Parental perceptions of touch between parents and infants in the neonatal intensive care unit

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Parental perceptions of touch between parents and infants in the neonatal intensive unit

by

Crystal Whittington

A dissertation submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Major: Family and Consumer Sciences Education

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Ames, Iowa
2010
Dedication

To my parents . . .

I cannot begin to describe my gratitude for your support and love during these last few years. I could not have done this without each of you. Dad, your encouragement to reach for the stars and your example of striving to better yourself have been a catalyst in my motivation these last 11 years. And Mom, you have let me cry, let me sleep, cleaned my house and cooked us dinner countless days. You gave me the love and support I needed when I did not think I could make it another day. Both of you have shown me what true love is through your selfless giving all of my life. Without your sacrifices I could not be where I am today.

To my friends . . .

Thank you for your laughter and company along this journey. Who would have saved me from a room top, kept me from being without shelter, told me how to escape from a hotel fire, and comforted me when I missed my children? I am thankful for each of you and the closeness we share.

To my children . . .

I hope that you will understand the sacrifices we made to allow for my continued education. I hope you will believe in yourself enough to know that you can change the world and be anyone you want to be. The sky is the limit so dream big and reach for the stars. I will always be there to support you on your journey. I love you.
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CHAPTER 1. GENERAL INTRODUCTION

Problem Statement

This study addressed the role of touch in the parental experience of having an infant in the Neonatal Intensive Care Unit (NICU). Previous research has examined the physiological benefits of touch for infants. However, there is little research that has examined the parents’ perspective in touching their medically fragile preterm infant. With the compounding factors and environmental stressors surrounding the preterm birth, research has suggested that these parents and caregivers need additional support. Additional research is needed to further understand the parents’ desires, emotions, and needs in regards to touching their premature infants. Insight into this phenomenon will assist professionals in becoming more family-centered in their approach and ultimately improving health care.

By examining parents’ experiences of touching their neonatal infant, one is able to better understand the bonding process of parents with their infants in the NICU through the means of touch. Increased awareness of parents’ desires and needs will assist those in the health care field and the broad array of professionals serving families during their stay in the NICU. By understanding parent fears or stressors in the NICU one may be better able to facilitate attachment between parents and their hospitalized preterm infants. Increasing the understanding of this issue may lead to changes in hospital practice and policies.

As technology continues to evolve and families continue to change, there will be an ongoing need for increased family-centered care (FCC) that facilitates touch in the NICU. Although society has changed, parental desires in wanting to bond with their babies through the means of attachment touch appear to have remained consistent. Touch is a natural part of
the bonding process. Not only does it have health benefits for both parents and their infants, it increases attachment and parental efficacy. The professional pedagogy of the medical field must redefine itself as it assists these families in the NICU. As awareness of the benefits of touch continues to spread, more parents and infants will benefit. Providing these families with the support and instruction needed will continue to strengthen attachment through the means of touch, consequently improving the physical and mental health of both the parents and their child.

Definitions of Key Terms and Acronyms

*Arkansas Children’s Hospital (ACH)*: the only pediatric medical center in Arkansas and one of the largest in the United States serving kids from birth to age 21.

*Attachment*: the physiological process by which people form emotional bonds with significant others.

*Attachment touch*: purposeful touch performed by parents as a natural part of bonding.

*Bonding*: a relationship that usually begins at the time of birth between a parent and offspring and that establishes the basis for an ongoing mutual attachment.

*Family-centered care (FCC)*: all aspects of service delivery and resource provision determined by families’ needs and desires. Professionals are seen as the agents and instruments of families and intervene in ways that maximally promote family decision making, capabilities, and competencies.

*Health Insurance Portability and Accountability Act (HIPAA)*: a privacy law that ensures that sensitive personal health information can be shared for core health activities with safeguards in place to limit the inappropriate use and sharing of patient data.
Infant massage: a system of touching that includes containment holds, gentle touch, stroking, and caressing an infant.

Institutional Review Board (IRB): the regulating board at both the university and the hospital that monitors research.

Kangaroo care: a form of touch characterized by placing preterm infants skin-to-skin and chest-to-chest inside parents’ clothing.

Necessary touch: staff’s touch that is necessary for medical reasons; in this dissertation, also refers to routine procedures such as bathing and diaper changes that are not performed by parents.

NICU: neonatal intensive care unit.

Parental role acquisition: the increased feelings of control and comfort in taking on more routine care practices such as diapering and providing some basic medical care.

Still, gentle touch (SGT): touch that consists of the parent placing his or her hands on the infant and remaining still, otherwise known as containment hold.

Vagal tone: a cranial nerve controlling bodily functions.
CHAPTER 2: LITERATURE REVIEW

Introduction

This study addressed the perceptions of touch between parents and their infants in the NICU. This exploratory study allows researchers and practitioners to better understand the emotional responses parents have before, during, and following the first touch interactions with their premature baby. This dissertation was written in first person and includes personal anecdotes.

The Neonatal Intensive Care Unit

The dynamics of the NICU create a unique setting for the development of a healthy attachment between infants and their parents. These dynamics often include limited space for families in the NICU, no available housing for families who live a long distance from the NICU, comfort level of parents, and lack of support or FCC (Affonso et al., 1992; Holditch-Davis & Miles, 2000). Jamsa and Jamsa (1998) interviewed 11 parents of 7 infants who were in the NICU. These parents were asked about their experiences in the NICU. Parents reported appearance and equipment sounds in the NICU added stress to their experience and specifically described being frightened and intimidated by the sounds and sights of the NICU. As a result they felt less able to develop a relationship with their infant during their time in the NICU. Studies examining the perspectives of fathers revealed that the NICU environment itself, such as the incubator and surroundings, is a barrier to the bonding process (Lundqvist, Westas, & Hallstrom, 2007; Pohlman, 2009).

An infant’s hospitalization is a difficult transition time for families. Researchers have explored familial responses with premature infants since the 1960s (Kaplan & Mason, 1960).
McGettigan, Greenspan, Antunes, Greenspan, and Rubenstein (1994) found that many parents experience depression and distress during their NICU experience. Research has indicated that sources of stress for parents of a preterm baby include the difference in appearance of their baby, fear of the infant’s death, possible disabilities, sights and sounds of the NICU, alterations of their parenting role, and relationships with hospital staff (Affleck, Tennen, & Rowe, 1991; Holditch-Davis & Miles, 1997). Mothers of preterm infants have reported being depressed at the time of their child’s discharge from the hospital (Doering, Moser, & Dracup, 2000; Zanardo, Freato, & Zacchello, 2003), and Feldman, Eidelman, Sirota, and Weller (2002) suggested that parents and preterm infants engage in less responsive communication. This early emotional distance can lead to compounding difficulties for the family. Studies show that the quality of parent–child interactions during the first two years can predict the cognitive development of a premature infant at age two (Magill-Evans & Harrison, 1999).

Gaiter and Johnson (1983) conducted one of the earliest studies on fathers of preterm infants. They found that fathers who touched their infants during the first visit to the NICU were more likely to visit more often and fathers were more likely to visit than were mothers. Much of the foundational research describing the NICU and parent–infant touch was conducted between 1977 and 1995. Additional research is needed to further examine these dynamics in relation to emerging family dynamics.

Family-Centered Care

Part of the NICU experience is the aspect of FCC, which is based on, to varying degrees, each hospital’s policies and staff practices. FCC has changed how hospitals serve infants and families today. It is critical to understand FCC and the implications it has for
facilitating bonding between parents and their infants. FCC practices may utilize touch as a catalyst for facilitating bonding between parents and their preemies. FCC has been described by Dunst, Johanson, Trivette, and Hamby (1991) as when “families’ need and desires determine all aspects of service delivery and resource provision. Professionals are seen as the agents and instruments of families and intervene in ways that maximally promote family decision making, capabilities, and competencies” (p. 118). The American Academy of Pediatrics (AAP) defined FCC as the family being the infants’ primary source of strength and support (AAP, Committee on Hospital Care, 2003). FCC is a key component of developmental care as it supports parents and promotes their involvement and competence as the primary nurturers of their infants (Als & Gilkerson, 1997). Some practices of FCC include allowing families time for decision making, providing ample information that is easily understood rather than in medical jargon, and respecting families’ parenting styles and cultural behaviors. FCC also allows for flexibility in routines and procedures to accommodate the families’ needs. Studies have shown that supporting the infant–family relationship includes positive interactions with families, supporting families’ choices in participation, and respecting privacy during times with their infants (Klaus, Kennell, & Klaus, 1995; Lawhorn, 2002). When FCC practices are implemented, parents are not seen as outsiders but rather as members of the team (Griffin, 2006).

This paradigm shift toward FCC has presented an opportunity to increase the amount of loving touch by parents. In the 1960s parents were not allowed to participate in their infants’ care. During this time, parents were allowed only to view their preterm infants through glass. Parents slowly became involved in the care of their infants through the 1970s. It wasn’t until the 1980s that siblings were allowed to interact with this population
(O’Donnell, 1990). This history shows the evolution toward more family involvement in the NICU. It is generally agreed that the more families are involved in their neonates care, the more benefit is derived (Field, 1994).

Neonatologist Adik Levin has pioneered the Humane Neonatal Care Initiative to promote maximum contact between mothers and infants. These mothers assume primary responsibility for their infants’ necessary care, with nurses assuming a supportive role as a resource (Harrison & Klaus, 1994; Levin, 1994, 1999). This model has gained attention from other hospitals and exemplifies the movement toward more FCC.

Another facet of FCC is the willingness and support of the medical staff who are providing the care for these infants. As nurses provide much of the routine care for these medically fragile infants, the majority of touch stimuli originates from them. Raines (1998) interviewed 14 mothers of hospitalized infants in the NICU to explore preferences and values with the involvement in care of their infants. Mothers consistently voiced a desire to be involved in their infants’ care. Mothers indicated their participation was not encouraged by NICU staff. It appeared there was a disconnect between what mothers were wanting and what care practices nurses were providing for parents.

Lawhorns (1997) reported that families felt more comfortable being with their babies if they were acknowledged and respected as a collaborator in their children’s care (p. 56). Kenner and McGrath (2004) described this by saying, “This kind of caregiving includes acknowledging that parents and families are partners in caregiving and not ‘visitors to the NICU environment’” (p. 38)

Affleck et al. (1991) found that, among others, one of the sources of stress for these parents are the relationships the families have with the NICU staff. A number of studies have
suggested that parents often experience anxiety and depression following a high-risk birth (Blackburn & Lowen, 1986; Gennaro, 1986, 1988).

