understood by the participant and researcher through the language of the interview (Langdridge, 2007). Furthermore, he believed that as a researcher moves in the 'hermeneutic circle' he/she can establish the truth, discover and interpret the phenomenon (Langdridge, 2007)

As a discipline, the methods and results define phenomenology. It seeks the conscious experience from a first-person point of view and the meanings that it has for the person experiencing the phenomenon (Spinelli, 2005). Analysis of storied accounts furthers the interpretive expression of meaning. Experiences do not only include the passive experiences of vision and hearing but also the actual experiences which are unique to each person. This first-person experience "of being" is part of our nature and consciousness. During the experience "of being," we use language such as "I see/I think/I desire/I do" although often one is not capable of characterizing an experience, but gains familiarity with the experience by living through it and examination of lived experiences produces the interpretation rendered in results.

In summary, hermeneutics phenomenology is a qualitative research method grounded in Heideggerian and Gadamerian philosophies. The goal of hermeneutics is to

understand the lived experience of another, and the meaning derived from that experience. Critical to understanding the experience is language and being (Gadamer, 1976). In phenomenological research, the researcher seeks to understand human experience by exploring the lived experience of the *life world* of the participants.

Hermeneutics is a way of thinking about our being, can interpret human experience, and provides a means of questioning existing knowledge. The goal of hermeneutic interpretive phenomenology is to return as carefully as possible to the primordial experience, or '*being*' (Heidegger, 1995). Hermeneutic phenomenology sheds new light on a phenomenon through *contextualization* and *interpretation*. In this study, hermeneutic phenomenology informed by philosophies of Heidegger and Gadamer was used to examine the experiences of fathers with their premature or unhealthy infants.

### **Key Methodological Terminology**

Underpinnings of hermeneutics phenomenology, also known as philosophical hermeneutics (Deikelman & Ironside, 2011) include the concepts of time, language, dialogue, being and understanding. These concepts do not function in isolation but rather interact with each other in a state of constant change. More specifically the primary focus of Heidegger's philosophy is the concept of *Being* and *being*, where *Being* refers to how humans relate to or understand themselves in a situation, and where *being* refers to the components of life that remain unchanged from situation to situation (Heidegger, 1959/1971). *Being* and the *world* cannot be separated, and the experiences of *Being* and *experience* cannot exist without the other.

*Language* is the mode in which beings communicate meaning to one another. Language provides a framework for understanding *being* (Heidegger, 1959). In research, the interview process and language seek this knowledge. As the participant and researcher co-create the experience, language gives presence or voice to the speaker's own being. The listener, listening to the speech, listens for what he/she finds significant in any given situation (Heidegger, 1977, 2008). The back and forth of the interview process or hermeneutic circle generate the understanding of a specific event or experience.

In hermeneutics, understanding occurs through interpretation. Interpretation is a three-fold structure: (a) the fore-structure is the premise that all interpretations are based on familiarity with the phenomena (b) fore-sight is the interpretive lens that forms our perspective and understanding, and (c) fore-conception is the anticipated sense of expected interpretations (Ironsides & Diekelmann, 1998).

Key terms such as *Being*, *being*, *time*, *language*, and *understanding* are critical concepts in philosophical hermeneutics. These concepts guide and influence the entire research process, from the development of the plan of research, implementation, and interpretive analysis. In each step of the process, these concepts will be critical to understanding the meaning of a specific situation and experience.

Based on the assumption that understanding is deeply rooted in experience, hermeneutic phenomenology, or philosophical hermeneutics, was the guiding methodological approach used in this study. Hermeneutic phenomenology was chosen as the theoretical framework for my study as it fits with the aims to explore the lived experiences of fathers whose premature or ill neonate were hospitalized in the NICU. Heidegger's (1962) concern with *being in the world* offers guidance that fathers are



active participants *in the world of the NICU*, where they can create an understanding and meaning to their existence.

Using phenomenological data analysis described by Max van Manen (1990), a textual description of the phenomenon of fathering preterm or ill infants was generated. This knowledge occurred through increasingly more in-depth interpretation of the participants' language recorded in the narrative texts. The more in-depth interpretations enabled me to explore the participants' experience based on the text, myself and my co-analysts theoretical and personal knowledge (Ajjawi, 2007).

During the interview process, specific questions about fathers' NICU experience helped disclose the meaning of the phenomenon. Narrative accounts of an actual situation differ from questions about a person's opinion. The spoken word allows the participant to give considerable input into their experience and perceptions of the event (Benner, 1994). Storytelling is central to the understanding of shared knowledge and circumstances because the participant can tell their accounts of the experience. They can access their responses and generate a meaningful account of what they perceive as essential.

The transcripts are written interpretations of a lived experience 'giving voice' to the experience and focusing on peoples' perceptions of the world (Langdrige, 2007). Using this type of phenomenology, the researcher applies his/her skill of reading the transcripts to understand the personal accounts of the experience. Through subjective interpretation of the text, a better understanding of the experience can be understood (Baker et al., 1998).

Using this methodology, I sought to gain a more in-depth insight and understanding of fathering a premature or ill infant through fathers' told stories and the

analysis of the narrative text (Gadamer, 2004). Through interpretative phenomenology, fathers' stories and the richness of their experiences provided a more profound insight into fatherhood.

### **Situating the Researcher in the Research**

In hermeneutic phenomenology, preconceptions, presuppositions, and context all play a vital role in the interpretative process. In hermeneutic phenomenology, it is customary for researchers to identify and clarify their assumptions. Central to Heideggerian phenomenology, researchers are unable to eliminate their presumptions because they cannot extract themselves from being-in-the-world. Researchers must consider themselves inseparable from their assumptions and preconceptions, particularly about the phenomena under investigation (Lopez & Willis, 2006). The researcher must recognize the importance of experiences, where these fit into the process, and the contributions these can make. It is significant to be aware of one's biases so that the text may present itself in all its newness and can assert its own truth against one's own fore-meanings (Being and Time, 1982; p. 238). Central to hermeneutic phenomenology, the researcher first must conduct a self-awareness check, enabling them to understand their presumptions and their inability to eliminate them from the research process. The researcher must also consider how their assumptions may or may not influence the interview and interpretative process (Dowling, 2006; Lopez & Willis, 2006).

This study's assumptions were grounded in my three decades of clinical practice as a neonatal nurse who has cared for thousands of premature or ill infants, and their parents. My pre-assumptions were based on observations of fathers who visited their

NICU hospitalized premature or ill infants. These presumptions were: (1) fathers want to be present and more involved in the care of their premature infants, (2) due to their need to work, societal or self-imposed gender ideologies or expectations (breadwinner vs. primary caregiver) this may not be possible (3) neonatal nurses can positively impact a fathers' involvement and (4) fathers often see themselves more as a support person for the mother than as the primary caregiver. This perception again may be influenced by historical gender perceptions, as well as societal and neonatal nurses' gender identity expectations.

I explored different perspectives of fathers to understand their personal experiences better. I believed to do this well, I needed to form a relationship of familiarity between the fathers and myself to “understand what they are saying” (Creswell, 2007, p. 18). As I conducted my interviews, I assumed the fathers would speak freely with me. A comfortable interaction between them and me would provide a richer and more meaningful description of their experiences.

### **Operational Definitions**

The operational definitions used in this study include premature infant, father, involvement, experience, Neonatal Intensive Care Unit. For purposes of this study, the definitions are as follows:

Premature infant- A premature infant is an infant born before 37 weeks gestation (American Academy of Pediatrics, 2002).

Father- A father is a self-identified, gendered role who has begotten a premature or ill infant

Neonatal Intensive Care Unit- A neonatal intensive care unit (NICU) provides comprehensive care for infants including those born less than 37 weeks gestation, weighing less than 1500 grams, or born at all gestational ages and birth weights and with a critical illness -American Academy of Pediatrics (2002).

### **Setting/Sample**

Eleven fathers participated in the study. Fathers of varying ages and demographics were sought for interviews allowing for identification of commonalities or differences across texts. The aim of participant selection in hermeneutic phenomenological research is to select participants who have lived an experience that is the focus of the study, who were willing to share their experience, and who were diverse enough to enhance the possibilities of rich and unique stories of the particular experience (Polkinghorne, 1983; van Manen, 1997). The number of participants necessary for studies of this type varies depending on the extent the information they provide and the extent to which the data fully answered the research questions. The final size of the sample is considered adequate when the interpretations are visible and apparent, and when new informants revealed no new findings (Benner, 1994). The inclusion criteria were deliberately broad to capture as many fathers as possible to understand the experiences of fatherhood.

#### **Inclusion criteria included:**

- Fathers 18 years of age or older
- English speaking

- Any father whose infant has been discharged from a Level 3 or Level 4 neonatal intensive care unit (NICU) within the last five years
- Any father who visited their premature or ill infant at least once during the infant's hospitalization in the NICU
- Any father willing to be audio-recorded

**Exclusion criteria included:**

- Fathers less than 18 years of age
- Non-English speaking
- Fathers unwilling to be audio-recorded
- Fathers of infants born with an identified congenital anomaly
- Fathers of infants diagnosed with Grade III or Grade IV intraventricular hemorrhage

**Recruitment process**

Fathers were recruited from four university affiliated hospitals located in the Midwest during out-patient follow up clinic appointments and snowballing sampling. Participants included fathers of discharged premature or ill infants of varying ages, diagnosis and acuity levels. The study's aim, which was to better understand the phenomenon of fathering in the unique setting of the NICU was explained to each participating father. I explained that the interview process would last approximately 30 to 60 minutes, and I would be audio-recording the interviews, which would allow myself to pay full attention to fathers' stories and create a verbatim transcript. Confidentiality concerns were addressed by explaining all identifying information would be deleted.

The informed consent form was approved by the University of Missouri, St. Louis Office of Research Compliance, SSM Health Cardinal Glennon Research EBP Council and SSM IRB. If time allowed and the father agreed to participate, a face-to-face explanation of the study was conducted in a private exam room in the clinic area. If time did not allow for this, the father was given a flyer that stated the intent of the study. The flyer also provided background information regarding the primary researcher (PI), including a password secure phone number. The phone number allowed fathers to reach the (PI) for further information or to schedule a phone or web-based interview. A sample of the fathers' flyer is included in Appendix G. A sample of the recruitment script is included in Appendix F.

All potential participants were encouraged to ask questions and were made aware that participation was voluntary. When participants contacted me with their interest, I explained the interview process and confidentiality protections. Informed consent was obtained before the interview (Appendix D). A demographic survey was completed at the time of interview which included the fathers' age range at the time of the interview, racial ethnicity, their level of education and whether they are first-time dads. Demographic information was helpful when looking for commonalities or differences across text or narrative stories. See Appendices A and B. for demographic questionnaire and code sheet

### **Ethical Considerations**

Approval to conduct this study was obtained from the University of Missouri, St. Louis Office of Research Assurance, SSM Health Cardinal Glennon Research EBP

Council and SSM IRB. Informed consent was obtained before interviews were conducted. All transcripts were de-identified, and pseudo-names were used. (Appendix E and F) are included. All participants were told they had the right to withdraw from the study at any time and not to answer any question. Risks of participation in this study, including stressful issues, were explained to the participants although talking and reflecting upon their experiences, men may be able to make meaning of them, a sense of purpose, empowerment, and increased self-esteem. A copy of the informed consent is included in Appendix D.

Fathers were randomly assigned simple three to four letter male pseudo-names which were the only identifiers to appear on the transcript. A master list that linked the pseudo-names to the participant was available only to the PI. The master list was kept in a locked file cabinet and accessible only to PI. Folders were set up on a secure Google Drive and shared with experienced research transcriptionist. The transcriptionist transcribed the interviews verbatim, uploaded the transcripts to the appropriate secure Google folder, and then destroyed the audio recording. I retained the audio in case the audio was needed during data analysis and in case of an audit.

One year following completion of this study, the pseudo names and audio recordings will be destroyed. The transcripts will be kept for an indeterminate time for possible future research. The data for this study were kept confidential to the extent allowed by federal and state law. No published results will identify the father by name thereby decreasing the risk associated with the identification.

## Data Collection

I obtained informed consent before the telephone interview process began, according to university and federal requirements that protect the rights and dignity of human subjects.

Interviewing from a phenomenological perspective means the ability to shift modes of consciousness between the subject-subject relationship to the subject-phenomenon relationship. It seeks for a complete description of an experience through which a participant has lived. Following the principles of the hermeneutic interview process, there should be an exchange of information that is open to what a participant provides.

An open interview guide was used to direct the interviews. The use of an open interview guide helped focus the interview on the experience, while at the same time allowed for the natural progression of the conversation and the fusion of horizons. Field notes were also collected to provide an additional source of data for analysis (Hamersly & Atkins, 2007).

The fusion of horizons is heavily influenced by a person's culture, which may also include gender. Interviewing and using interpretative analysis of the narrative texts brought to light the relationship or essence of the phenomena of fatherhood and fathering. For a fusion of horizons between a researcher and participant to happen requires careful questioning, observation, and listening (Stanford, 2013). It allows participants the flexibility to narrate their experiences without being tied down to specific answers (Vandermause & Fleming, 2011). Field notes were also analyzed, which explained events that were observed, such as vocal tones and physical gestures that were discerned



from the audio-recordings. The intricacies of field notes added to the understanding of the phenomena under investigation (Crist & Tanner, 2003).

Demographic questionnaires provided descriptive information and were collected at the time of interview. The data gleaned from these questionnaires included education, fathers' age range at the time of the interview, if they are first-time dads. This information was helpful when looking for commonalities or differences across narrative texts. See Appendix A and B for demographics and code sheet

### **Interviews**

When conducting philosophical hermeneutic interviews, researchers are not bound to the traditional definition of time known as *kronos*, which measures time in hours or minutes. According to phenomenology, time is based on *Kairos* time, which means it measures time, not in seconds but in moments. *Kairos* time refers to the right moment or the salient experience of living within time. The impact of the experience will dictate participants memories (Haney & Kline, 2010). What stands out to a participant is often a meaningful event, regardless of whether the facts of the story change over time (Vandermause & Fleming, 2011). There is no right time from which to gain the perfect perspective. Even years later the story will still be the same (Smythe, 2011).

Participants were initially prompted to speak broadly about parenting before progressing to a more specific discussion of fatherhood, and fatherhood of a premature or ill infant. Beginning broadly eased the transition into more personal and sensitive areas. This allowed for observation of any contrast between broader perceptions of parenting, fatherhood and specifically fatherhood of a premature or ill infant.

The interviews consisted of 'hermeneutical questions', meaning that the questions asked steered away from emotions and feelings but encouraged participants to share their experiences. Conducting interviews over the phone with people who are strangers can lead to interviews that are rich in data. Being able to interview over the phone also meant fathers could participate at a convenient time and could speak about traumatic events in a comfortable setting.

At the beginning of the telephone interview, each participant was informed of their rights verbally and by written consent. They again were told that the interviews would be audio-recorded. The interview began with broad opening remarks: *I am attempting to understand fathers' experiences with their premature or ill infants in the neonatal intensive care unit by listening to your stories. Our discussion will concentrate on these stories or experiences.* These opening questions were intended to elicit told stories of experiences with following questions furthering the discussions about their experiences.

During the interview process, participants were asked to describe in detail their experiences providing an in-depth description of how fathers were involved with their premature or ill infants and how the fathers perceived the experience. The answers to the research questions were dependent on the stories told by the fathers. Changes to the interviews and research questions occurred as needed, based on the experiences during the interview. The interview guide consisted of open-ended questions aimed at evoking participants' feelings and thoughts related to becoming a father of a premature or ill infant and the NICU experience. A copy of the interview guide is provided in Appendix C. (Interview Guide)

## Data analysis

Phenomenological analysis aims to explore in detail how participants make sense of their lived experiences or their essence. During data analysis the hermeneutic researcher seeks for a textual description of human actions, behaviors, intentions, and experiences of the *lifeworld* through a dialogue with the text (Crist & Tanner, 2003). These descriptions of the experience offer a deeper understanding of the phenomena.

I did not change fathers' words or slang terms to keep their experiences as authentic as possible. I did, however, delete repetitive phrases (like, you know, or huh) when they were repeated numerous times and did not strengthen the meaning of the narrative. Ellipsis points were used to condense lengthy excerpts if they did not change the meaning of the fathers' experience. Throughout the interview process, vocal intonations, physical expressions, and gestures were included in field notes. Field notes were recorded and added to the end of the corresponding transcript, for later incorporation into the transcribed narrative texts.

Hermeneutic principles for research (HPR) were used inductively from my previous life, clinical practice and research experience. These attributes were enhanced by a critical review of interpretive research and philosophical literature. Hermeneutical research demands pathways that value 'individual' experience and allow for interpretation in a reciprocal manner between the respective parties and the research. Revisions occurred concurrently within and throughout the study.

The interviews were transcribed verbatim and then compared with tapes for integrity. The analysis team and I reviewed the de-identified transcripts. The team consisted of me and experts or students in hermeneutic phenomenology and content area

experts of the phenomena under investigation. The text was analyzed, compared for similarities and differences to understand the content and the complexity of meanings rather than the frequency of the responses.

In hermeneutic phenomenology, analysis of the text involves scrutinizing for meanings of the experience by searching for themes, engaging with the data, and allowing the phenomenon itself to dictate how the data is analyzed. During data analysis, the researcher is attempting to make sense of the participant's experience (Aisbett, 2006). The researcher wants to adopt an "insider's" perspective while standing alongside participant. Observing the person from a different angle allows the researcher to see what it is like to be in his/her shoes or how he/she make sense of something (Smith et al., 2009, p. 36).

Pattern analysis involves searching for patterns across language and does not require adherence to a specific theory of language or framework which works well with a range of questions related to experiences or a specific phenomenon (Smith et al., 2009).

The process of pattern development was based on the texts which were used to explore the phenomenon of fathering or fatherhood. Each transcript was read multiple times with each reading having the potential to bring new insights, thereby bringing the unsaid into the open from the text (Smythe, 2011). We looked at the use of language, similarities across texts, as well as possible contradictions in what a father was saying (Diekelmann & Ironside, 2011). Meaningful text segments were initially organized into different patterns and then merged to form constitutive pattern and sub-patterns that emphasized the principles in the text.

During data analysis, exemplars and paradigm cases emerged. Exemplars are salient excerpts or passages that are representative of stories or instances that have similar meanings within participants' stories. An exemplar captures the meaning of the situation so that the reader can see the meaningful connection (Crist and Tanner, 2003).

It is crucial from an interpretative approach to seek out modalities and fluctuations in any one person's way of thinking, which would reflect how people incorporate and respond to their unsettled sense of existence in the world. This ideology is consistent with Heidegger's thoughts about "Being" and "time" or "historicity" (discussed below). Interpretation of a paradigm shift reflects hermeneutic movement consistent with the "hermeneutic spiral" and the non-static nature of our existence in the world.

Recognition that paradoxes exist is integral in everyday existence and acknowledges that change is possible in and endemic to life. One's existence has elements of historicity (past, present, and future) which shape and inform our lives as we shape others'. This recognition moves us past the idea of life being concrete and static into a position where everyday interpretation merges with re-interpretation, where our life in the world is co-constructed with the lives of others and our knowledge of the world is not constructed in an individualistic fashion.

Paradigm cases were used as a strategy of recognition and as a presentation style (Benner, 1994). In this study no one paradigm case was found. Each interview contained aspects of the constitutive pattern. An exemplar is a case that demonstrates consistency in concerns, meanings, knowledge, and skills common to a participant's experience of the world. Through exemplars, a case can show up as an archetypical example of something.

The goal of exemplar development is to make qualitative distinctions having to do with intents and purposes where possible intention grows within practical experience, and where there is a recognition of alternative possibilities and a choice in action, of one of these (Benner, 1994; MacMurray, 1957). Written interpretations then show connections between the meanings found within and across stories (Diekelmann, 1993). However, this should not be viewed as a linear model, where one cannot proceed to the next phase without completing the previous step; instead, the analysis is a simultaneous, and interrelated process (Clark & Braun, 2013).

Second-order ideas were then generated using theoretical and personal knowledge. A secure Google Drive was created for each second-order pattern and excerpts from the transcripts were copied into corresponding files. Interpretations of these excerpts were then used to form an understanding of the phenomena under investigation. Each relevant construct was then used to answer the research questions.

I conducted the primary data analysis with consultation and guidance from dissertation chair, Roxanne Vandermause, an experienced hermeneutic researcher. The research team consisted of the dissertation committee, faculty members, and students of phenomenology. After the transcripts were transcribed, interpretative readings were completed to develop a familiarity focusing on finding common themes across texts to understand the world of fatherhood. Attention was not only given to what a participant said, but how they said it. Scrutinizing moods and emotion offered significant insight into the experience meanings.