Miller and Holditch-Davis (1992) reported that parents provide more social touching than do the nurses. This indicates that parents still provide the majority of the attachment touch described previously. Yet, touch is still an obvious concern for parents and staff. Studies have shown that parent–staff communication can be a barrier in FCC, which could result in decreased touch interactions and in providing for felt needs of parents (Reid, Bramwell, Booth, & Weindling, 2007). As a result parents often feel uncomfortable asking for information from nurses (Kenner & McGrath, 2004; Raines, 1998). This decrease in communication could result in less FCC. Dan (in Kenner & McGrath), reported that a good nurse would:

> come up and tell you everything. . . . They saw you come in and, as soon as they got a chance, they would come over and fill you in on what’s going on with your baby, if anything changed. They’d ask you if you want to do this with her. A lot of times we didn’t know we could do that. So then we’d know we should’ve been doing that. (p. 368)

Although much of the research on FCC demonstrates positive outcomes, there are concerns from medical staff regarding its implementation. Possible reasons for this perspective include the nurses positioning themselves as experts who maintain control in the unfamiliar NICU setting (Fenwick, Barclay, & Schmied, 2001; Miles & Holditch-Davis, 1997). Barriers toward full implementation of FCC practices include confidentiality issues if parents are so involved that they gain information about other patients through rounds or other involvement (Grunwald, 1997) or the perceptions that it will take away time from
schedules that are already overfull (Griffin, Wishba, & Kavanaugh, 1998). Fenwick et al. (2001) found that some neonatal nurses are hesitant to release control over the infant’s care for fear that sharing the responsibility with parents could be harmful to the infant’s well being. Mason (2003) found major arguments against this level of family presence included the increase of malpractice suits; insufficient evidence that supports this change; disagreements between medical staff on these issues; family presence during invasive procedures increasing staff anxiety, which could have a negative effect on caregiving; and lack of knowledge about the psychosocial impact on the family observing these interactions. Although not all families desire this level of involvement, it should be their choice and to what extent they choose to participate (Mason).

Although many programs are gradually changing to FCC, there are still barriers prohibiting this change. Griffin (2003) noted that many institutional policies distance infants from their families. In one multisite study examining FCC in the NICU, it was found that, although units embraced support of visitation policies, there was a lack of education and performance. The unit’s culture still acted as a barrier to full implementation of FCC (Moore, Coker, DuBuisson, Swett, & Edwards, 2003). Barriers such as nursing staff’s personal value regarding FCC practices and environmental barriers in the NICU are two more examples (Hendricks-Munoz & Prendergast, 2007). Therefore, it is evident that there remains a need for increased FCC practice, rather than mere policies that may not be practiced. Some recent studies have begun to examine things such as communication practices between staff and parents (Reid et al., 2007), parental participation (Wigert, Hellstrom, & Berg, 2008), and environmental barriers (Hendricks-Munoz & Prendergast).
Medical Staff Considerations

As discussed, staff must be cognizant of their actions and their implications in relation to FCC. Demoralization of families and them losing confidence in their ability to parent occur easily if steps are not taken to facilitate FCC (Fenwick et al., 2001; Lawhorn, 2002). For example, I personally never massage an infant. I instruct and facilitate the parents in touching and massaging their child. When instructors massage the infant, they take the power away from parents. It is the parents’ right to provide that loving interaction. Likewise, when nurses engage in necessary touch and the parents are bystanders, the nurse is taking away that parental right to provide that touch interaction. The majority of touch contact is typically given by nurses, and research has suggested raising awareness of that for nurses to help parents bond with their babies (Casteel, 1990; Lundqvist et al., 2007; Pohlman & Beardslee, 1987). Nurses have an influential role in infants’ future development, as they are a catalyst in the bonding relationship between infants and their parents. They can provide excellent support by voicing concerns for families and validating parental dreams and hopes for each infant (Bondurant & Brinkman, 2003; Conz, Merighi, & de Jesus, 2009).

Inadequate social and emotional support by nurses can affect parental visitation and participation in the infant’s care (Gottfried, 1985; Lawhorn, 2002; Raines, 1998). Kenner and McGrath (2004) quoted one father describing his caregiver role:

[The baby’s mother] has changed his diapers a couple of times. It depends on the nurse, we don’t push, you know. I don’t like to get on the bad side of a nurse that’s watching my kid, and she’s the same way. . . . If they say “do you want to change his diaper?” she’ll change his diaper. (p. 367)
Parents report that “best nursing behaviors” facilitate the parental role, reinforcing the family as a whole (Harbaugh, Tomlinson, & Kirschbaum, 2004). Fenwick et al. (2001) interviewed 28 mothers and 20 nurses in a grounded theory study of women’s experiences of mothering in a NICU in Australia. Women indicated that they gained information about their infant primarily from the nurse, seeing the nurse–mother relationship as significantly influencing their experience as a mother. Nursing behaviors that were seen as facilitating the mothering role were consistent with FCC. These included actions that were nurturing and encouraged parental participation in their infants care. Results reinforced the belief that FCC principles increase positive parenting and minimize stress for parents of hospitalized infants.

Fathers have reported the importance of being supported by friends and family as well as staff (Lundqvist et al., 2001). Fidler (2002) found that fathers reported staff as being seen as parent-like, resulting in important milestones being lost (cutting the cord, holding the child right after birth). Cleveland (2008) reported that nursing behaviors identified to assist meeting parents needs include: (a) providing emotional support, (b) empowering parents, (c) providing a NICU environment that welcomes and supports parents, and (d) providing parents with education and guiding parents as they participate in their child’s care.

One phenomenological study of fathers’ experiences of caring for their babies in the NICU revealed that fathers felt loneliness, but saw staff as very busy and did not want to disturb them. They reported feeling like “spectators” in their child’s care. Communication appeared to be a powerful contributor to the parental experience. Fathers described one-way communication as staff transmitted information to them concerning treatment decisions, resulting in fathers feeling a lack of involvement. Feelings of inadequacy manifested as fathers perceived the staff as more competent in providing care than were they. Fathers
reported that, as their own feelings of importance developed, they became more involved in their infants’ care (Lundqvist et al., 2001).

Als and Gilkerson (1997) reported that there can be a separation between those who support developmental care and those who do not, which can result in the sabotage of FCC efforts. Change from staff as the authority to a more team effort, which includes parents, could cause uncomfortable feelings among staff—feelings of guilt over past caregiving styles and feelings of loss of roles that expert neonatal nurses previously held before parents become more empowered (Kenner & McGrath, 2004, p. 43).

Medical staff must also examine their own cultural beliefs and values related to touch. As previously mentioned, medical staff also contribute to the quality of care provided. Berlin, Johansson, and Tornkvist (2006) found a majority of the nurses experienced difficulties in their interactions with children and parents of foreign origin. Lynch and Hanson (1992) suggested that there be a close cultural fit between families and staff to facilitate interactions. However, if this is not possible they suggest that clinicians be knowledgeable about the families’ cultural values.

Medical staff who value the need parents have to provide touch and massage may advocate and allow for more touch than that which was done in the past. Nurses often have the power to decide if and when parents can hold or touch their neonate, therefore it is critical that they value this need. Apathy toward parents’ intense desire can result in a prolonged time of noncontact between the parent and child. Maroney (2004) quoted a mother of a preterm infant who said, “Imagine missing your baby’s first bath because the nurse couldn’t wait until you were there” (Michelle, cited in Maroney). Careful planning and scheduling between nurses and parents could increase opportunities for parental caregiving, which
includes touch (Raines, 1998). Early touch experiences should be encouraged by nursing staff to facilitate attachment behaviors and feelings in mothers (Tilokskulchai, Phatthanasiriwethin, Vichitsukon, & Serisathien, 2002). Karl, Beal, O’Hare, and Rissmiller (2006) suggested the nurses take an “attacher” approach, which facilitates bonding between the parents and the infant. They reported that nurses benefit from this practice as well by gaining a depth of gratification toward their work. Findings from the Fenwick et al. (2001) study revealed that nursing interactions that facilitated the mothering role included nurturing actions that helped mothers learn about their infants and encouraged participation in their infants care.

On the other hand, inhibiting nursing interactions was viewed as authoritarian and led to behaviors that were categorized as “struggling to mother.” Kenner and McGrath (2004) quoted one father’s experience of nurse coercion:

I was in there by myself. . . . They said, “do you want to hold him?” And I said, “Yes,” and they said, “Have you changed his diaper?” And I said, ”No,” and they said “Oh, if you don’t change the diaper, you can’t hold him. That’s a rule.” They all got a big kick out of that. (p. 368)

Although this quote appears to sound like nurses may have been kidding, this father perceived it negatively. Pohlman (2009) suggested that nurses may use coercion as a way to motivate parents, and closer examination may reveal dominance of the nursing staff over parents. Families must “obey” the rules established by nurses in order to interact with their child. Parents must also have the nurses’ help, so the dynamics keep the staff in control over the parents. One father recalled:
We didn’t feel as informed as we could have about our boundaries. I mean it was like our own child, but we didn’t know what we could do with her. It’s kind of a strange feeling where she’s yours, but you have to ask permission to do things. (Kenner & McGrath, 2004, p. 367)

These studies reinforce the importance of practicing FCC to promote positive parenting, which may minimize stress for parents of hospitalized infants. Nurses play a crucial role in facilitating bonding between parents and their infants. The relationship between parents and the medical staff are a critical component of the bonding process between these fragile infants and their parents.

Infants Born at Risk

Increases in medical technology over the past several decades have shifted health care goals and approaches to ensure optimal outcomes for premature infants. Low birth-weight infants, defined as weighing between 1,500 and 2,499 grams, have a survival rate that has increased from 91% in 1960 to 98% in 2000. Survival rates for very low birth-weight infants, defined as weighing between 1,000 and 1,499 grams, have risen from 45% in 1960 to 93% in 2000 (Driscoll, 2005). According to the March of Dimes (n.d.), in 2006, one in eight babies (12.8% of all live births) were born prematurely in the United States. The rate of premature births increased more than 16% between 1996 and 2006. The newest data released on births shows that of the 4.25 million births in 2008, the percentage of births born preterm slightly declined to 12.3%. Infants who were once thought to be too premature and fragile to live now have a greater chance of survival. As a result of this increase in survival rates, the medical community has redefined health goals and anticipated outcomes for premature infants. This shift has led to overall improvements in the health care provided to infants and families that
are more holistic in nature. In a recent study, Örtenstrand et al. (2010) examined the effect of parental presence in the NICU and its influence on infant outcomes. They found when parents spent increased time in the NICU their infant’s hospital stay was 5.3 days shorter.

The age of viability has decreased to 24 weeks gestation, with each additional week in utero increasing the odds of survival and decreasing the likelihood of long-term disability (Driscoll, 2005; Hack & Fanaroff, 2000). Research has confirmed the likelihood of disabilities depending on the severity of a child’s prematurity (Wood, Marlow, Costeloe, Gibson, & Wilkinson, 2000). Cognitive and neurological impairments have contributed to educational disadvantage (Hack & Fanaroff, 2000); cognitive and achievement differences (Saigal et al., 2003); and executive dysfunction, emotional, attention, and peer problems. There are also psychosocial and educational vulnerabilities that extend into adolescence (Grunau, Whitfield, & Fay, 2004). These are all concerns for the future of these infants. Closer examination is needed to understand early experiences and interactions that contribute to or lessen these consequences of prematurity.

Touch with premature infants is often limited for fear of over stimulation. Research has shown parents provide less touch to infants younger than 28 weeks gestation (Harrison & Woods, 1991). Premature infants do not have fully developed sensory systems that allow them to perform multiple functions at the same time. For instance, breathing patterns may get interrupted, their vital signs may change, or they may develop brain bleeds if they are over stimulated. Despite the fact that touch can be dangerous for very premature medically fragile infants, Symon and Cunnigham (1995) reported that preterm infants in the NICU may be handled 28 to 71 times, for a daily total of approximately 3.5 hours. Infants on ventilators receive the most handling. This is typically because they require so many medical
interventions with more invasive treatments, resulting in more touch interactions for care.