Syntheses of the narratives were used to capture the nature of how participants experienced the phenomenon. During the interpretative process, patterns and themes

represented the understanding using verb forms (Altman, Kantrowitz-Gordon, Vandermause, 2014). This final section was concerned with moving from the final pattern to a write-up and final statement, outlining the meanings inherent in the participant's experience. This stage was concerned with translating the patterns into a narrative account. The patterns were the basis of the accounts of the participants' responses which took form from the narrative extractions of the transcripts to support the case. Care was taken to distinguish clearly between what the respondents said and the analysts' interpretation of the account. Patterns were structures of the experience which cannot be categorical statements because they are lived experiences that we are attempting to understand and interpret.

In summary, the steps in analyzing text include

1. Read the transcript carefully, start to finish
2. Re-read the text line by line
3. Make notes about concepts or situations that stand out
4. Review notes and observations, indicating the frequency of related ideas, position in the text, responses to interview questions, style of the replies, including field notes
5. Develop a beginning list of emerging patterns of ideas
6. Review transcripts again to refine patterns
7. Name patterns
8. Write a summary of the transcript with supporting textual exemplars (Vandermause, 2011)

## **Data Management**

A data management plan is an integral part of the research plan. The data plan was reviewed and expanded during the research, but the main principles and procedures were determined before the research started. Data management planning aims to ensure that sound scientific practice was followed in the research, that data were kept safe and secure at all stages, and data sharing was possible after the original research was completed. All transcripts were downloaded to a secure Google drive, accessible only to the professional transcriptionist and the PI. After verbatim transcription of the transcripts and the removal of all identifying information, the transcripts were uploaded to the secure Google drive accessible to me and the research team. We reviewed the text for areas of overlap. Pieces of the transcript were chosen as exemplars of the phenomena under investigation. Exemplars were used in more than one pattern when necessary.

## **Rigor**

A structured process for conducting phenomenological research as described by Pollio & Thomas (1997) helped ensure rigor. See Appendix F for recruitment script. All attempts at understanding in hermeneutic phenomenology starts with the researcher as an active participant and involves moving back and forth between self, data and the literature. (See Table 3).

Table 3.

*Practical Expression of Rigor*



Practical expression of rigor	Characteristics of rigor	Application in study
Balanced integration	Intertwining of philosophical concepts in methods and findings. Balance between the voices of participants and philosophical explanation	Philosophical framework described in methods and applied to findings. The researcher's voice, that of the participants and phenomenological exemplars give voice to the experience
Openness	Systematic process of accounting for decisions made throughout the study	Transparent audit trail of decision making in relation to design and evolution of the study
Concreteness	Usefulness for practice found in study	Implications for practice and study limitations discussed
Resonance	Effects of study findings on the reader	Findings from study will be disseminated after completion of the study
Actualization	Future research needed will be discussed	Implications for further research will be discussed

van Manen (1997) believed that orientation, strength, richness, and depth are the significant aspects of rigor in hermeneutic phenomenology. He felt that (1) orientation is the involvement of the researcher in the world of the participants and their stories, (2) strength refers to the extent the text represents the essence or meaning of the phenomena expressed by the participant through their stories, (3) richness is the quality of the text and how well it narrates the participant's meanings; and (4) depth is the ability of the researcher to explore more in-depth the meanings of participant's experiences.

Another essential aspect of rigor in hermeneutic phenomenological research is to pay close attention to rhetoric or the reporting style of the researched work. It is how the

spoken word is interpreted and written expertly. By continually cross-checking the researcher's interpretations with the original transcripts, faithfulness to the participant's constructs were maintained, thereby grounding the analysis in the data (Lincoln & Guba, 2000). Ensuring quality of any research requires the use of systematic methods of data collection, analysis, transparency in documenting these practices, and consistency in operating within the philosophical assumptions and traditions (Lincoln & Guba, 2000). The rapport between participants and me gave the participants the comfort and freedom to discuss their experiences, increasing the rigor and trustworthiness of the research findings.

There was a greater understanding of the phenomena and reduced bias in my interpretations of the data because of the use of multiple methods of data collection including interviews, field notes and demographics survey (Denzin & Lincoln, 2013). Fathers from diverse backgrounds who had infants of differing gestational ages and diagnoses were recruited, thereby offering different perspectives on the phenomena. The use of the verbatim transcripts and computer files helped to achieve reflexivity, rigor, and transparency of the research process, ensuring that the "voices" of the participants were "heard" enhancing its authenticity.

Guba and Lincoln (1981) used four tests of rigor, including (1) truth value which refers to how close the interpretations are to what the participants were trying to say; (2) applicability which is how useful the research is considered to be by the participants and the readers of the research; (3) consistency referring to equal treatment for all participants; and (4) neutrality which is ensured through external blind reading of the texts and the interpretations (Conroy, 2003). Immersion in the participant's world and

data provided added credibility, fittingness, and applicability. Rigor was preserved through the articulation of the lived experience of the participant and researcher, themes, paradigms, and exemplars (Conroy, 2003). The research team analyzed the transcripts independently and discussed the patterns until consensus was reached.

## Chapter IV: Results

This phenomenological study is based on Heideggerian hermeneutic traditions and interprets the lived experiences of 11 fathers whose premature or unhealthy neonates were admitted to an NICU. This study provided fathers an opportunity to share their experiences bringing to light a phenomenon that many times is misunderstood or goes unnoticed.

Father involvement and the positive correlation with child development have been studied for years starting in the 1980s with parenting experts such as Pruett (1987) and Lamb (1981). Studies continue today (e.g. Lucassen, van IJzendoorn, Tharner & Tiemeier, 2011; American Academy of Pediatrics, 2015; Martel, Milete, Bell, Tribble & Payot, 2016) indicating that the NICU experience is associated with long-term effects on parents' emotions and the infant's developmental outcomes. Findings from this study corroborate these findings and add to our understanding of gender specific challenges fathers face in the NICU and how these challenges can affect the father and family now and in the future. This research encourages new questions to be asked on how the NICU can affect the father-infant attachment process and families in the future.

Imagine you're a father visiting your infant for the first time in the NICU. You must relinquish many parts of your control, an aspect of your gender identity and life. You must stop at the front desk, asking permission to see your own infant. You are expected to scrub up to your elbows for two minutes, then are led back to a room that is so high tech it looks like the inside of a spaceship. You hear all kinds of information that you are supposed to understand and then explain to mom when you go back to the birthing hospital. A person you don't know hands you a visitor list and instructions on

how to log into the NICUview camera. When leaving, you leave your infant behind in that bed, with people you don't know, and who just told you more information than you could absorb. You now quickly come to the realization that you have no control over the situation or outcomes.

### **Participants**

This study included 11 Caucasian fathers with a mean age of 33 years and a range of 21 to 42 years. All who lived with their partners at the time of the interviews. Six of the 11 interviewees held college degrees, while two fathers had some high school and three fathers had some college credits. Fathers' occupations varied widely.

Characteristics of the infants born to these fathers ranged from 23 weeks gestation to full-term. Days spent in the NICU ranged from four days to 437 days and with infants of varying diagnoses. Two sets of twins were included in this cohort. (See Table 2) for detailed participant demographics. All identifying information was removed from this discussion; pseudonyms were used in the exemplars.

For some fathers, the journey of constructing fatherhood of a premature or unhealthy neonate includes stress and uncertainty that begins at birth. They are often faced with very difficult decisions including continuation of the infant's care and the associated possible adverse sequelae or withdrawal of medical support. The delivery can be the start of an unpredictable journey, very different than what they had envisioned and all that can have a significant effect on a fathers' being-in-the-world of fatherhood.

When the infants are transferred to the NICU fathers often visit for the first time alone or with a family member due to the mother's post-partum hospitalization. For example, Dave (pseudonym) described his experiences as follows:

I know like the first night there – or the night he was born – you know, it was an emergency C-section, so my wife was still at St. Joes (pseudonym) and so my dad and I went to – to see him. And I have no medical background, so it's all a shock to me completely.

And he's hooked up to all these things, you know, the ventilator and all these machines. And it was a complete, ah, shock to the system. 'Cause I'm already nervous about being a first-time dad, and then they're like, "Okay, well, with him here's all that's wrong. Here's all these machines and here's all this." They did a good job that first night of really trying to explain it as much as they could in layman's terms to me and my dad, but – and it's nothing on them, but no matter how much explaining they did, it was still like, oh, my God. You know, holy crap. (Dave)

Dave verbalized the shock that all participants expressed, and which is well supported in previous qualitative research. After multiple readings of the texts the following constitutive pattern were found.

### **Constitutive Pattern: Being Thrown into Groundlessness and Gaining Resoluteness**

The experiences of fathers in the NICU are complex and multifaceted. After many careful readings the following patterns emerged from the text. The overall constitutive pattern of *Being Thrown Into Groundlessness* and *Gaining Resoluteness* was found in this phenomenon. Within the constitutive pattern several overlapping dynamic experiences (patterns) were found. These included patterns: *Knowing/Not Knowing*, pattern: *Being Present/Being Absent* and pattern: *She And I Are Different*.

Heidegger used the word groundless to characterize the nature of Being and refers to Being that lies behind the scenes. Only through Being, which is a way of interacting

wholly in the world, do we experience meaning as humans (Heidegger, 1927, 1962). *Being Thrown Into Groundlessness* in this study relates to fathers' finding themselves jolted into a situation which they have no reference, having feelings of no support, their voice being unheard and finding themselves 'groundless'. Heidegger described resoluteness not as a complete answer to all the mysteries and unknowns in our Being but a willingness and openness to the unknown (Heidegger, 1927, 1969). For fathers *Gaining Resoluteness* in this study means fathers must acclimate themselves to the perceived hostile environment of the NICU and the premature or unhealthy birth itself and find a way in which "to be". Finding ways "to be" means finding a balance with *Knowing/Not Knowing, Being Present/Being Absent and She And I Are Different*. *Gaining Resoluteness* helps fathers begin to 'get their feet under them' enabling them to begin to construct their fathering role on more stable ground. *Gaining Resoluteness* allows fathers to be open to insights or ways to move forward in this groundless world.

In this study the constitutive pattern centered on *Being Thrown Into Groundlessness* and *Gaining Resoluteness* begins with the delivery and continues through the admittance to the NICU. Feelings of instability, fear, shock and uncertainty all can lead to feelings of *Groundlessness* or an unstable world. A fathers' 'Being' is now grounded in the new and unfamiliar realities in which they find themselves. This new and unfamiliar type of fatherhood has jolted them into uncertainty and a new gender identity. The following section describes the experiences these 11 fathers relayed. In this phenomenon there are three overlapping patterns that are described and exemplified throughout the text using fathers' own words and from the interpretative explication from the interpretative team.