Findings from two studies that examined touch indicated infants received little or no comforting touching in the NICU (Blackburn & Barnard, 1985; Werner & Conway, 1990). It is important to note these are older studies, and, with the shift to FCC, there has been an increase in nurturing touch.

There have been some studies that reported negative immediate effects of massage. For instance, Adamson-Macedo and Hayes (1998) compared the physiologic and behavioral responses of extremely low birth-weight ventilated infants. Their examination of both moderate and deep pressure stroking reported that infants exhibited distress behaviors following deep pressure stroking. Considering these dynamics there is an obvious need for the increased use of comforting touch by parents that is appropriate for both the gestational age as well as the individual sensory threshold of the infant. Examining parental contributions to their infants’ recovery would be beneficial in finding a balance between appropriate comforting touches.

Research suggests that parents are an important part of an infant’s recovery and, yet, the dynamics of the NICU sometimes keep families away during this critical time. Studies have shown that premature birth and subsequent separation between mother and infant have negative effects on the mother–infant relationship (Dawson, Ashman, & Carver, 2000; Haut, Peddicord, & O’Brien, 1994). Yet, still 86% of NICUs in the United States practice a minimal touch policy that drastically limits touch (Field, Hernandez-Reif, Feijo, & Freedman, 2005). Additional research revealing the etiology for these policies is needed to determine if they are a result of attempting to protect the baby at all costs from stimulation, or if they could be modified to increase more developmentally appropriate touch experiences
for mothers. Recent studies have highlighted the benefits for early parental touch experiences with their babies in the NICU (Aagaard & Hall, 2008; Fenwick, Barclay, & Schmied, 2008). It appears touch can be a catalyst for increased positive outcomes for these infants despite all the obstacles they will face in their future.

Premature infants face many challenges including learning disabilities, poor academic skills, and potential emotional difficulties (Ohgi et al., 2002). Families are often not prepared to deal with a preterm birth, which may further complicate the adjustment process. There are significant consequences of prematurity for infants, which may also have a significant impact on parents and their family members. An infant’s unexpected admission to the NICU presents families with a situation they are seldom equipped to handle (Driscoll, 2005). As a result, parents may experience stress due to the alteration of the caregiving role, the differences in appearance of their infant than previously expected, fear of the infant’s death, anxiety of potential disabilities, the environment of the NICU, and the relationships parents have with the NICU staff (Catlett, Miles, & Holditch-Davis, 1994; Miles, Carter, Riddle, Hennessey, & Eberly, 1989; Miles & Holditch-Davis, 1997; Raeside, 1997). The situation may be further complicated depending upon available social supports; parental employment status and personal responsibility, health, finances, education level, socioeconomic level, housing, and financial stability (Driscoll, 2005).

Parent Perspectives on Preterm Infants

It is important to understand the dynamics and perspective of the parenting role in the NICU. The birth of a preterm infant may present families with unexpected stressors (Aagaard & Hall, 2008; Caplan, 1960). It is critical to understand what parents are experiencing and how they perceive the experience of parenting their preemie. Research suggests that an
infant’s admission to the NICU may hinder the interactions of parent and children (Beckwith, 1977; Cleveland, 2008). Holditch-Davis, Cox, Miles, and Belyea (2003) found mothers and premature babies interacted differently than did mothers and full-term infants. Mothers of chronically ill infants gave their babies more attention by gesturing and touching, looking and interacting, and spending more time than did mothers of full-term, healthy infants.

One of the earliest studies on parental stress related to parenting a premature infant was conducted by Kaplan and Mason (1960). They interviewed 60 families who had premature infants. Major themes revealed concerns for deformities, belief that the NICU was an emergent and dangerous place, and the weak appearance of their infant. Mothers also described anger resulting from separation from their infant and helplessness from a lack of involvement in care for the infant.

Studies have revealed that parents’ perceptions of what their unborn child will look like is nothing compared to the reality of their preterm infant’s appearance (Coster-Shulz & Mackey, 1998; Hynan, 1991; Martinelli, 2005). Maroney (2004) presented statements that emerged from mothers in an on-line discussion that represented the experiences of having a preterm infant. The discussion led to helping other professionals understand by providing analogies that began with the word “imagine.” Marguerite (in Maroney) stated:

Imagine the nurse pulls back Saran Wrap for you to touch him, and you just can’t bring yourself to do this; for your finger is longer and thicker than his arm, and his hand is only the size of your fingertip.

Typical parental adjustment to the preterm experience has been studied by multiple researchers as a triadic relationship between the infant and the two parents. Von Klitzing (2006) found the following aspects of parental capacities: the parental partnership dynamics,
the flexibility of parental representations concerning their child, the way in which parents internally conceptualize parent–child relations, the parental dialogue, and the continuity of their past experiences with their own family of origin. Today, there are multiple family compositions, and additional research is needed to assess the parental role acquisition in nontraditional familial dynamics.

Research literature has addressed general aspects of parents’ experiences when their child is in the NICU, but there is a need to look more at individual and family characteristics. Garfinkel, McLanahan, Tienda, and Brooks-Gunn (2001) examined what they termed “fragile families.” The impact of chronic stress has significant and long-lasting implications for both the parents and the child (Brooks-Gunn & Duncan, 1997). Miles and Holditch-Davis (1997) presented a framework for identifying factors of influence for parents with prematurely born infants. Summarizing two decades of research and using a qualitative study with 31 mothers, they suggested six overall concepts they based on the preterm parent distress model. The three factors that had a negative effect prior to the admission to the NICU included: pre-existing and current family factors; prenatal, labor, and delivery experiences; and the birth of a premature infant. Fragile family outcomes with potentially less than optimal outcomes identified during the NICU stay were the loss of the normal parental role; severity of illness, treatments, and appearance; and concerns for the infant’s outcome. By reducing the stress parents experience by assessing their known risk factors while their infants are in the NICU, the hospital community may support improvements in parent–child relationships. These may have a positive impact on the overall development of the child (Beckwith, 1977).
Bacon (2000) interviewed mothers of preterm infants and, using a grounded theory approach, discovered that mothers’ beliefs about what mothering a child would be like were very different from the actual lived experience. Caregiving tasks were perceived as more complex and demanding than anticipated. Competence was also a challenge for these mothers. Studies have revealed that mothers may feel exclusion and a sense of not belonging in the NICU, resulting in a negative effect on her feelings. However, if mother feels a sense of participation and continuous communication is available to meet each mother’s unique needs, then maternal feelings have a more positive effect. It was suggested that nurses work to decrease stress for mothers and increase their feelings of participation in the NICU (Wigert, Johansson, Berg, & Hellstrom, 2006).

Johnson (2008) reported that fathers are much more difficult to engage in caretaking roles in the NICU. Pohlman (2009) interviewed fathers in the NICU to explore their role and perceptions. The sample consisted of 8 fathers, between 22 and 40 years old, who had preterm infants between 25 and 32 weeks gestation. This was the first fathering experience for all but one of the participants. Interviews were conducted beginning within a month after the birth and continued after discharge for up to 3 to 4 months. Larry was a father who stayed with his 25-week-old every day. Larry described his feelings toward protecting Leah, his daughter, to whom he was already attached. He explained:

I don’t like not being around her. If it was up to me, I’d take her down here [in the residence] . . . ‘cause I don’t like her being up in the NICU around people that doesn’t care about her . . . it’s not their baby, so they don’t know how it feels to be close to her like I am. (Kenner & McGrath, 2004, p. 364)
His feelings reflect his need to protect his daughter from staff who he viewed as apathetic toward his daughter’s well-being. Larry was temporarily unemployed and was able to spend every day with Leah. This may have contributed to his strong emotional ties. Larry later described his second skin-to-skin holding experience:

The nurse . . . was all right, but she wasn’t too good about it. . . . She didn’t get the drape and put it around us and she just gave us the rocking chair and said “take off your shirt and sit down there.” We didn’t like it too much. The other nurse, she was really cool. (Kenner & McGrath, 2004, p. 368)

With this example provided by Larry, one sees how parental experiences and perceptions of nursing interactions can be positive or negative in relation to touch experiences. Parental perspectives on touch yield critical insight to the values, beliefs, and cultural backgrounds of families. Lappin (2005) argued that infant massage be taught in a social context as a social phenomenon. Most families desire to hold and touch their newborn, with each family valuing a different level of contact and interaction with their infant. Massage is a vital part of mothering in Far Eastern cultures as they routinely massage infants daily for their first months of life, a tradition passed down for generations (Field, 1994; Porter, 1996).

Gender can also play a role in perceptions of touch interactions. The majority of research in the NICU on parental perspectives has involved mainly mothers’ experiences. However, the experience of fathering an infant can be very different, and new studies are beginning to research fathering roles. Martinelli (2005) interviewed fathers of preterm infants and found that fathers reported the first time they held their infants was to lift their child so bedding could be changed underneath. They did not describe the first time of holding their
child as particularly meaningful. Themes emerged that many of the fathers did not engage in the stereotypical holding for up to 3 more months following birth. Sullivan (1999) examined attachment between fathers and their preterm infants and reported that fathers did not experience feelings of attachments with their babies until they were between 1 and 5 months of age. In addition, research suggests that fathers and mothers hold and touch their baby differently. Fathers tend to hold their infants “like a football,” which produces feelings of closeness unique to them (Anderson, 1996). It is my belief that although parents desire to bond with their babies through touch, environmental and emotional factors have an impact on their ability to bond in this way.

In Pohlman’s (2009) study on fathers, among other themes, fathers described touch experiences as a part of “getting to know” their infant in the NICU. Kyle (father of a 27-week-old) described being scared of holding his son:

I’m really excited about it, to tell you the truth, just being able to feel his skin up against mine and know that I created this. . . . But on the other hand, I’m scared because he’s still so small and I don’t want to do nothing wrong . . . I’ve never really had to deal with anything that small before. I’ve never changed a diaper before. I’ve never done any of that stuff before. . . . There’s a lot of things going through my mind and what if I do this wrong, what if I do that wrong. I guess I start questioning myself on those things, and maybe that’s why I haven’t held him yet. (Pohlman, 2009, p. 14)

He held his infant at 3 weeks of age, but was under pressure at the time from staff:

The nurse forced me into it to tell you the truth. I really wasn’t ready for it. . . . I was still pretty nervous as far as actually doing it. They told me I wasn’t leaving until it
happened so they got a gown and I ended up holding him. I held him for about an hour and a half . . . [pause]. I guess it was all that I expected. (Pohlman, 2009, p. 14)

The experiences from this father illuminate the impact that medical staff can have on families. It is difficult to understand the motivations of the nurses in this father’s quote. Additional research is needed to understand the nurses’ perspective in this dynamic process for parents. Each nurse involved during this time has the ability to facilitate the bonding process and efficacy of parents or to inhibit its development.

Recent studies on mothers reveal valuable insight into their experience of role changes during their NICU stay (Fenwick et al., 2008; Lupton & Fenwick, 2001). Aagaard and Hall (2008) reported that mothers described five separate metaphors for their journey. The first was described as “from their baby to my baby” revealing the progress from seeing the medical staff as parenting their child to eventually acquiring more control of their parental role. They reported “striving to be a real normal mother” and the influences of the environment as “foreground to background.” They described their role evolving from “silent vigilance to advocacy” and described their relationships with staff as changing from “continuously answering questions to sharing knowledge.”

A significant finding from Fenwick et al.’s (2008) study was the effects of interactions between nurses and mothers. This relationship had critical significance in how mothers perceived their connection to their infant as well as their increase in confidence for caring of their infant. They believe this dynamic evidences the intense work mothers do to establish control over the NICU parenting experience. Reports from mothers revealed that they strived to “re-establish some sense of competence in the eyes of the nurse and to achieve control over the situation” (Fenwick et al., p. 77). Mothers also linked their progress with
physical closeness to their infants as a way to gain knowledge and understanding. It gave them the opportunity to demonstrate ownership and authority in assuming the perceived parental role. This resulted in a parental perception of an increase in delivery of services to these families. When parents experience more control and support in the NICU environment they can better bond and acquire their role of parent to their infant.

Parent and Infant Bonding

Klaus and Kennell (1976) were pioneers in the research on bonding with newborns and parental preparation for typical childbirth. The Klaus and Kennell model of parental preparation and bonding included nine steps that began with the initial planning of the pregnancy and spanned to the postnatal caretaking role. The steps include: planning the pregnancy, confirming the pregnancy, accepting the pregnancy, feeling fetal movements, accepting the fetus as an individual, birth, hearing and seeing the baby, touching and holding the baby, and finally caretaking. Touching and holding the baby are one of the last steps in this process. Although much research has subsequently been done that builds upon this base, it stimulates much reflection on the bonding process.

Bonding was defined by Kennell and Klaus (1998) as “a unique relationship between two people that is specific for those two and endures through time” (p. 4). Both external and intrinsic factors play a role in the development of this bond between parents and their infants. The NICU creates a unique dynamic for the bonding process as the role of an additional caregiver, the nurse, can create potential barriers or be a facilitative mechanism for bonding. Haut et al. (1994) examined three distinct levels of bonding that can affect families in the NICU. The first level includes labor, delivery, and admission into the NICU. The bonding during this time can be lengthened based on labor and stabilization times. During this time
the family contemplates potential problems and may pull away. Their fear may be described as anxiety toward picturing the child as a real person for the current situation.

The second bonding stage includes the lengthy hospital stay. During this time, the initial touch and look by the parent leads to the beginning of the caregiving. Parents may feel more separated and distant from their infant than in the previous level. Bonding attempts at this level are often hindered by the length of time parents are separated from the infant, machines surrounding the infant, inconsistent progress, and the increasing demands of family and work. Parents have described feeling unable to parent as they would like and feeling inadequate compared to the care NICU staff are able to provide to the infant. Their inability to hold or provide comfort to their infant further complicates this process.

Finally, pending discharge propels families into the primary caregiver role, and a new threat arises that threatens the bonding process. The transition from hospital to home requires parents to learn difficult tasks of caring for their infant. They also must mentally and emotionally assume responsibility for decision making about their infant’s care. Haut et al.’s (1994) study highlighted the need for staff to support families in acquiring this new role of parenting, including parenting a hospitalized infant.

A parent and staff partnership supports both the infant and parental needs. This acute need for information and education further requires staff to be cognizant of family needs. Researchers have suggested that parents are informed consumers of professional services and often have strong treatment preferences (Hobbs & Sodomka, 2000). Woodwell (2002) suggested beginning this facilitative role in bonding with an assessment of where the parents stand in their understanding. Increased knowledge about their infant’s medical status and individual needs can empower parents to become partners with NICU staff. This knowledge
may decrease parental anxiety and increase their interactions and ability to provide care for their infant (Brazy, Anderson, Becker, & Becker, 2001).

Recent studies have begun to examine comparisons between mothers’ and fathers’ experiences of bonding in the NICU. Fegran, Helseth, and Fagermoen (2008) interviewed six mothers and six fathers at their baby’s discharge from the NICU and examined the experiences related to the first week of admission to the NICU. They found that two themes emerged for parents. The first theme was “taken by surprise,” in which mothers reported feelings of powerlessness in the surreal experience. Fathers reported the birth as a shock, but were able to become involved immediately. The second theme was the building of a relationship. Mothers reported the need to gain the temporarily lost relationship with their baby, whereas the fathers experienced a new relationship beginning with their baby. They concluded that parents should be encouraged to have early skin-to-skin contact with their premature infants early in the admission. Multiple studies reported attachment behaviors being linked to touch in the NICU (Livingston et al., 2009; Tilokskulchai et al., 2002).

Touch Defined

Harrison and Woods (1991) reported there are many types and amounts of touch provided by parents during NICU visits. Touch between parents and infants depends on many factors, some of which include the neonate’s gestational age, medical status, as well as parental anxiety, parental availability, and staff values. Some touch includes only tactile stimulation, kinesthetic stimulation, or vestibular stimulation. These may include gentle touch, swaddling, stroking/massage, and kangaroo care. Kangaroo care refers to laying the infant skin-to-skin on the parent. Fegran et al. (2008) reported that medical professionals should encourage early skin-to-skin contact between parents and their premature infants.
Limitations of studies on touch have largely been due to the different types of touch and the differing gestational ages, as each age allows for only certain levels of stimulation. The ambiguity of definitions has made it difficult to replicate studies and compare them. Precise definitions are critical to understanding the implications derived from studies. Adamson-Macedo and Attree (1994) suggested specific definitions for common terms. For example, stroking implies caressing the skin softly in one direction. Massage implies kneading and rubbing replies to applying friction. These authors recommended clearly articulating the type of tactile stimulation.

Still, Gentle Touch

Still, gentle touch (SGT) allows for assessment to see if the infant is ready for massage or other forms of kinesthetic touch. It is also most appropriate for extremely premature infants. The calming effects of swaddling and facilitated tucking, otherwise known as hand swaddling, have been recommended multiple times as a nonpharmacological option to assist with pain management in the NICU (Fearon, Kisilevsky, Haines, Muir, & Tranmer, 1997; Short, Brooks-Brunn, Reeves, Yeager Thorpe., 1996).

SGT consists of placing hands on an infant and remaining still. Some refer to this form of touch as a containment hold, which includes no stroking or other kinesthetic sensations. The earliest known study of this type of touch was based on a dissertation study by Jay (1982) in which he examined ventilated, preterm infants. These infants received SGT four times a day for 10 days beginning at 96 hours of age. There were few differences between the experimental group and the control group. However, the experimental group had higher hematocrits, received fewer blood transfusions, and required less oxygen.
In a small pilot study, Harrison, Groer, Modrcin-McCarthy, and Wilkinson (1992) randomly assigned three infants to either an experimental group or control group. The experimental group received SGT for 10 days beginning at 7 to 9 days of age. The experimental group had fewer days on oxygen, greater weight gain, decreased serum cortisol levels, fewer blood transfusions, and a shorter length of hospital stay. Limitations of this study were that despite random assignment, the experimental infants had higher birth weights and older gestational ages at birth. SGT is typically the first form of touch used in the NICU. It provides the least amount of stimuli.

*Infant Massage*

Infant massage can be defined as a system of touching that included containment holds, GTS, and caressing an infant. Ferber et al. (2005) researched the intervention of infant massage in the NICU. Instruction of infant massage typically includes learning basic infant cues, appropriate touch interactions, and understanding of basic child development in response to touch interactions. Ferber et al.'s study followed 51 mothers and infants who were divided into three groups using a random cluster design: a control group who received no massage, another who received massage from a female researcher, and a treatment group whose mother performed the massage. At 3 months, mothers and infants were videoed at home and behaviors were coded to reveal changes in these positive behaviors. Findings revealed that mothers who received instruction on and were able to perform infant massage were more appropriate in interactions with their infants and had more reciprocal behaviors, and infants were more socially involved than were those in the control groups at the same age.
Lappin (2005) conducted a case study of a mother being taught infant massage following a stay in the NICU and argued that infant massage can be a tool for facilitating attachment between parents and infants. Her study found that the mother reported infant massage gave her something to do other than the physically required interactions with her child such as diapering. The relationship between the mother and infant appeared more reciprocal and pleasurable with increased levels of attachment. Lappin concluded that NICUs need to encourage attachment by allowing parents to participate in their child’s care, including the facilitation of infant massage.

Field et al. (2005) surveyed U.S. neonatal intensive care nurseries to determine types of stimulation that mothers and babies experience during this critical period. This survey revealed that among others, common practices included skin-to-skin contact following birth in the delivery room (83%), rocking in the neonatal intensive care unit (85%), and kangaroo care (98%). Infant massage was found to be practiced in 38% of the 82 neonatal nurseries surveyed. Massage has historically not been practiced due to the perception of fragility in these neonates (Browne, 2000; Modcrin-McCarthy, Harris, & Marlar, 1997).

Kangaroo Care

Kangaroo care is another form of touch utilized in the NICU and is characterized by placing preterm infants skin-to-skin and chest-to-chest inside parents’ clothing. Kangaroo care originated in Bogota, Columbia in 1983 where preterm infants were dying from infections from the practice of sharing beds due to limited resources. Mothers were encouraged to hold their infants skin-to-skin until discharge to decrease the spread of infectious diseases. This practice decreased infant mortality, abandonment, incidence of apnea and bradycardia, and enhanced maternal lactation (Gale & VandenBerg, 1998).
Kangaroo care typically starts at 30 weeks gestation. Engler et al. (2002) found that over 82% of NICUs practice kangaroo care. In another survey of 90 U.S. hospitals, Field et al. (2001) found that 98% of NICU’s utilized skin-to-skin holding as an intervention. These studies highlight the wide acceptance and practice of kangaroo care. Chiu, Anderson, and Burkhammer (2005) found that the body temperature of full-born infants reached and maintained stable levels during skin-to-skin contact, suggesting that mothers possess the ability to regulate their newborn’s body temperature when given the opportunity. This practice is in contrast to typical policies of keeping infants in warming beds (Sheridan, 1999).

Preterm infants receiving kangaroo care have rapid maturation of vagal tone, exhibit longer periods of quiet sleep, alert wakefulness, and have shorter periods of active sleep (Feldman & Eidelman, 2003). These infants also exhibit less fussiness (Ellett, Bleah, & Parris, 2004). Chow et al. (2002) found mean temperatures were more stable, less weight loss, more optimal behavior states, and shorter length of hospitalization. Infants were also found to be more mature neurodevelopmentally and parents were more sensitive during later interactions (Feldman, Weller, Sirotा, & Eidelman, 2003; Ferber & Makhoul, 2004).