In each pattern there will be parts of the constitutive pattern of *Groundlessness* and *Resoluteness* that affect the father and the family now and possibly in the future.

Pattern: *Knowing/Not Knowing*

What should be an exciting experience, that of becoming a father, has taken an unexpected turn with the premature or complicated birth. It is now an experience of uncertainty and fear. Their lives have been disrupted by crisis and trauma, they feel completely unstable and they are filled with uncertainty. For fathers to *Gain Resoluteness* a new way of being is required.

From the onset of the NICU journey, fathers find themselves in an environment that is perceived as hostile due to the terminology and equipment used and feelings of no control. The NICU is a place of uncertainty, a place where fathers don't speak or understand the medical language and see the medical equipment as foreign and feel afraid of this tiny person in that bed. They have lost control and now live in a world with rules and schedules that make little sense to them. Constant activity and heightened noises that they cannot interpret and someone they love is now going to live there. *Not Knowing* what's in store for their future and/or their infants manifested itself in experiences of uncertainty and fear. For many the *Not Knowing* world of the NICU begins at the door. The transition into the fathering role and building a healthy relationship with their infant now must be constructed in an unfamiliar, uncertain and often intimidating environment. The uncertainty of their infant's survival, conflicting masculine roles and being a 'vulnerable male' all can alter a father's perception and construction of their fathering role. This new world requires fathers to acclimate themselves to this hostile environment.



They must attempt to understand the realities of being a father whose child may not survive or who may have uncertain outcomes and potentials. The multiple aspects of uncertainty include the survival of their infant, immediate and long-term complications and their own uncertainty of who they are as a father or where they should be. Many times, the primary and lingering cause of uncertainty is *Knowing* that their premature or unhealthy neonate's condition could change at any time and they are unable to control or predict this or their infant's outcome.

Initially, a father's reaction to the premature or complicated birth and admittance to the NICU is that of shock. They are shocked for a variety of reasons including the delivery happened sooner than predicted, the baby is smaller than any they've ever seen, and their partner's health may be in jeopardy. They now find themselves thrown into an unfamiliar place, a place where they are forced to deal with unfamiliar people and their infants' uncertain outcome.

When fathers were asked about the birth of their infants, they described the experience and subsequent admission to the NICU as traumatic. Fathers experiences of *Not Knowing* were expressed in terms including uncertainty, the unknown, frustration and stressful, all of which had a significant effect on a father's world. This unstable ground can have a negative impact on paternal confidence and their perception about having control over the situation at any time. For example: Cody says

like the only thing I knew about NICU is like Nickelodeon and Zac confirms this with his statement ...it really is a different world. I didn't have any familiarity with the NICU at all actually and it opened my eyes

Cody and Zac saw the NICU as strange and frightening which were similar to those in other studies.

Most infants are born full-term and healthy. Hospitals and birthing centers now use family-centered care to include the family in the delivery and care of their infants, but the birth of a premature or unhealthy neonate can drastically alter this normal event. The anticipated and exciting event of becoming a father is now tumultuous and unstable. The premature or complicated birth and admittance to the NICU brings the father to a place of shock, *Not Knowing* and uncertainty. A place of unknown people, terminology, equipment and outcomes all make starting the fathering journey begin on *Groundlessness* and *Gaining Resoluteness* more difficult.

The first sight of their infant in that bed places fathers in a *Groundless* world full of uncertainty and unknowns. The sight of the size of their infant is only a symptom of the overwhelming vulnerability these dads experience due to uncertainty. The shock of the size of the infant has been echoed in previous research and my pilot study (Cummings, 207; Pohlman, 2009, 2005). This experience can lead to uneasiness for fathers because it's not 'normal'. The infant's appearance of looking 'helpless', 'vulnerable' and 'small' all can contribute to fathers' feelings of uncertainty. *Not Knowing* what would happen, whether your infant would live or die, or whether they will or have long-term complications can leave fathers searching for answers. This searching can leave fathers highly emotional when searching for answers.

I guess I had several emotions...I was – I was nervous, scared... it was mostly just not knowing was the worst part (Tom). Dave relates the first probably two months were pretty rough, you know, up and down. We didn't know if he was going to make it or not (Dave).

Tom and Dave both show that *Not Knowing* was a constant source of many emotions and feelings of uncertainty.

After the initial shock of seeing their premature or unhealthy infant fathers then experience *Not Knowing* the environment, language and machinery attached to their premature or ill infant as well as the medical diagnosis and possible short and long-term complications. Terms used by the staff daily such as bradycardia, endotracheal tube, and sepsis again puts fathers in a world of *Not Knowing*. John expressed this sentiment:

Not knowing what was wrong with my baby was one of the parts that was frustrating, it was frustrating not knowing what was wrong with him, that was the hardest part of being a father in the NICU (John)

Others have echoed this sentiment,

What's going around me? Like I could catch – if I saw people out there talking in the hallway. Immediately was like, alright, what are we talking about here? What's going on here? Are they talking about us? Is there something going on with us...Because I see the group huddle first before they would come into the room, and I'm like, alright, what plan are we making here, what are they not telling us? And I would pay attention to stuff like that. I didn't like the feeling I would get when I'd see that. But I know you guys gotta do it, but maybe don't do it in the hall right there, maybe if there is a place that it could be done. Because that – it was my thought that, alright...because obviously they can't tell us stuff, so they're thinking of a game plan about to approach us and tell us what they're going to tell us? (Tom)

*Knowing/Not Knowing* here is a desire to understand what's happening in this world of uncertainty, but also a desire not hear too many potential problems that may lie ahead. While some fathers want as much information as possible, others feel overwhelmed by the sheer volume of disconcerting details. When fathers are not given information about their infants or infants' care, they may feel excluded in their parenting role. One of the fathers even admitted later in the transcript to eavesdropping, in an

attempt to gain control. The above exemplar demonstrates the emotional ups and downs fathers experience and how they “hang on” to every word spoken by the staff. Fathers expressed a need for information and reported that timely provision allowed them to focus on their infant. Information or lack thereof, seemed to be related to how much control the fathers believed they had over the situation. Fathers of premature or unhealthy neonates can spend days to months in a highly technological environment where the infant’s medical condition and the ‘normal’ paternal role may be altered.

The preceding exemplars reveal how uncertainty and fear of the present and future cause fathers to start on ‘shaky’ or unstable ground, making the construction of their fathering role more difficult and influencing how fathers will parent in the future. These experiences and exemplars bring to the forefront the next hermeneutic question: How will the NICU experience shape a father’s sense of security in the future?

The uncertainty of the NICU experience results in various but common behaviors exemplified in this study. Specifically, fathers experience tension between the amount of time they can spend with their infants and providing for their family or Being Present/Being Absent.

### Pattern 2: *Being Present/Being Absent*

When fathers were asked what they believed their role was while in the NICU, the common response was “it’s very different than I expected”. The premature or complicated delivery has jolted fathers into the protector role that is bound to their hegemonic masculinity. The normal male protector role now starts in a world of uncertainty and little control. Previous research, including my pilot study (Cummings,

2017) has shown that fathers progress through a series of experiences during their infants' hospitalization. Initially fathers are concerned with the survival of their partner

...because it was tough because once we were up there in the NICU, you had to stand up a lot to be with Robbie (pseudonym). And so, we were – I was very concerned with – with her as well (Tom)

Likewise, Tim says, “just knowing how taxing it was on Lilly (pseudonym) was particularly tough on me” (Tim).

Once fathers have reassurance that their partner's health has improved, a father's protector role may turn to the protection of the infant. *Groundlessness* for fathers now is seen in their uncertainty of *Being Present/Being Absent*.

The one that really sticks out was the nurse that went to get him out of the incubator and hit his head on the incubator and played it off like nothing happened (Drew)

This was a salient moment in Drew's journey. He laughed about it at the time of the interview, but his outrage was heard and shows his struggle related to being able to care for and protect his child. The father's traditional gender role of the protector of his family places him in a struggle with where he should be, at work or in the NICU, with his wife or their child. Many fathers voiced their concerns with protecting and caring for their infant as well as having to provide for them. They felt they should fulfill both roles. Previous literature reports fathers have a strong attachment with their infant after discharge. Interestingly, these same fathers believe this attachment was due to *Being Present* during the hospitalization (McNeil, 2004; Moura & Ribeiro, 2016; Fontoura, Fontenele, Cardoso & Sherlock, 2016). Being a nurturing presence meant not fulfilling their masculine duty, their job as the traditional breadwinner. It placed them in conflict with what and where their gender identities and social expectations thought should do

and be. This altered start to fatherhood is important because the issue of father-infant attachment underpins the purpose of this study. In this study the role of ‘overseer’ or ‘protector’ seemed to apply to fathers’ partners and infants. Bill’s dual ‘overseer’ role is explained here:

I’d say the overall feeling I got was kind of a helpless, torn feeling. She, Kati (pseudonym) wasn’t in the same room as the baby, so – I didn’t know which way to go, if I should stay with her more... Yeah, I guess the overall feeling is just like a helpless feeling. When you’re with your baby, you feel like you should be with the mom. When you’re with mom, you feel like you should be with the baby (Bill). Zac adds to this when saying “It was just scary in the fact that, you know, I wasn’t sure if I was going to lose my wife and baby in the same day (Zac)

Many fathers react to the birth by moving towards a more traditional masculine parenting role of providing by returning to work. According to Pohlman’s research (2009, 2005) fathers at times return to work to fulfill their breadwinner role, while others return to work to gain control over some part of their lives. In this study paying the bills made fathers feel responsible for and in control of their family’s financial future. Interestingly, this also caused a paradox. As fathers returned to work and spent less time with their infants, they felt out of touch with all the issues going on with their infants and subsequently they felt they never quite became experts and/or primary caregivers. In short, returning to work caused a discourse between providing for the family and being actively involved. These conflicting priorities emphasize the unique gender role issues father face in the NICU. Several fathers reported going back to work, *Being Absent* or *Being Present* at the hospital created a push/pull paradox which added to their stress and feelings of *Not Knowing*. Dave felt this paradox:

I didn't feel as up on what was going on – the changes and what they were doing ... because of the medical bills I kinda was forced to go back to work a little early – earlier than I would've like to (Dave)

Tom even compared life in the NICU as a job. “I kind of look at it like my job is my job, whether that's literally my job or being there for the family as well” (Tom). For these dads having a job was synonymous with being a father and husband. These exemplars illustrate how these three concepts, provider, husband and father are inter-related and convey that a father's identity is very much about the provider role. These findings speak to how perceptions of fatherhood are linked and influenced by a man's view of the traditional gender role within the family. These conflicting roles create a tension for fathers as they try to navigate fathering, careers and gender identity demands. This push/pull paradox between the traditional gender identity of breadwinner and protector and *Being Present* at the hospital adds to a father's stress during the NICU experience. One father stated that he even thought his wife blamed him for going back to work. In addition to addressing issues related to the baby, and supporting their partner, fathers had to consider their occupational demands. Dave stated:

When I would get back there, she would be telling me all this stuff like that I was really behind on with his care...I felt like she was almost blaming me for being back at work and not knowing exactly what they were doing...every day that was probably the worst part was just like I felt behind, and she wanted me to be on the same page. And it was kind of hard because I'm not there all the time... I'd say sometimes we might argue just a little about like – when I would get back there, she would be telling me all this stuff like that I was really behind on – with his care. And I don't think she meant it that way, but I felt like she was blaming me for being back at work and not knowing exactly what they were doing with Timmy (pseudonym) every day. And we didn't get into shouting matches. It was just frustrating little arguments kind of things (Dave).