Attachment and bonding are often hypothesized to be promoted by kangaroo care (Kenner & McGrath, 2004). Feldman et al. (2002) examined kangaroo care and its effects on parent–infant interactions. Seventy-three infants selected based on similar criteria (birth weight, gestational age, medical severity, and demographics) received kangaroo care and were compared with 73 control infants receiving traditional care. Mothers and infants were observed at 37 weeks, prior to discharge, and at 3 and 6 months’ corrected age following discharge. Prior to discharge, kangaroo care mothers demonstrated more positive affect, touch, and responsiveness to infants. Their infants showed significantly more alertness and
less gaze aversion than did control infants. Kangaroo care mothers reported less depression and perceived infants as normal compared to control mothers. At 3 months, kangaroo care mothers appeared more sensitive to their infants’ needs and exhibited increased organization of the environment, and experiences were more optimal for kangaroo care infants than for controls. By 6 months, kangaroo care mothers were scored as more sensitive and adaptive to their infant’s needs and more affectionate toward their infant. Additional studies are needed to provide increased reliability of these findings, but implications are that kangaroo care promotes bonding between parent–infant interactions as well as the parenting role.

Benefits of Touch

As touch is the first sense to develop during gestation, it has critical importance. Skin is the largest sensory organ, having developed from the same embryonic tissue as the brain. Amazingly, embryos can sense touch to the lips or nose by just five and a half weeks post conception (Eliot, 1999). Touch begins early as the fetus receives a large amount of sensory stimulation prenatally (Muir, 2002). Following this intense sensory time, the preterm infant then lies in an isolette for fear of overstimulation. Plass (1994) reported that increased technology and more specialized personnel have taken over the caregiving role.

Attachment touch has emotional benefits. In my own pursuit of certification as an infant massage instructor, my trainer stressed the implications of touch between parents and infants in regards to attachment. She asserted that it was unethical to ever perform a massage on the infant as the instructor. The parent is always to be the one bonding with his or her baby. The effects of infant massage for both parents and infants have been shown in repeated studies. Cullen-Powell, Barlow, and Cushway (2005) found that when parents gave children with autism routine massages there was an enhanced emotional bond. These parents reported
feeling emotionally and physically closer to their children. The children also initiated 
massages at home. Using a grounded theory approach through semistructured interviews, 
Bacon (2000) found mothers of premature infants experienced more emotional impact from 
contact with the infant. First touch experiences between parents and their neonates have been 
reported by fathers as a feeling of realness in the existence of their baby, increasing their 
ability to care for their baby, as well as an expression of what they believe was best for their 
baby (Lundqvist et al., 2007).

Studies have shown touch as benefits for parents as well. Massaging their preterm 
infants improved mother–infant interactions at 3 months post-birth, and mothers reported a 
decrease in depressed mood (Goldstein-Ferber et al., 2005). Mothers’ mood and anxiety 
levels are reduced after massaging their preterm infants (Feijo et al., 2006). Similar results 
indicate that mothers who massage their preterm infants feel closer to their infants and less 
fearful of handling and touching them and have decreased guilty feelings about their infants’ 
preterm status (Feijo & Piccinini, 1998). Scholz and Samuels (1992) found that fathers who 
massaged and bathed their infants received more eye contact, smiles, vocalizing, reaching, 
and responses from their infants. These infants also showed less avoidance behavior.

Significant immediate and long-term health benefits have been described by 
researchers. Massage of preterm infants has resulted in greater weight gain, earlier hospital 
discharge, and greater gastric motility (Diego, Field, & Hernandez-Reif, 2005; Field, 
Hernandez-Reif, & Freedman, 2004). Massage of full-term infants has improved sleep and 
orientation as well as reducing excitability (Field, et al., 2004). According to Field (1999), 
studies conducted over the last two decades have revealed consistent weight gain for infants 
receiving premature infant massage. One meta-analysis has indicated daily weight gains of
up to 5 grams and reduced hospitalization by 5 days on average (Vickers, Ohlsson, Lacy, & Horsley, 2000). These infants had increased organization in sleep patterns, performed better on the Brazelton scale, and were discharged earlier from the hospital. Bones also appear to benefit from preemie massage. Moyer-Mileur, Brunstetter, McNaught, Gill, and Chan (2000) found that massage-like stimulation increased bone mineralization, bone length, and head circumference.

There are no known long-term negative effects of attachment touch. Longitudinal studies have indicated positive outcomes. Adamson-Macedo, Dattani, Wilson, & de Carvalho (1993) reported that a follow-up study of eight preterm infants who received stroking interventions in the NICU demonstrated positive long term effects. At 7 years of age, these eight children were compared with six controls. The children who received the stroking intervention had higher scores on mental, sequential, and simultaneous processing tests and general intelligence. Resistance to touch and infant massage has been related to cost of training for massage and other touch therapies; however, the benefits of massage are more cost-effective as a therapy to stabilize medically fragile preterm infants (Dieter, Field, Hernandez-Reif, Emory, & Redzepi, 2003). With such overwhelming positive effects, it is important that everyone involved understands what touch means for the preterm infant and his/her parents.

Summary

Current research does not sufficiently explore how parents view touch interactions with their preemies. This study was designed to gain a better understanding of what the emotional responses are of parents before, during, and following touching their infant. Research questions were designed to facilitate dialogue between me and the parents. It is the
intention of this study to better understand what role touch has in bonding from the parents’ perspective, what touch experiences are like emotionally for parents, and what the role of the nursing staff has in touch experiences. As the population of preterm infants has grown so rapidly over the last decades, research must address the concerns and needs of their parents. Hospitals can utilize this research to improve the services they provide to these families through increased emotional support and preparation. Overall FCC may improve as a result of the information that parents shared during this study. Facilitating touch interactions and a conducive environment for the acquisition of the parental role will enhance and increase attachment between parents and their baby.

The research questions that guided this study are: (a) How do parents feel about touching their infant? (b) How do parents feel during touch experiences? (c) How do parents feel after their touch experience? (d) Do parents feel more attached to their infants as a result of the touch? and (e) Did parents feel that staff supported the touch experience?

Nursing questions used to examine this phenomenon of touch interactions between preterm infants and their parents were: (a) What sort of touch interactions do you observe between parents and their babies in the NICU? (b) What is typically the comfort level of parents before and during early touch interactions? (c) What moods and experiences do parents typically have following a touch interaction with their infant? (d) Who usually initiates the touch interactions between parents and their babies? and (e) What are your feelings toward parents touching their babies?
CHAPTER 3: METHODOLOGY

Introduction

This study addressed the role of touch in the parental experience of having an infant in the NICU. A growing literature base has highlighted the development of the birthing couple and their neonate (Fegran et al., 2008; Gaiter & Johnson, 1983; Zanardo et al., 2003). Hospitals and NICUs have attempted to increase their practice of FCC, which has included more parental presence and support for families with preemies (Griffin, 2003; Moore et al., 2003; Reid et al., 2007; Solhaug, Bjork, & Sandtro, 2010). However, research from recent years has failed to give adequate insight into the experiences of parents touching their infant, specifically parents’ feelings of bonding through touch (Cleveland, 2008; Fegran et al., 2008). Through the use of a narrative qualitative methodology I was able to gain deeper insight into this phenomenon.

Researcher as an Instrument

Maxwell (2005, p. 38) described the researcher’s technical knowledge, background, and personal experience as a significant source of credibility for a proposal. Fisher and Reason (1988) discussed “critical subjectivity” referring to:

A quality of awareness in which we do not suppress our primary experience; nor do we allow ourselves to be swept away and overwhelmed by it; rather we raise it to consciousness and use it as part of the inquiry process. (p. 12)

Creswell (2005) suggested that the values, experiences, and priorities a researcher brings influences the study design.
I am the lens through which this study was conducted and reported, so my personal biases and experiences must be considered as a factor in this study. Two ways I planned to minimize my transfer of bias was to (a) remain open to alternative views from the parents by facilitating their responses and comfort level and (b) answering any questions parents had about my personal experience in the NICU. If parents asked, I told them that I also had a child in the NICU, but refrained from details of that hospitalization. My infant had been a patient at another hospital and had no connection with Arkansas Children’s Hospital (ACH), where I undertook this study. I have been professionally trained to keep personal details of my life separate from families in the hospital. If a parent had asked additional questions, I would have gladly and openly answered as I realize that is an important dynamic in qualitative research. However, I did not disclose any additional information as only one mother asked if I had ever had a baby in the NICU. The focus of this study was to explore parental feelings and experiences from their perspective, so I wanted to make an effort to keep the focus on them, avoiding my own perceptions and experiences. It is my hope that the readers will see how my personal beliefs, values, and opinions have shaped the interpretation of this data while, at the same time, not influencing its transparency.

Webb (1992) suggested using the first person pronoun “I” as a meaningful reflective methodological approach. Using this approach with qualitative research reveals researcher influence in the study and exercise choices, and aids in making decisions about the different directions the research will take. Implications of the conclusion may also be influenced as a result. I kept a field journal during the study to reveal and explore assumptions and compatibility concerns (Maxwell, 2005). As I later coded for themes, this journal helped me reflect on my understanding of sections of text where I journaled about specific body
language in reaction to a question or perhaps moments where participants cried or showed deep emotion. That helped me gain an increased understanding of their story.

The theoretical foundation that guided this study included Bronfrenbrenner’s Ecological Systems Theory, also called Human Ecology Theory. The families this study examined had a sudden change in their microsystem. Their immediate environment changed from home and family life to a NICU with new sights, sounds, and experiences. Other children are left at home and families often stay in or near the hospital to care for their preemie. There is no preparation or transition for this change. When examining the macrosystem, there is also a larger cultural context for which this phenomenon is occurring. Various cultures perhaps value different levels and type of touch interactions with their babies. The cultural implications for touch interactions could perhaps place pressure on parents to touch their very fragile baby when parents are not emotionally ready to take that step. Hospital protocols may also limit parents in their ability and desire to touch their babies as well. Some of the health issues facing these babies will result in life long health issues which also change the expectations and life plans for these families thus affecting their chronosystem.

A second theory that guided this study was the work from Erik Erickson and his theory on the psychosocial stages of development. The majority of the parents in this study appeared to be in the Intimacy vs. Isolation Stage. One mother, Yolanda, in this study was perhaps still in Identity vs. Role Confusion as she was only 18 years old and did not appear mature in her understanding. She also appeared to struggle with identity issues in her confusion of her personal life, and instability and transition prior to the birth of her babies. Perhaps the older set of parents, Michelle and Jim, may have been in the early stages of
Generativity vs. Self Absorption. Jim discussed his urgent return to work, perhaps also as a need for income. These parents appeared to have had a previous control over their life and appeared mature in their decisions and home life with stability. This stage is often characterized by “being in control” and the dynamics in the NICU can present a conflict to this paradigm.

In my effort to better understand the experiences of parents touching their babies in the NICU, it was crucial that I acknowledge personal biases and experiences that influenced my interpretation and data analysis of this study. The incorporation of knowledge and researcher identity has gained philosophical support in recent years (Denzin & Lincoln, 2000; Jansen & Peshkin, 1992 Maxwell, 2005). I work as a child life specialist (CLS) in the hospital where the interviews took place and have a background in working with families and infants where value is placed on FCC. I hold a certification as an infant massage instructor and value the importance of touch and massage as a means of bonding for both the infant and the parent. Although I am employed as a CLS in the hospital where the research took place, I did not work as the primary CLS in the NICU, so I had no prior interactions with the parents and I did not personally know any of the nurses.

_Myself, Mommy to Aidan and Eli_

I have a son, Aidan, who was a patient in a NICU shortly after his birth. Although my son was full term, he experienced complications caused by an aggressive form of jaundice. He spent 1 week in the NICU at a hospital in my hometown. Due to his condition, my touch interactions with my son were limited, as he could not be taken out of his isolette and removed from the phototherapy treatment. My own lived experience of having a little baby in an isolette with an IV, monitors, and limited touch interactions was a powerful
catalyst for this current study. I pumped breast milk in the lactation rooms and carried around coolers of milk in the hope that I would soon be able to nurse Aidan and would be prepared for him. I eagerly waited for permission from the nurses to be able to take him out and hold him for a maximum of 5 minutes a day for the week of his stay.

My husband and I had no communication with our son’s doctor and received limited support from nurses. I also remember the constant feeling of confusion in not knowing what was going on or what would happen next. It was a time of limbo for us. We balanced having our 3-year-old daughter, Mia, at home with family. We slept on waiting room floors so we could be near Aidan in the hospital. We live approximately 1 hour from the hospital where he was delivered. My mother brought our daughter to the hospital daily so I could see her as well. It was a time of great emotion and uncertainty. I so dearly missed Mia but felt the need to be near Aidan and provide for his needs. I wanted to be near him in case something “happened,” so I chose not to leave the hospital for the duration of this stay.

Although I did not experience any anticipatory grief in the form of his possible death, extreme procedures were presented by medical staff as possible treatments because he was not responding the way they had hoped to the phototherapy. It was an emotional and scary time when I felt distant from him due to all the variables surrounding his birth. We were uncertain for a few days what procedures would come next and how that would affect our son.

I feel it is also important to note that I had lost a child previous to the birth of Aidan. My lived grief experience was different than that of the families in this interview, but it must be disclosed in an effort to fully reveal potential researcher bias. My husband and I planned to adopt a little boy two and a half years before this study. His name was to be Eli. We had
grown to know and love his birth mother in our open adoption where we had met family and had regular meetings. All the preparations had been made for Eli’s birth by cesarean delivery, the nursery was ready, the overnight bags packed, and family had flown in for his birth. Two days before his arrival, the birth father arrived breaking the restraining order the mother had placed when he had tried to kill her once before. He also began to abuse the toddler of this mother who was living in her home. The state quickly took custody of her little boy, and she disappeared with the birth father. Both her family and the agency lost contact with her and we do not know whatever happened to her and the child we had already loved in our hearts.

Although this is a different experience than that of the parents in this interview, I am still emotional when I recall those 48 hours when we didn’t know what was happening with that precious little baby. I remember crying and waiting to pack up the nursery because my hope was that Eli’s birthmother would be okay and have had a healthy delivery despite the abuse and abduction. We hoped she would make the decision that was right for her and Eli at his delivery, and if that included us, I kept my heart and plans open in anticipation that there might still be “hope” for him—hope for a life free of the domestic abuse he was born into and full of the love I knew we had for him.

The loss of my expectations for Eli was overwhelming. I believe it is similar in many ways to those parents who lose a biological child. We had no control in the situation and stood quietly as bystanders. I realize it is also different because we do not know what happened to him, as opposed to the loss of a biological child. We still hope for him and remember him often, praying that he is healthy and happy. However, it is unlikely that there will ever be any end to his story for us. He will always be a memory for us without the closure of knowing his life story.
It was my intention that by sharing this, I have given the reader a better insight into how I perceived and connected to the emotions of the parents in these interviews. As I wrote this chapter I began to see similarities in my lived experiences to those of the families who participated in the study.

**Narrative Inquiry**

This study focused on the experiences of parents of premature infants. Parenting a medically fragile preemie is an emotional and highly stressful experience. To approach these parents with preconceived notions of their values and backgrounds would diminish their experiences in this research. Assumptions and biased interpretations of the data collected could alter the understanding of themes that emerge. “Assumptions structure all research, and the least we can do is to recognize this and theorize the impact of these assumptions” (Banister, Burman, Parker, Taylor, & Tindall, 1994, p. 50). Examining assumptions, limitations, and agendas help clarify the meaning and experiences of the participants. A qualitative methodology was chosen because I wanted to understand more about this phenomenon. The descriptions elicited by the semistructured interviews allowed me to gain a glimpse into their journey.

The use of a narrative inquiry allowed me to better understand the stories of the participants and provided a “window” into the cultural and social meanings (Patton, 2002). Whie and Epston (1990, cited in Patton) suggested that people may have a difficult time adjusting to the stories of their lives, as created by themselves or others, as it may not match their experiences. As families revealed their stories to me, I began to see the difference in their expectations and their experiences. Each of the mothers in this study had unexpected, emergent deliveries where there was no time to mentally prepare and rewrite the stories in
their minds. They are only lived experiences, much different than the hopes and plans they had had just hours prior. Patton, in explaining the basis of narrative analysis, stated “How to interpret stories and, more specifically, the text that tell the stories, is at the heart of narrative analysis” (p. 164).

Strauss and Corbin (1998, p. 11) suggested that the qualitative method is most appropriate when trying to understand the meaning of experiences for people with problems. I utilized the seven major characteristics of narrative research as described by Creswell (2005) to guide me in conducting this study in that I:

focused on individual experiences, reported the chronology of their experiences, collected the parents stories told to the researcher by both parents and nurses, restoried the individual reports, coded the stories for themes, described my understanding of the context and setting of the stories, collaborated throughout the process of research with individuals whose stories are being reported through attempted member checks. (Creswell, pp. 477-483)

I initially began this study to understand the experience of touching a very premature baby and better understand the experience of bonding in the NICU setting. However, as Clandini and Connelly (2000) reported, it is possible for the purpose or focus of the study to shift. Although I began with a certain purpose and focus, I found a shift occurred as parents began to tell their stories and nurses reported their perceptions. The focus grew to not only encompass the greater understanding of these parental experiences, but then to explore the implications in the practices and policies of FCC. The research revealed a need for a greater exploration of the interaction between the experience of parents and the perceptions of the nurses.
Strauss and Corbin (1990) described what they call “theoretical sensitivity” of the researcher. This concept refers to the researcher’s skill and readiness to attempt a qualitative inquiry. Theoretical sensitivity is believed to come from professional literature, professional experiences, and personal experiences. I have conducted a thorough literature review as the basis of the study and I have spent time professionally and personally in the NICU environment.

Assumptions

For the purpose of this study, it was assumed that parents desired to touch their infants as part of the bonding process. I approached this study with the understanding that each family had different values ascribed to touching their infant and there was the possibility that touch would not play a significant role for some of the parents in this study. It was also assumed that parents would feel supported by nursing staff in touch interactions. Another assumption was that parents would be anxious about the environment and touch experiences. Interviews were held within 2 weeks of the infant’s admission into the NICU. These surrounding factors elicited a difficult dynamic because families were adjusting to a new setting, experiencing grief as a result of the loss of previous expectations, and experiencing fears associated with a preterm birth. I anticipated that it would be difficult to hold interviews with these families due to distance or familial concerns such as the need to be at home with other children or the hospitalization of the mother at another hospital due to complications of the emergent delivery.

Participant Selection

Participant selection in qualitative research is purposeful. Participants and sites are chosen based on the opportunities they provide for data collection to be implemented.
(Strauss & Corbin, 1998). Additionally, qualitative sampling is not as concerned with
generalizeability as is quantitative sampling (Martinelli, 2005). Understanding the individual themes may allow the researcher to see a larger picture resulting in some limited generalizing to other similar groups. According to Lincoln and Guba (1985), the most useful strategy for participant selection is maximum variation sampling. Maximum variation sampling provides a group of people that are more likely to encompass a variety of experiences, thus making the sample more generalizeable. This approach allows themes or outcomes to emerge that span a large range of participant variation. There has been much discussion about heterogeneity being a problem for small participant groups because individual cases are so different from one another. However, the maximum variation sampling strategy resolves that weakness under the logic that common patterns that emerge capture the shared aspects or core experiences (Patton, 2002).

Research studies have used varying numbers of participants in qualitative approaches. Typically “saturation” is recognized as the point at which no more participants are needed to further understand the phenomenon. It is difficult to operationalize the concept of saturation (Guest, Bunce, & Johnson, 2006). I was given permission from the IRB to recruit 15 parents. I contacted a total of 15 parents throughout the course of the data collection. Many parents did not return at the time of our scheduled meeting or failed to follow up with me in setting a time. Therefore, I ended up with a total of 6 participants in this study.

Nurse interviews were also selected as a form of data collection in an effort to gain a more objective perspective of this touch phenomenon. In an effort to gain a different perspective that was less emotionally connected to the lived experience of parents, four nurse interviews were conducted. The focus of this study was not specifically to reach saturation in
the perspective of nurse interviews, but to include their perspective of the phenomenon based on their professional distance. A heterogeneous group of nurses was selected by the nurse research director. Their interviews lasted approximately 20 minutes and were transcribed and coded following the same procedure as for the parent interviews.

Setting

ACH was selected because it has the largest NICU population in the state of Arkansas and its care focus is on premature and medically fragile infants. This hospital is located in central Arkansas, serving between 75 and 85 infants daily in the NICU. Each infant has a nurse who sits at his/her bedside at all times to provide continued care.

Secondly, ACH was selected because it is a research hospital and supports research efforts. I believe this research will benefit the institution as it will directly serve the patients. As an ACH employee I already had access to this population and experience working in this NICU. Finally, ACH serves patients from the entire state as well as patients from surrounding states. This provided a more heterogeneous group from which to select participants. A single hospital was selected because a variety of hospitals might have brought additional variables into the study, consequently taking away from its intended focus.

Martinelli (2005) noted that differences in staff training, unit policies, service areas covered, and the population demographics could become confounding variables.

This NICU at ACH can care for 85 infants at one time and is currently expanding to accommodate 110 infants. Each infant is in an isolette or warmer, which is numbered according to the room it is in. The isolettes are close to one another. Each room is called a pod, and there are a total of 10 pods. The ratio of care is approximately one-to-two with a
nurse at each bedside. The setting has some sound absorbent materials and appropriate lighting, and efforts are made to minimize other stressful stimuli.

Parents are welcome any time of the day, but may be asked to step out of the unit during invasive procedures on their or other infants in the pod. Visiting hours are 9:00 a.m. to 9:00 p.m. for other family or friends. There are no living quarters provided for parents, but parents or primary caregivers are welcome to stay in the waiting room if they need or want to stay overnight. A Ronald McDonald House is situated next to the hospital, and parents may be placed on its waiting list if they meet the requirements. This allows parents who live a distance from the hospital to be close to their infant.

The unit is family friendly, providing support and education to parents and family members during the patient’s care. Parent education is available and parents are encouraged to developmentally interact with their baby when appropriate. Showers, laundry rooms, and meals are also available. The unit has a lactation room provided for nursing mothers to pump. Rocking chairs are positioned in the unit and privacy partitions are placed for families during kangaroo care, nursing, or other private time. A family room is also available to allow family to grieve and spend last moments in private with their infant during times of loss.