For Dave, gender identity explains his return to work, since returning to work is what is usual, perhaps safe.

Fathers many times attempt to model themselves as the supporter to their partners, which many times means staying strong and not showing their emotions, which highlight one of the male and female gender differences. Also due to the dual roles of *Being Present* vs. provider, some fathers struggle with *Not Being Present* and *Not Knowing* because of receiving information second-hand.

Cause it's nice to feel like you have some sort of control. So not being there and kind of getting things second-hand was a little tougher ... She knew I was there whenever she needed, but there – there was like a struggle there to, you know provide for the family, being at work as well as provide for the family being there in the moment (Tim)

For Tim, and corroborated by previous research (Fagan & Barnett, 2003; Schoppe-Sullivan et al., 2008) when fathers received information from his partner, they felt modifications in the information could not be avoided, since what their partner remembered or what they found important could be different than what they wanted to know. These exemplars echo the dual roles fathers feel they must fulfill, providing for the family's present and financial future or *Being Present* in the moment.

Further, when a father is seen as *Not Present* by the nursing staff, nurses may treat the father as a secondary parent and alter the way they communicated with them. When fathers are treated as equals to the mother and encouraged rather than **allowed** to care for their infants, the physical contact is valued and their *Knowing* and sense of control is enhanced. For Drew physical contact between himself and his infant helped relieve some of the *Not Knowing*.

Oh, yeah, very much so. Getting to hold him skin-to-skin helped



me a lot, you know, as well as it did him, it just comforted me and kind of helped me to know that everything was going to be alright. Getting to hold my son for the first time and just having him in my arms and close, ah, put a little comfort in me (Drew)

Physical contact for Drew shifted his fathering role from being one of a secondary parent to one of being a “father”. Drew like other participants craved *Knowing* how to be a father. He needed to *Be Present* in all ways. Holding his infant served as a significant moment in the development of the father-infant attachment process. After days of *Knowing* his infant in superficial ways such as the name they shared, the first moment of holding his infant solidified their attachment. The hermeneutic question here becomes: How will these NICU experiences shape fathers’ *Presence* or *Absence* in the future?

### Pattern 3: *She and I Are Different*

For many fathers, NICU rules, policies and biases make the NICU a place where being a father is difficult and at times what seems to be an unwelcoming place. A difficulty for many fathers in this study was the stereotypical gender roles of male (father) and female (mother) and *How She And I Are Different*. Fathers themselves along with historical, societal and NICU personnel biases placed them in a place where they needed to be acknowledged. Recognizing the difference between themselves and the mother was an important aspect for fathers. When fathers were not recognized as being an important person in the care of their infant, they felt more like a visitor rather than a father when in the NICU.

Being a dad...you’re just a visitor really...it is different being a mom than a dad in the NICU ... Recognizing a person is the father and recognizing him as the father ... Only to acknowledge that this is the father...show the father that he is welcome (John).

The above repetition seems like a cry to feel important. Later in the transcript, John confessed that because he felt unimportant, and not recognized as a father, he felt the need to repeatedly assert himself in an effort to establish his legitimacy. This *Not Knowing* me, and his needs was an unacknowledged suffering. Healthcare providers must understand that the male gender role generally consists of staying strong and in control amid crisis. For fathers in the NICU, their struggles are associated with emotions that are historically, socially and culturally bound. Fathers and mothers may share these challenges, but a father's gender identity challenges can present differently. Fathers recognize early that *She And I Are Different*. The hermeneutic question that arises here is: Do the different gender challenges fathers face in the NICU impact the father-infant attachment process in the immediate and distant future?

For fathers to *Gain Resoluteness* and find a comfortable place to father they must first begin to acclimate to their unexpected role, where their new abnormal has become normal. They must overcome their fears as well as come to the realization that the infant in that bed is theirs with all the uncertainties. Fathers must find a balance between their hegemonic masculine roles and their own personal needs.

The challenge of *Gaining Resoluteness* for fathers in the NICU is compounded by fathers' *Not Knowing, Being Present/Being Absent* and uncertainty. *The Not Knowing* and uncertainty relates to the infant's survival, health outcomes, and the *Not Knowing* the environment and not being acknowledged as 'the father' all can make a father question his role.

*Gaining Resoluteness* entails finding the meaning to fathering a premie or unhealthy neonate and assuming the role of fatherhood. *Gaining Resoluteness* for these

fathers required gaining control, protecting their infant and striving for a positive outcome. In short, through striving for a brighter future, being positive and *Gaining Resoluteness*, fathers were able to take control of their lives and identity.

Fathers search for *Resoluteness* through planning for a bright future, for themselves and their infant. Statements like “we want to go home” shows their drive for hope and a positive outcome. The search for a brighter future is a way for fathers to stay healthy during periods of crisis and trauma and a way to *Gain Resoluteness*. Joe and his wife lost a twin: their experience amplifies *Groundlessness and Resoluteness*,

No, I would say that everything else in our life was pretty stable. Um, and we knew – we knew with the twins, you know, that it was probably going to be a not smooth sailing. But, you know, certainly, we’d never – you never considered that – you know, what – what did end up happening. So – ‘cause we – we went through the, you know, IVF – you know, the fertility treatments for my wife, so um, you know, the twins were definitely not a natural thing. There’s no twins in our family. And it’s kind of – you know, not everybody is geared up to have twins, and I don’t think my wife was. So – but obviously, we didn’t get a choice in that matter. So, I think – I think we both knew it was probably going to be a rough road (Joe)

In these lines we can interpret in the back of Joe’s mind there is guilt associated with pursuing invitro fertilization. This pregnancy was “not a natural thing”. For this father the loss of control began with not having a “natural” conception. “I’m sad that I lost my son who, you know, at two pounds looked exactly like me. Um, you know, I still had this huge chance with my baby girl” (Jack) He further stated:

Another weird thing is when Kevin (pseudo name) passed away, like I was so um, because when he was in that incubator. Even though it was only for two days, at the same time, there was nothing I could do to help. And, you know, it was just watching this, you know – this piece of me just being in pain and suffering. and I just wanted it to be over (Jack)

In these exemplars even losing his son gave Jack *Resoluteness* through being able to take control of his son's pain. Although the decision to remove life support was extremely difficult Jack's "protector" gender identity as well as the general male identity of being in control was apparent. Everything that happened to his son mattered in the moment but could also affect the future. Helplessly watching his son suffer stimulated feelings of powerlessness as seen in this excerpt

"Yeah, it was tough to not feel like I had any control...feelings of helplessness" (Jack). Clearly for Jack and others, the NICU is a place that is controlled by the doctors and nurses. There are policies and procedures that belong only to the medical team. The unexpected and overwhelming environment and the feeling of no control over the situation or the infant's outcome jolts fathers out of their traditional masculine identity of being the protector, keeping their family safe and being confident in many situations.

Some fathers attempt to navigate their new normal by attempting to *know* more about the NICU, the technology and equipment. Becoming more knowledgeable means learning the new social and physical aspects of the NICU. Previous investigations have shown that fathers often focus on the monitors and other technologies to find out how their infant is doing at that moment. Improved health status was seen in weight gain decreased oxygen demands, increasing feeding. Tracking data of this kind gave fathers a concrete focus and provided a way of obtaining direct information about their infant. Clearly, fathers want empiric data rather than 'they look fine' or 'everything is ok' (Pohlman, 2009, 2005). A father's *Groundlessness* is amplified when he lacks tangible knowledge. For example, one father described asking a physician about his baby's fluid

retention. The physician's response was: "Oh, big babies are healthy babies". The lack of respect to the father's question led to loss of familiarity, security and caused further *Groundlessness*. When fathers on the other hand were given concrete information and involved in their infant's care, their infant's prognosis became clearer and they felt a greater sense of control.

Nurses and other healthcare professionals can significantly impact a fathers' experience in the NICU. Interpersonal relationships with the nursing staff and continuity of care were perceived as a reassurance and an aspect of control for fathers. The fathers in this study spoke of the NICU staff generally in positive terms. They felt a sense of reassurance and control when there was continuity of care.

Primary nurses had a better understanding of the situation. Like they could better relay the messages when there were times that we couldn't be there ourselves...

You get so tired going from work to the hospital – and I actually work an hour-and-a-half away from where the hospital is. Um, so, it definitely was wearing. We – we felt a lot better when her primary nurses were there with her when we were not at the hospital for the entire time (Zac)

Parents described distress over their infant's medical condition and were grateful when the doctors and nurses communicated clearly. Not surprising, when communication was clear and unhurried, fathers became more confident in their ability to care for their infant. Conversely, when answers to their questions were uncertain, lacked clarity, fathers felt vulnerable. They became worried and imagined the worst. Zac saw his child's primary nurses as individuals he could rely on.

Similar findings were reported by Turner et al., (2014) who found when fathers felt there was a lack of senior nurses or understaffing in general, their burden heightened.

Fathers in this study echoed that having continuity of care made them feel a bit more in control. This is likely due to powerlessness associated with entrusting the care of their vulnerable infant to strangers. Fathers already feel they must trust the care of their infant to people they don't know, and they must accept the expertise of others but trusting others can also bring uncertainty.