The CLS provides daily schedules for infants to assist in facilitating a routine. Developmental materials, such as mobiles, sensory toys, and photos, are provided for cognitive stimulation. The CLS provides a weekly therapeutic scrapbooking session where all materials are furnished for the parents. The CLS takes photos of each infant, however parents are encouraged to bring their own photos as well.

Parents are encouraged to bring personal items as well such as a personalized name plate to hang on a crib or photos of the family. Families are also encouraged to bring clothes
from home for their baby when possible in an effort to help families experience a greater parenting role in dressing their baby. Siblings were not allowed to visit at the time of the study because of increased infectious diseases during the winter months.

Parent Participants

Parents selected for this study had an infant or infants born before or at 28 weeks gestation. Their infants were considered medically stable, and they had the physician’s permission to touch their infant. This provided me the opportunity to collect data from a group of participants who were experiencing similar dynamics in terms of the developmental level of touch experiences.

Biological parents who were single, partnered, or married were interviewed for this study. This population was the most representative of the parents in the NICU with the hopes that data would be more transferable to other similar hospitals. The omission of other groups was not intended to devalue or disrespect other family compositions. Additional family dynamics bring in other issues that could complicate this exploratory study. For example, an adoptive parent may be, in essence, a second set of parents given that the birthmother may still be involved at that point. These parents may be experiencing additional anticipatory grief issues for fear that the birthmother may change her mind, resulting in their loss of the child, and other facets of parental role acquisition unique to them. Selecting this particular group for the current study lays groundwork so additional studies can explore other parental groups in future research.

Selection of a data collection method presented a unique challenge with this population. A large percent of parents with preemies at ACH live a distance from the facility, resulting in limited visitation. Accessing this population required flexibility to meet when
parents were available or in town. A gatekeeper was utilized to facilitate the research. This individual was the director over the nursing research unit at the hospital. She helped me gain access to the participants, materials needed, and site administration.

Parents were invited based on the previously mentioned criteria. I spent time waiting in the NICU for new admissions in an effort to meet parents as soon as possible. Due to confidentiality laws, I could not directly solicit the participants without the hospital first initiating the contact because I had a dual role as a student researcher and CLS. The NICU admission desk or nurse asked parents who met the criteria if they would be willing to participate in the study. The nurse would recite the following script: “One of our child life specialists is doing a research study where she is talking to parents who have babies in the NICU. Would you be willing to talk with her?” Nurses also offered brief information about me as the researcher and my work at the hospital. All nurses had access to the information about the study as it was announced by the nurse director during staff meetings. No personal information about my past parenting experiences or personal life was shared by the nurses to potential participants at that time. If parents expressed an interest in participating, I delivered the IRB forms in person at the bedside, introducing myself. I explained details of the study and the forms required for IRB approval (including the Informed Consent Document; see Appendix A), HIPAA regulations, as well as a demographic form for collection of descriptive data (Appendix B).

Below is a brief biography for each of the participants, which I developed from the transcripts and field notes. These stories will assist in the reader becoming familiar with their stories and help in the understanding of the context for chapter 4. I created and used pseudonyms for parents and nurses to maintain their identity.
Kate, Mommy to Luke

Kate is a young mother in her early 20s. She is married and describes her husband as a source of support for her during this time. Kate had a baby born unexpectedly at 24 weeks gestation. Luke is her first child. Kate had high blood pressure but otherwise had experienced a normal pregnancy. At 24 weeks, she began to have contractions and then her water broke. She immediately went to the hospital.

This sudden delivery was done by C-section. Her son was born unresponsive, so the doctor quickly held him up above the curtain for Kate to see him. Then he was immediately removed to another part of the hospital room where the medical staff worked to resuscitate him. During this time, Kate was unable to see what the medical staff were doing and there was limited communication with her. She expressed that she asked multiple times about his condition and what was happening with her son, but no one responded. Kate expressed great concern and voiced anger because she felt the staff were hiding information from her.

Once her son was breathing, they immediately took him to the helicopter, which brought him to the NICU at ACH. As they passed by Kate’s bed she was allowed to reach into the port hole of her son’s isolette and touch his finger. It was the first time Kate ever saw her son alive. He grasped her finger and then he was “swept away” and taken to the other hospital. Two days following the birth she was released from the hospital. She immediately went to ACH and up to the NICU to see her son.

Kate lives about an hour away from the hospital, so she was limited in her ability to go back and forth from the hospital. She was sleeping in waiting rooms and hotels and spending some nights at the Ronald McDonald House next to the hospital. She was able to spend a lot of time at Luke’s bedside. He had a good prognosis at the time of the interview.
and appeared to be making progress. Kate had begun to participate in some of Luke’s routine care such as changing diapers. She had been pumping breast milk for her son and was hopeful to begin nursing him soon. She had been able to hold her son and do kangaroo care with him. Luke was 7 days old at the time of the interview.

*Jennifer, Mommy to Skyler*

Jennifer is a woman in her mid 20s. She gave birth to Skyler at 28 weeks gestation. This is her first baby as well. Jennifer is married and she expressed that her husband was a great source of support during this time. Jennifer and her husband were rotating time at the bedside so there was almost always one of them at Skyler’s bedside. She and her husband live within 15 minutes of the hospital, although at the time of the interviews, Jennifer had made minimal trips home. Jennifer’s husband is a doctor and a resident at ACH, where their son is a patient. Her husband does not work in the NICU department, and is not a neonatologist.

Jennifer had experienced a normal pregnancy and had no prior conditions that are known to have caused her preterm delivery. Her son was delivered vaginally and appeared to be doing well at delivery. He was placed in the warming bed where he quickly began to have complications, and appeared to be in respiratory distress. He began to have an extremely difficult time breathing and the medical staff had to quickly intubate him. This was all done where Jennifer and her husband could see what was happening. Further examination of Skyler’s lungs revealed that, although they appeared to be functioning properly and were mature enough to support him, his airway was not functioning correctly, so he was put on a breathing machine to support him until they could determine the etiology of the problem.
Skyler was taken to the NICU at ACH that day by helicopter. Jennifer was also able to touch him for just a moment following delivery. She was discharged the next day and went directly to the hospital. At the time of our interview, Jennifer had held her son twice with assistance from the nurse. She had frequently reached into his isolette and touched him through SGT, containment holds, and stroking his hands and feet.

Jennifer typically slept in the waiting room so she could be close to Skyler at all times. She left his bedside only to eat, pump breast milk, and sleep for 5 hours at night. Her son was still intubated at the time of the interview and the complications did not appear to be subsiding. Although they had hope for his recovery, he was not making much progress at that time. The neonatologists had told them they did not have any idea why Skyler could not breathe independently. They were continuing tests at the time of the interview. This appeared to be Skyler’s only current complication.

Jennifer’s husband had assisted in some of the medical care for their child as he was trained as a medical doctor. Jennifer appeared to participate the most in her child’s routine care such as changing diapers and wiping his secretions, as compared to the other parents who participated in this study. Skyler was 11 days old at the time of our interview.

Lori, Mommy to James

Lori is married and in her mid 20s. James is Lori’s first child. Lori’s husband was present for the birth and Lori described him as a great support during that time. Her husband had returned to work and was making frequent trips to the hospital to visit her and James. They live approximately 30 minutes from the hospital, but had chosen to make minimal trips home.
Lori experienced a normal pregnancy until she began to go into labor at 26 weeks gestation. The labor could not be stopped and Lori gave birth vaginally to her son, James. At the delivery, the doctor immediately took James to examine and provided support in an effort to help him survive. Her son was in respiratory distress at that time and the medical staff worked to stabilize him. During this time, Lori and her husband could not see what was happening to James because their vision was blocked by the medical staff working to save his life. Lori reported that she and her husband did not ask questions during this time and waited, holding hands, for the doctor to tell them James had survived.

There was no communication between the staff and the parents during this time of waiting, which lasted approximately 10 minutes. Finally, the doctor announced that it looked like he might “make it” but needed additional medical treatment at a NICU. The doctor said they needed to immediately transport him to the pediatric hospital. Lori saw her son pushed by the bed as they exited, but was unable to touch him at that time.

She reported anxiously waiting for the next 2 days to pass until the doctor released her from the hospital. At that time, Lori went straight to the ACH to be with her son. She was staying in waiting rooms and hotels this last week. Her son was doing much better and was expected to make a full recovery in the next few weeks, per the neonatologists, after which he was expected to be discharged. Her son was 7 days old at the time of the interview.

*Jim and Michelle, Parents to Jett*

Jim and Michelle are a married couple in their early 30s. They have one daughter who is 2 years old. They live approximately 2 hours away from ACH. Michelle delivered Jett at 24 weeks gestation at their local hospital. They reported family as a major source of support for them during this time. Jim had to return to work immediately so he had not made a visit
to see Michelle and Jett until the weekend of the interview. Jim had been staying with his sister, who is caring for their 2-year-old daughter during this time. This was allowing Michelle to be at the hospital with Jett. When I spoke with Michelle at the bedside, she requested that her husband be present for the interview as well so they could both participate.

Michelle’s delivery was an unexpected vaginal birth. Michelle had experienced a normal pregnancy until she began to have contractions. As she was given medication to stop her delivery, her water suddenly broke and there was no way to stop Jett’s birth at that time. These parents were then told by the nurses and doctors that their son would not survive the delivery. A delivery at 24 weeks gestation is very early, but it is not clear why the medical staff at their hospital were so explicit about Jett’s death. Jim and Michelle both reported that the medical staff had informed them that Jett would not survive and they should be prepared for his death. In trying to understand the medical staff’s expectations, I can only assume it may reflect on the access to medical care they had at that facility. Their community is small and serves individuals with lower socioeconomic status. It could be possible that they knew Jett would be in critical condition and they might not have the resources available to save his life. It is not uncommon for babies to survive a delivery at 24 weeks, so their determination that survival was not likely is not clear.

Jim stepped out while the anesthesiologist was preparing Michelle for her epidural, but when they positioned Michelle for it, she suddenly began to deliver and there was no time. Jim was there for Jett’s birth and witnessed the delivery as he heard Michelle and turned the corner to enter the hospital room. At their son’s birth, Jett cried out and had survived the delivery. The doctor quickly took him to check his status and reported that Jett was too premature to survive alone. Jett’s lungs could not support him at that time. As a
result, Jett was intubated and stabilized for transport. The doctor also reported to Michelle and Jim that Jett could have further complications that would require additional tests. Their local hospital did not have an adequate NICU to provide the needed services so Jett was moved to ACH. At that time, Michelle touched his hand and foot as they wheeled him out of the room.

Jim had driven in the night before the interview to see Michelle and Jett. They had spent the night in the waiting room on fold-out chairs with blankets provided by the hospital. They had been in to see Jett that morning. Michelle had been spending most of her time at Jett’s bedside. She left to eat, sleep, and pump. Otherwise she was typically at the bedside. She was hoping to get a room at the Ronald McDonald house because she and her husband knew it would be a long road ahead until their son was ready to go home.

Jim had touched Jett’s hand the night before and the morning of the interview. Michelle had touched Jett each day she was at the hospital. Their son’s condition was stable, and they hoped for recovery. This was their second experience in the NICU. Their 2-year-old daughter had spent a short amount of time in the NICU. She was born full term, but experienced difficulty breathing at birth and had a short NICU stay at the local hospital. Michelle and Jim described their son’s hospitalization as much more invasive because he was intubated and had so many tubes and monitors. Their daughter mainly had had a hood over her to provide oxygen, monitors, and an IV.