For Jack and many other fathers in this study the lack of control was a powerful issue. The lack of control often is intimidating and was interpreted as a failure. Jack's sentiment

It was, you know, frustrating at times. Um, but – but – I – I took away so much more positive experiences there than anything ... I know that there are challenges she faces now because of the, um –you know, both physically and developmentally. But that's just stuff that we are, you know, working through  
(Zac)

In this exemplar Zac projects himself and his infant into a positive outcome. The hermeneutic question becomes: Does projecting themselves and their infant into a positive future affect the father-infant attachment in the NICU and the future?

### **Summary**

Hermeneutic analysis of the 11 fathers in this study revealed a consistency of patterns that comprise the lived experiences of fathers in the NICU. The world of the NICU is one of uncertainty. *Knowing/Not Knowing*, *Being Present/Being Absent*, and *She And I Are Different* are all parts of the NICU journey. Positively navigating these aspects of *Groundlessness* and *Gaining Resoluteness* may have a positive impact on the father-infant attachment process and improve infant outcomes.

Within the patterns found in this study, three sub-patterns were found 1) *Knowing/Not Knowing* 2) *Being Present/Being Absent*, and 3) *She And I Are Different*.

The first sub-pattern (*Knowing/Not Knowing*) reflects a father's need for concrete information leading to decreased uncertainty and a feeling of control. 2) *Being Present/Being Absent* shows a father's frustration in the dual role (provider vs caretaker) he feels he must fulfill. 3) *She And I Are Different* brings to light the hegemonic gender differences and needs of fathers when compared to mothers. Fathers need to be acknowledged as 'the father' and as an equally important contributor to their infant's care, and their outcomes. These patterns and sub-patterns bring to light the challenges encountered by fathers during their infant's stay in the NICU and their journey to fatherhood. The exemplars throughout this study display the fear, uncertainty and conflicting gender roles fathers face when their babies are placed in a situation of crisis. The inability to be present, noninvolvement and feelings of powerlessness threaten aspects of fathers' masculinity adding to the sense of Groundless for a dad. Fathers' biggest need in this study was to be recognized as 'the father'. The aspects of masculinity, being present, protecting their partner and infant and *Gaining Resoluteness* are male characteristics nurses can foster. As fathers take on their new gender identity and role of a father of a premie or unhealthy neonate: How can healthcare providers foster fathers in establishing a healthy fathering role?

## Chapter V: Implications and Conclusion

The findings of this study offer insight into the experiences of fathers whose premature or unhealthy infants are admitted to an NICU. It was a privilege to have the opportunity to listen to these fathers' stories, stories that have the potential to benefit future fathers, and practicing and future nurses. This study yielded the interpretations of the lived experiences of *Groundlessness* for fathers in the NICU and their need to *Gain Resoluteness*. It affirms that fathers of premature or unhealthy neonates seek acknowledgement of their worth and parenting role which is vitally important to developing their ability to withstand the pervasive uncertainty of the NICU. The evidence found in this study expands on the limited amount of research that focuses solely on fathers and offers a starting point upon which to build an expanding body of knowledge advancing the state of the science of nursing.

The experience of *Groundlessness* and *Gaining Resoluteness* is a complex, multifaceted phenomena. The many aspects fathers must accomplish to go from *Groundlessness* to *Resoluteness* can be seen through subthemes *Knowing/Not Knowing*, *Being Present/Being Absent* and *She And I Are Different*, all suggesting a greater need for nurses to help fathers become more knowledgeable about their infants' condition and be more sensitive and supportive of their gender differences and needs.

Feeling powerless and not in control emerged as figural experiences in the NICU. Although some aspects of powerlessness are inevitable in preterm or complicated birth, much can be done to help fathers gain control. In this study fathers' powerlessness manifested itself as not being acknowledged as 'the father'. When fathers struggled with not being acknowledged fathers found it more difficult to find a comfortable place to



father. When a fathers' worth was acknowledged by nurses, the better father dealt with the uncertainties of the NICU and their new fathering role. Unfortunately, due to the infant's condition and the highly technological environment of the NICU, nurses' priorities center on the needs of the infant first. In addition, fathers are often seen as the secondary parent, leaving them feeling frustrated and at times unwelcome. In this study fathers' acknowledgement depended greatly on the nurse. Nurses were the primary source of positively or negatively influencing a fathers' ability to *Gaining Resoluteness*. Fathers wanted to be acknowledged and recognized for the multiple roles they felt they must fulfill. Since research suggests fathers' involvement positively affects an infant's outcome, it is no longer acceptable for fathers to be treated differently than mothers due to nursing staff gender biases. Rather the father-infant dyad should be supported, and fathers should be encouraged to find a comfortable place to father.

In the face of uncertainty, fathers attempt to *Gain Resoluteness* through projecting themselves and their infants into a positive future. This future can again be influenced positively or negatively by neonatal nurses. Even the smallest involvement helped fathers in this study find a comfortable place to father.

### **Implications for Education, Practice, Policy and Research**

The findings of this study are applicable to all nurses in the NICU whether at the bedside or in a management role. In order to ensure optimal paternal involvement nurses must seek to understand the NICU experience from a father's point of view. By understanding the factors that influence a father's decisions and actions, we as nurses can help identify paternal stressors in the NICU and provide needed support. Acknowledging

that fathers have gender related needs is a fundamental step in NICU father care. This statement is supported by Ringheim (2002) who stated that ‘providers who deal with male and female clients must be sensitive to their gender roles and how they factor into client-provider interaction’ (p. 174). When nurse providers interact with fathers, they need to meet fathers at their gender identity which many times is different than mothers. Healthcare providers, particularly nurses, must remain open to gender differences and not make blanket assumptions about what fathers should or should not do and where they should be. Father involvement has changed over the years, yet barriers remain including fathers’ uncertainties, fears, work and gender biases displayed by some nurses and hospital routines. I believe NICU primary nurses have the ability to foster confidence and fathers would gain confidence with primary nurses with whom they have built a rapport, making it easier to feel a sense of control and begin the journey to *Gaining Resoluteness*.

### **Nursing Education**

Nurses bring to practice their own communication skills. During their formal education and orientation to the workplace they receive limited training in interacting with patients and families. It is important that techniques of communication be brought to the fore. Many nursing students and new graduates believe the ‘skills’ of nursing are the most important parts of their profession at the expense of their communication skills. Nurses should be educated on the benefits of practicing family-centered care (FCC) because nurses who truly practice FCC recognize the importance of the father in their infant’s life and developmental outcomes. When nurses connect emotionally with fathers, they can help fathers find a comfortable place to father.

## **Nursing Practice**

Based on the importance of the father-infant attachment process, a fathers' involvement with their premature or unhealthy neonate is vital in neonatal care. Fathers should be recognized as equally important as the mother in the care of their premature or unhealthy neonate. It is important for healthcare providers to familiarize themselves with the unique challenges fathers face both inside and outside the NICU. The findings of this study have multiple implications for neonatal nursing practice.

1. First and foremost, the experiences shared by these fathers serve as a reminder to just how fragile fathers are while their infant is hospitalized in the NICU. They are sensitive to professional communication both verbal and non-verbal. Neonatal nurses need to care for fathers with the same tenderness and respect they give mother and infant. One-way nurses can accomplish this is to acknowledge fathers as 'the father' and welcome them. The perception of mothers being the primary caregiver has been historically and socially perpetuated for decades. Considering the evidence from this study and others, it is time that neonatal nurses commit to creating an environment in which fathers know and feel that they are critically important to the well-being of their infant. The climate of the NICU needs to change from fathers as visitors to fathers as a contributor. Fathers need to be seen and heard as a positive contributor to their infant's health. Using words like 'we' instead of "I" can communicate a shared responsibility and sends the message to fathers that they are equally important to their child's wellbeing and they are 'the father'

2. This study provides nursing with an additional framework in which to care for the NICU father. Individualized father care will enhance fathers' experiences of being known and heard thereby, potentially increasing paternal involvement. With improved paternal involvement a significant advancement in the father-infant attachment process may be made thus improving the growth and development of the infant.
3. Enhanced nursing communication and identification what gender identity the father is at will allow nurses to incorporate fathers' needs into the plan of care
4. Initiatives aimed at supporting fathers should be individualized with a father's gender identity in mind. Purposeful observations should be made to discern fathers' verbal and nonverbal cues on how fathers are adjusting to the NICU and their fathering role. Health care practitioners should provide information to fathers about their infant's medical status with sensitivity to the father's state of shock and uncertainty in mind.
5. Fathers' opportunity to be close to their infant facilitates attainment of the paternal role while in the NICU; because of this, fathers should be encouraged to care for their infants as soon as possible. When fathers can be close to their infants it facilitates attainment of the paternal role
6. For staff to better understand the effects of gender biases, nurses would benefit from training related to fathers' unique strengths and vulnerabilities. This may eradicate the assumption that a father's silence is due to either a lack of questions or lack of interest.

7. Nurses can strengthen the shaky ground fathers encounter in the NICU by welcoming and acknowledging them. Neonatal nurses need to remember parenthood in the NICU begins as a frightening and often pathologic journey, but our goal during and at discharge should be a well-functioning family

From a practice perspective, neonatal nurses need to reflect upon their own past experiences, beliefs and attitudes concerning fathers and fatherhood knowing that could affect their judgements about fathers and their involvement. This study makes clear that healthcare providers need to guide and intervene when necessary to help fathers gain a strong healthy relationship with their premature or unhealthy neonate.

### **Nursing Policy**

Nursing policies and procedures should be developed that are specifically aimed at facilitating and supporting paternal involvement. Programs that support fathering such as Fathers Support Groups need to be built on the reality that fathers are an important factor in their child's life. These programs must build on a father's strengths and acknowledging that fathers are different than mothers. Social policies need to be developed to include paternity leave for fathers, enabling them to be present and involved with their infants.

### **Future Research**

Although this study provided fathers a chance to tell their experiences, it would be beneficial to interview NICU nurses to obtain a comprehensive view of the interactions, beliefs and culture of the NICU. Also, future research should be aimed at ways to facilitate building a healthy father-infant attachment and how this affects the father-child

relationship after discharge. The stories told by these fathers clearly reflect the uniqueness of challenges faced by fathers in the NICU. Would these stories be different for adolescent fathers, fathers who may live in impoverished areas, or those of further diverse cultures and races?

### **Strengths and Limitations**

Previous studies have primarily focused on the experiences of mothers or mothers and fathers combined while this study focused exclusively on fathers. The strength of this study is that it is from direct contact with fathers who have experienced the phenomenon under investigation. This study reinforces the notion that there is much to be learned from listening to fathers' stories. The study had several strengths which enhance its value within the body of nursing research.

1. The study used a qualitative methodology whereby the participant is seen as the expert. Fathers described their in-depth experiences. The narratives produced the patterns found from the data.
2. The sample of fathers was diverse in age and their infants were of varied gestational maturity and length of stay in the NICU.
3. The time from discharge to interview ranged from four days to 14 months allowing fathers to have time to adjust to being at home and to reflect on what remained salient for them.
4. The strength of this study lies in its methodological foundation and the analytical team provided a consensus of results

There were limitations in this study, including:

1. The study was based on the nuclear family, a father, mother, and child/children which does not necessarily reflect today's complex family makeups and dynamics
2. Results of this study are based on the experience of 11 fathers. It does not include experiences of all fathers who may have experienced the unique phenomenon of prematurity. However, these common human experiences may be similar across populations of fathers of premature/ill infants
3. Fathers of premature infants with any severe perinatal injury were excluded from the study
4. I had limited association with some of the fathers due to working at one of the level four NICUs. Due to this limited association I journaled about my own experiences prior to the start of the study and continued reflexive journaling throughout the study. Being aware of my own preexisting ideas helped me separate them from the emerging findings, thereby avoiding undue influence on the study.

### **Conclusion**

This study corroborates findings of previous studies that fathers experience stress and uncertainty while in the NICU. It extends scholarly research on how fathers process NICU experiences and what is possible for them to be comfortable in uncertainty. Theoretical collaboration was consistent with Bowlby's Attachment Theory and Identity Theory. These theories manifested in the findings. This study also provided additional implications for nursing education, policy, practice and future research. The findings of this study yielded the interpretations of the lived

experiences of *Groundlessness* for fathers in the NICU and their need to *Gain Resoluteness*. The study provided affirmation that fathers of premature or unhealthy neonates seek acknowledgment that is vitally important to their ability to withstand the pervasive uncertainty of life in the NICU. With the limited amount of research based on fathers' experiences in the NICU, the evidence provided by this study offers a starting point upon to which to build an expanding body of knowledge and advance the state of the science of nursing.

In this study the constitutive pattern and sub patterns provide a glimpse of the real-world phenomenon of fathering a premature or unhealthy neonate and what it means to be such a father. Studying fathers exclusively provided insights into their experiences and will help nurses move away from the assumption that mothers are the primary caregiver and fathers are the supporter.

Fathers of premature or unhealthy neonates face unique challenges in the NICU. They experience feelings of *Groundlessness* while developing their fathering role. For fathers to *Gain Resoluteness* they need to find a comfortable place to father by overcoming or finding a balance between *Knowing/Not Knowing, Being Present/Being Absent and She And I Are Different*.

Fathers often desire to be active participants in the care of their infants and want to be seen and heard, acknowledged as equals to the mothers when caring for their infants. Often there is a disconnect between healthcare providers and fathers. The relationship between practitioners and fathers is centered around "doing" or "telling" them what to do rather than "asking" or considering a father's gender role, expertise and opinions. The goal of the NICU should be to foster a positive father-infant dyad



leading to positive infant developmental outcomes. This study provides new and deeper understanding of the needs of fathers of premature or ill neonates while their infant is hospitalized in an NICU.

Nurses in the NICU play a vital role in helping fathers come to terms with the birth of a premature or ill infant and find a comfortable place to father. Understanding the complex gender issues affecting fathers is an essential part of supporting them during the infant's stay in the NICU, as well as preparing them for the infant's discharge home. A thorough understanding of these issues is especially important when it comes to providing support to fathers whose infant may suffer delays. Recognition of the unique needs of fathers in these circumstances is crucial. To neglect the needs of fathers is to neglect the needs of the infant.

Little is known about the needs of fathers in the NICU. This is troublesome, since fathers react and cope differently than mothers to having an infant in the NICU and this may affect the father-infant attachment. We do know that fathers of premature neonate's experience feelings of stress, frustration, fear, uncertainty and the need to gain control. All these feelings can threaten a father's sense of masculinity.

A father's first impression of the NICU environment, whether hostile or friendly, can have a profound impact on a father's ability to successfully acclimate to the NICU. Successful navigation may be a first step in *Gaining Resoluteness*. Fathers need to be assured by the words, actions and attitudes of nurses that their *Presence* at the infant's bedside is every bit as important as the mother's. Encouraging hands-on interaction with the infant will further the goal of a positive father-infant attachment.

The aim of this study was to explore the lived experience of fathers of premature or ill infants in the Midwest within their real-life context, in order to discover what it means to be such a father. The study was ultimately successful in these goals, as it enabled the voices of 11 fathers of premature or ill infants to reveal the meaning of their experience. To neglect the needs of the father is to neglect the needs of the infant.

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Table 2. Sociodemographic and Personal Characteristics (n= 11)

<b>Father's Age Range</b>	<b>N (%)</b>
18-25	1 (9.09%)
26-35	6 (54.5%)
➤ 35	4 (36.3%)
Singleton Birth	9 (81.8%)
Twin Birth	2 (18.1%)
<b>Marital Status</b>	
Single but cohabiting	1 (9.09%)
Married	10(90.9%)
<b>Race</b>	
White	10 (90.9%)
Black	0 (0%)
Ethiopian	1 (9.09%)
<b>Educational Level</b>	
Some High school	0 (0%)
High school graduate	2 (18.1%)
Attended college	3 (27.27%)
College graduate	6 (54.5%)
Postgrad study	0 (0%)
<b>Employment Status</b>	
Full-time	11 ( _100%)
Part-time	0 (0%)
Unemployed	0 (0%)
<b>Birth Gestation of Infant</b>	

< 25 weeks	2 (18.18%)
26-32 weeks	3 (27.27%)
33-38 weeks	2 (18.18%)
>38 weeks	4 (36.36%)
<b>Duration in the NICU</b>	
1-4 weeks	6 (54.54%)
1-2 months	1 (9.09%)
>3 months	2 (18.18%)
➤ 1 year	2 (18.18%)
<b>Time from Discharge to Interview</b>	
1-3 months	7 (63.63%)
4-8 months	2 (18.18%)
9 months	1 (9.09%)
>1 year	1 (9.09%)

Demographic Questionnaire Appendix A

Fathers real name: \_\_\_\_\_ pseudo name: \_\_\_\_\_

Interview date: \_\_\_\_\_ Phone number: \_\_\_\_\_

Email: \_\_\_\_\_

Are or are not first-time dads Y N If not number of births \_\_\_\_\_

Education level: \_\_\_\_\_

Gest. Age of infant at birth: \_\_\_\_\_ (weeks + days if known at time of interview)

Birth weight: \_\_\_\_\_ DOB: \_\_\_\_\_

Weight at time of interview: \_\_\_\_\_

Infants age at time of interview: \_\_\_\_\_ Corrected gest. Age at time of interview:

\_\_\_\_\_

Number of days in NICU \_\_\_\_\_ Discharge date: \_\_\_\_\_

Detailed history of stay

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Any lasting effects of premature birth (Physical and Cognitive)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Father's age: \_\_\_\_\_

Employment: \_\_\_\_\_

Marital status: \_\_\_\_\_

Lives with mother: \_\_\_\_\_

Mother present during interview: \_\_\_\_\_

Hospital originally transferred from \_\_\_\_\_

Discharge diagnosis \_\_\_\_\_

## Appendix B Code Sheet

Participant number	Pseudo name	Age	Occupation	Ethnicity	Highest education level
Marital status	Were you present at time of birth? Y N	Number of births	Interview date	Infant's date of birth	Gest. age at time of birth
Current corrected gest. age	Infant's gender M F	Birth weight	Infant weight at time of interview	Was mom hospitalized prior to birth? Y N How long?	Did you have a pre-birth diagnosis? Y N Discharge diagnosis
Any additional information					

## Interview Guide Appendix C

I am doing this research study because I am interested in the experiences of fathers whose premature infants were hospitalized in a neonatal intensive care unit (NICU) so please describe in as much detail as possible. I will be audio-recording our conversations allowing me to pay attention to what you are saying.

### **Opening questions will include:**

1. Please tell me about a situation or experience that stands out for you about what it means to have an infant in the NICU or to have a premature infant?

### **Possible subsequent questions based on the responses:**

1. Can you tell me the story of your premature infant's birth?
2. What happened immediately after birth?
3. What was it like to be a father in the NICU?
4. Can you tell me about any support you received to help be an involved father in the NICU?
5. Who or what hindered this?
6. Do you have any advice for the nursing staff to help future fathers?
7. Do you have any advice for future fathers of preemies?
8. Do you have any suggestions for policy makers of NICUs to make it easier for father involvement?
9. Tell me about your overall thoughts about the NICU
10. Describe an experience of when the NICU nurses were helpful. How did they shape your role as a dad?
11. Describe what resources (such as support groups) were available to you in the NICU
12. During your baby's stay did you see anything in the NICU that made your involvement more inviting?

Some questions will be partial statements to provide encouragement for the participant to continue sharing their story such as:

1. Tell me more about that
2. What was that like for you?
3. What else was happening?
4. Anything more you remember...?
5. Was there anything else going on?

I want to thank you for taking your time to participate in this research study. Thank you again, Lisa



## IRB consent Appendix D

**Consent:** To be read to participants prior to phone, face-to-face or web cast interviews

### **What is the study about?**

This research study is being done to learn about the experiences of fathers of premature infants. You are being asked to take part because your infant was born prematurely and was hospitalized in a NICU.

### **What will I be asked to do if I am in this study?**

If you take part in the study, you will be asked to participate in either an audio recorded face-to-face, phone, or web-based interview where you will be asked to share your story about your experiences in the NICU and with your premature infant.

- You will be asked to participate in either in an audio recorded phone, face-to-face, or web-based interview
- Lisa will ask questions about what happened during your infant's hospitalization and what it was like for you
- The interview will last from 30 to 60 minutes, depending upon what you have to say. You are free to end the interview at any time
- You do not have to answer any questions that you do not want to answer
- An example of some of the questions that will be asked: Tell me what it was like to visit your baby for first time? What is it like to be a father of this tiny baby?
- Your voice will be recorded during the interview and this is required to participate in the study

### **Are there any benefits to me if I am in the study?**

There are no direct benefits to you from being in this study. Some fathers might enjoy or feel good about talking about their experiences and sharing their own challenges with others.

### **Are there any risks to me if I am in this study?**

**The potential risks from taking part in this study are:**

- Psychological or emotional discomfort may occur after talking about your thoughts and feelings surrounding your experience
- There is a risk that your confidentiality will be broken, although I will do everything in my power to keep your identity secure and confidential.

### **Will my information be kept private?**

The data for this study will be kept confidential to the extent allowed by federal and state law. No published results will identify you, and your name will not be associated with the findings. Under certain circumstances, information that identifies you may be released for internal and external reviews of the project. Reports of intentions to harm yourself or others must be reported by law.

- Each person that participates in the study will be given another name by the interviewer so that you can remain anonymous
- Any information with your name on it and your voice recording will be kept separately from the de-identified written form of the interview
- The interview will be transcribed by an experienced transcriptionist, who will take out the names and places or identifying information. Before each interview you will be asked for permission to record the interview
- The voice recordings will be kept on a password protected computer in the home of the primary investigator until the interview is transcribed and checked for accuracy by the PI.
- The de-identified transcribed interviews will be kept in a locked cabinet in the home of the primary investigator
- The following people will have access to the voice recordings and typed anonymous interview:

All researchers and research staff (Lisa Cummings, Roxanne Vandermause, and the transcriptionist). When we tell other people or write the research study's findings, I will not include your name. The voice recording for this study will be destroyed immediately after transcription is completed and verified. The anonymous paper copies will be kept indefinitely for further learning purposes.

### **Who can I talk to if I have questions?**

If you have any questions about the study or the information given to you about consent, please contact the researcher Lisa Cummings at (314) 591-4655 by email at

lacrk6@mail.umsl.edu or by regular mail: 609 Pinellas Drive St. Louis MO. 63126

### **What are my rights as a research study volunteer?**

Your participation in this research study is completely voluntary. You may choose not to be a part of this study. There will be no penalty to you if you choose not to take part.

You may choose not to answer specific questions or to stop participating at any time.

### **What does verbal consent mean?**

Your verbal consent means that:

- You understand the information given to you
- You will be able to ask the researcher questions and state any concerns
- The researcher has responded to your questions and concerns
- You believe you understand the research study and the potential benefits and risks that are involved

### **Statement of Consent**

I give my verbal voluntary consent to take part in this research study.

Name: \_\_\_\_\_

Date: \_\_\_\_\_



## Appendix F: Recruitment script

After introducing myself I will ask the fathers if I can have a moment of their time. *Can I discuss with you a research study opportunity? I am a PhD student at the University of Missouri, St. Louis and I am conducting my dissertation research on fathers' experiences in the neonatal intensive care unit (NICU) while their infant was hospitalized. I am interested in how fathers experience the NICU. I expect this information to be of great benefit to future fathers in the NICU. This study is under the direction of nursing faculty at the University of Missouri, St. Louis and in no way be connected to your infant's follow up care. The study will involve either a telephone, face-to-face or web-based interview which will last no longer than one hour. You can decide at any time not to participate and all information about you will be kept confidential. There are a few screening questions I must ask to determine your eligibility. If the father agrees to answer screening questions I will proceed with the following questions.*

Screening questions for eligibility for the study:

1. *Are you older than 18 years of age?*
2. *Was your baby born earlier than he/she should have been? If so, how long?*
3. *Does your baby have any medical problems you know about? (Infant should be free from serious congenital anomalies or Grade III or Grade IV IVH)*

If eligibility requirements are met, I will ask if: *they have time to complete the interview while there at their clinic appointment. If not, I will give them a flyer with my contact information to further discuss the study or to set up a mutually convenient time to answer any questions you may have or set up an interview time.*



Fathers Information Sheet Appendix G



## **CALLING ALL DADS of Premature Infants**

### **Research Study**

UMSL Institutional Review Boards have reviewed and approved for human subjects' participation

### **Volunteers needed**

For a study about fathers' experiences with their premature infants

### **Fathers**

What did it mean to you to have a premature infant or the meaning of being a father of a premature infant?

**Will you share your story?**

Confidential face-to-face, phone or web cast audio-recorded interviews with a PhD candidate.



## Phone Referral List Appendix H.

<b>Hotlines</b>	<b>Phone Numbers</b>
Life Crisis (Suicide 24 hr)	314-647-4357
Behavioral Health Response (24 hr)	314-469-6644
Kids Under Twenty-One (KUTO) (24 hr)	888-644-5886
Rape Hotline & St. Lois Regional Sexual Assault Center (24 hr)	314-531-7273
Child Abuse Hotline	800-392-3738
Domestic Violence and Rape Hotline	314-531-2003
RAINN (Rape, Abuse, Incest)	800-656-4673
Safe Connections (24 hr) (DV, Rape, Group Supports)	314-646-7500 ext 100
<b>Police and Criminal Justice</b>	
St. Louis Police-Sex Crimes/DART	314-444-5385
Missouri CVC	800-347-6881
St. Louis Sheriff's Office- Criminal Records	314-622-4766
<b>Services for Children</b>	
Child Support Unit	314-622-4021
Children's Advocacy Center- UMSL	314-516-6798
Children's Advocacy Center- W. Pine	314-535-3003
St. Louis Crisis Center-City	314-768-3201
St. Louis Crisis Center-St. Charles	636-947-0600
Family Resource Center	314-534-9350
Jewish Family and Children's Services	314-993-1000
Clayton Counseling Associates	314-781-9181
St. Louis Behavioral Medicine	314-534-0200
Psychology Dept@ Children's Hospital	314-454-6069
Community Alternatives	314-772-7449
<b>Family Counseling</b>	



Center for Counseling and Family Therapy @ SLU	314-977-2505
Family Resources Network	314-534-9350
Family Support Network	314-918-3362
<b>Domestic Violence Support</b>	
Legal Advocates for Abused Women	314-664-6699
Adult Abuse Office	314-622-4434
Legal Services/Lasting Solutions	314-534-4200
ALIVE- Alternatives for Living in Violent Environments	314-993-2777
Comtrea Community Treatment (Jefferson County)	636-931-2700
Fortress Outreach-Shelter (24 hr)	314-381-4422
Life Source Consultants-Ferguson	314-524-0686
Life Source Consultants-Lindell Blvd	314-534-2093
St. Martha's Hall	314-533-1313
The Woman's Center	636-946-6854
Womaen's Place	314-645-4848
Women's Safe House (24 hr)	314-772-4535
LEAD Institute	573-445-5005
Oasis Women's Center and Shelter-Alton IL	618-465-1978
Phoenix Crisis Center	618-451-1008
Weinman Center	314-423-1117
A Safe Place (24 hr Jefferson County)	877-266-8732
The Spot-Supporting Positive Opportunities with Teens (online listing of resources)	<a href="http://thespot.wustl.edu/st_area_resources_dome.html">http://thespot.wustl.edu/st_area_resources_dome.html</a>
RAVEN (Rape and Violence End Now)	314-289-8000
<b>Homicide</b>	
St. Louis PD-Homicide Detectives Unit	314-444-5371
Families Advocating Safe Screen	314-306-6809

MADD-Gateway Chapter	314-426-1595
Parents of Murdered Children	618-972-0429
<b>General Counseling</b>	
BJC Behavioral Health	314-729-4004
<i>Community Psychological Services-Umsl</i>	314-516-5824
St. Louis Behavioral Medicine Institute	314-534-0200
Provident Counseling	314-533-8200
SLU Psychological Services	314-977-4800
WashU Psychological Services	314-935-6555
<b>Psychiatry Clinics/ Services</b>	
Barnes-Jewish Behavioral Health	314-729-4004
SLU Psychiatric Clinic	314-977-4440
Catholic Counseling	314-544-3800
Hopewell Clinic	314-531-1770
Midwest Psychiatry	314-286-4545
Mental Health Association of Greater St. Louis	314-773-1399
Mercy (St. John's) Neuropsychology	314-251-4683
<b>Inpatient Programs</b>	
Hyland Psychiatric Center@ St. Anthony's (Adult and Children)	314-525-4400
St. Louis Psychiatric Rehabilitation Center	314-877-6500
Barnes-Jewis Psychiatric In-Patient	314-362-7777
Mercy (formerly St Johns) Intake	314-251-6565
St. Alexius Hospital	314-865-7000
DePaul Hospital	314-34-6700
St. Mary's Hospiatl	314-768-8000
Comprehensive Treatment Unit	314-344-7224
Hawthorne Children's Psychiatric Hospital	314-512-7800

<b>Info for Grandparents and Guardians</b>	
Ann Baue(family law attorney)	314-721-8844
Grandparents Raising Grandchildren	314-383-6539
Grandparents Support Group	314-872-3345

**ABBREVIATIONS Appendix I.**

NICU	Neonatal Intensive Care Unit
SGA	Small for gestational age
LBW	Low birth weight
VLBW	Very low birth weight
ELBW	Extremely low birth weight
IVH	Intraventricular hemorrhage
BPD	Bronchopulmonary dysplasia
ROP	Retinopathy of prematurity

**GLOSSARY Appendix J.**

Prematurity/Preterm	Less than 37 completed weeks of pregnancy
Term	Between 37-42 completed weeks of pregnancy
LBW	2500 grams or less at birth
VLBW	Less than 1500 grams at birth
ELBW	Less than 1000 grams at birth
Perinatal period	Period from 24 weeks of gestation (168 days) to 7 days of postnatal age, irrespective of birth weight and gestation at delivery
Neonatal period	First 28 days of life, irrespective of the gestation at delivery
Infant	A baby born from the moment of birth to his/her first birthday (365 days), irrespective of the gestation at birth
Neonatal mortality rate	Number of deaths occurring in the first 28 days of birth per expressed per live births
Infant mortality rate	Number of babies who die in the first year of life (0-365 days) expressed per 1000 live births
BPD	Respiratory sequelae in an infant requiring oxygen at more than 28 days after birth (Shennan, 1998)
IVH	Escape of blood from within the brain's ventricles. Four classifications: Grade 1 – isolated germinal matrix hemorrhage Grade 2 – rupture of the hemorrhage into the ventricle but without ventricular dilation Grade 3 - rupture of the hemorrhage into the ventricle with ventricular dilation

	Grade 4 – IVH with additional parenchymal hemorrhage
ROP	Changes in the developing retinal vasculature resulting in the development of new abnormal blood vessels, which may heal or progress to a chronic phase of scarring, retinal detachment and visual loss
Neonate	A newborn infant; especially an infant less than a month old