Jett currently had multiple IV’s and monitors and was hooked up to a breathing machine. He was showing progress and they were hopeful for a full recovery per the information they had received from the neonatologist. All the tests that had been conducted until the point of the interview had provided positive results, and they reported to me that Jett
was a “fighter” and was doing very well considering his extreme prematurity. Jett was 4 days old at the time of the interview.

_Yolanda, Mommy to Tyrell and Monique_

Yolanda is an 18-year-old mother of twins, Tyrell and Monique. These are Yolanda’s first two children. Yolanda delivered by C-section at 24 weeks gestation. She lives over an hour away from the hospital. She expressed that her support currently was coming from an aunt, however, no one had been to visit at that time other than the father, who had come the day of our interview. She was “sorta together with” the father of her two children. He had come down the day of the interview with his parole officer on a special pass. It appeared to me there was tension between he and Yolanda when we all met for introductions. There was no affection displayed between them either verbally or by physical contact. When she introduced him, she referred to him as “the daddy of the babies.” She later described their relationship and the frustrations they were feeling towards one another. This father was invited to participate in the study, but he declined per his lawyers’ request as there were some legal issues pending in his personal life.

Yolanda had experienced a normal pregnancy up to the point of her emergency delivery. Medical staff do not know why she suddenly went into labor. During the vaginal delivery Monique’s umbilical cord wrapped around her neck so they had to do an emergency C-section. Yolanda was anesthetized during the caesarean so she does not remember anything about the birth. She told me that they tried to wake her up to see Tyrell, but she was still too medicated. She claimed that she requested to see Monique, but the staff wouldn’t let her. She did not see her children until the next day. They were moved to ACH at that time.
Yolanda appeared to have a low level of education and had a difficult time finding many words to describe her story.

At delivery the medical staff realized her son had blood vessels that had ruptured in his heart and required urgent surgery. As Yolanda met with the neonatologist and discussed the health status of her children, the doctor explained to her that Tyrell had significant brain damage. At his young age of 7 days, Tyrell had had surgery and might be needing additional treatment for that condition. He had some other medical issues revolving around the current functioning of his brain. Brain examinations revealed that Tyrell’s brain had experienced a form of hemorrhage that had caused severe damage. Yolanda expressed little understanding of her son’s condition and could not report any information other than his brain had been a grade IV and the doctors told her that most parents would remove support because his quality of life would be minimal. This condition, periventricular hemorrhage, has been associated as the primary cause of cerebral palsy, as well as causing mental retardation and seizures. Brain scans are placed into four categories with Grade I being the least damaging and Grade IV being the most severe. The mortality rate for these children is 27 to 50%. This condition typically occurs within 7 days after birth, so screening for children at risk are typically conducted at that time (Annibale & Hill, 2008). Studies on this condition have shown little improvement in brain function. Some parents choose to remove support because children with this level of brain function will need life support to survive.

During the previous week, two doctors had approached Yolanda about possible removal of support from Tyrell. Yolanda reported that the doctors told her Tyrell’s brain would not get any better, so most parents would choose to remove support at this time. Yolanda expressed strong emotions of anger toward the doctors as she explained their
conversation. Although Yolanda appeared to have little understanding of the specifics, she knew that the doctors wanted her to “pull the plug” and she had chosen, at that point, to allow God to choose Tyrell’s fate. The day of our interview, she had received news that Tyrell’s brain function had been changed to a Grade III. She told me she was confused about that and did not understand what was happening given that the doctor had told her Tyrell would not improve.

Both of Yolanda’s babies had many monitors, equipment, and tubes. They were both intubated at the time of the interview. Yolanda expressed her concerns over the excessive bruising the twins had from all the IVs and lines they had. She was very concerned about seeing them like that and was spending minimal time back in the NICU. She went over every few hours to check in, but she said she didn’t like to see them looking so bruised up so she wasn’t staying back there.

Yolanda was staying by herself at the Ronald McDonald house. She described mixed emotions about the relationship between herself and the father of her children. She explained that it was stressful and they were “pickin’” at each other, which she attributed to their frustrations with the situation. However, Yolanda also explained how happy she was that he had come down to visit her. I am not sure where her happiness was originating from—that the father of her children had come to visit or that she had someone “to be with” her. She frequently described emotions of anger toward individuals and the situation she was experiencing. She had the least amount of information about her children’s health status, which perhaps was influenced by her low level of education and young age. She also was spending minimal amounts of time with the nursing staff at the babies’ bedside, so her access to information was limited as well. Both babies were considered stable, with the hope of full
recovery at that time for Monique and possible improvement for Tyrell. Her babies were 11 days old at the time of the interview.

Nurse Participants

Nurses were selected by the nursing director to provide a variety of experience and gender differences. The hospital protocol required that I not solicit participants, but that the staff working with the nurses would facilitate that process of nursing participant selection. The nurse participants comprised one male and one female with over 20 years of experience in the NICU and two females in their first few years of nursing. There were no other specific criteria required for nurses to participate. Below is a brief biography for each of the nurses to give further insight into their perspectives of this touch phenomenon. Pseudonyms have been provided to maintain their confidentiality as well.

*Mark, Male with 5 Years NICU Experience*

Mark is in his early 30s and has been a nurse for 5 years, the whole time in the ACH NICU. Mark is married and has a two year old who was delivered full term and healthy. Mark had had no previous experience in other units of the hospital. When I asked him to tell me about his choice to work in the NICU he explained that the reward of “perpetuating creation” was necessary given that there is so much destruction in the world. He told me that neonates were the logical starting point to make a difference. Mark reported he had no biases that he believed influenced his work in the NICU.

*Janet, Female with Over 20 Years NICU Experience*

Janet began her nursing career in the early 1980s as a licensed practical nurse and then 3 years later received her Registered Nurse license. She became a respiratory therapist, working in the NICU for approximately 5 years after that. She then became a specialty nurse
and has been stationed primarily in the NICU since 1993. Janet has children of her own that are grown. She did not discuss any NICU stays for her own children during our interview and stated that all of her children were alive. Janet’s interview provided very detailed information about the protocols for touch and the physiological responses to touch. Her interview provided rich in-depth perspectives about various groups she has worked with in her nursing experience, such as those with contrasting socioeconomic statuses, education levels, and gender differences. Janet also had the unique experience of extensive practice. She discussed joys that she had had as a nurse and experiences where she had served multiple generations of families in that some of her babies from 20 years ago were now having babies in the NICU. She laughed as she described her feelings of “getting old” in response to that dynamic. Janet did not report any biases that she attributed to influencing her work and service to these families.

_Liz, Female with 1 Year of NICU Experience_

Liz was in her early 20s and this is her first year of nursing experience. She is single and has no children. She reported her choice to work in the NICU as a result of the loss of her brother as a child. Her mother lost the baby at 9 months and Liz reported remembering the experience with deep emotion. She explained that her lived experience was the catalyst for her choice to go into working at an intensive care unit. She reported “falling in love” as she interviewed and began her NICU nursing career. Liz provided a rich discussion about her potential biases in working with diverse families.

Upon the exploration of the potential biases Liz might have, she gave me a moving list of areas where she struggles with FCC. She explained the personal difficulties she has had in serving parents who have tested positive for meth, cocaine, and other substances at
delivery. The physiological damage and repercussions of their actions are evidenced every day as Liz serves to heal their sick babies. She also described her feelings of confusion and frustrations in that some parents have multiple children in state custody and continue to conceive and have babies they are allowed to keep. She then explained her experience in working with parents who were as young as 12 as they deliver preterm infants while they themselves are still children. She expressed a desire for more abstinence, sex education, and administration of contraception to lower the incidences described. She reflected on her future children as well, describing how much she already loved them. Her passionate language describing her feelings of frustration in seeing sick babies left to suffer for the rest of their lives because of the parent’s mistakes led her to her final comments in which she described conceiving as a basic human right. However, she reported that she believed there should be laws enforced for those who do not take the responsibility to prevent pregnancy and are unable to care for their baby physically, mentally, emotionally, and financially. Although no other nurse participant directly addressed this topic so explicitly, there was evidence of its implications throughout the interviews as the others, too, described stories of young mothers and struggles unique to this population as it is linked to choices parents make.

Molly, Female with 2 Years of NICU Experience

Molly is in her early 20s. She has no children and is not married. Her two years of nursing experience has been only in the NICU. When I asked Molly to describe her choice of working in the NICU, she explained that she had a passion for babies. She described the acuity of patients ranging from very critically ill babies to babies who are drinking from a bottle and getting ready to go home. She reported the benefits of both challenges and rewards from working in the NICU setting. Her description of developing relationships with families
appeared consistent with how she explained her efforts to provide FCC. Upon her exploration of potential biases, Molly reported that she had a brother who was born 17 years ago with a severe heart defect. She described her family as “typical” in their hospital experience. Molly expressed her memories of how it felt to be treated with FCC practices as a young child. She told me that she strives to do her best to treat families the way that she would want to be treated if she had a sick baby in the NICU. Molly reported that she did not perceive having any potential biases in her work as a NICU nurse.

Procedure

Data Collection

Before recruiting any potential participants or conducting any data collection procedures, I obtained permission from Iowa State University’s Institutional Review Board (IRB) and ACH’s (IRB). A packet of information that explained the general process of the study about the study was provided to the NICU nursing staff.

Upon approval to conduct the current study, I collected data from the six parent participants by conducting semistructured interviews. Each interview was with one mother, with the exception of one interview that was conducted with both a mother and father. I transcribed each interview, dictated field notes following each interview, and collected a short demographic survey from each participant. Four nurses were selected by the nursing research director to participate in this study. These nurses varied in their years of experience and were interviewed for an objective perspective on the phenomenon of parents touching and bonding with their baby in the NICU. Overall, there were six parent interviews and four nurse interviews conducted. Parent interviews lasted from 45–60 minutes in length, and nurse interviews lasted approximately 20 minutes.
All participants signed informed consent forms prior to any data collection (Appendix A). Interviews were held in a small conference room with privacy blinds so no one could see in the room during the interviews. This allowed privacy for parents to show emotion and freed us from interruptions during the interviews.

The semistructured interviews were guided by a list of research questions (Appendix C, Appendix D). A tape recorder was utilized for later transcription. I explained the reasons why I wanted to interview them and what I hoped to gain from this research. I also thanked them for their time and participation. I delineated the process of their participation including:

- The initial interview
- My transcription and summary
- Simultaneously nurse interviews
- The transcript and member checks to verify I understood what they meant
- The final journal collection.

The expected time span between the first interview and the mailing of the transcription was approximately 4 weeks. Participants were to mail in the journals following the member checks for clarification, but as mentioned earlier, I never received any journals. I planned that, on receipt of the journal, I would leave a gift of gratitude at their infant’s bedside or mail it to them if their infant had been discharged. As no journals were returned, I provided the gifts at the close of the study. Copies of all IRB forms were provided to all participants to ensure they knew their rights, had appropriate contact information, and would have a reminder of their participation and responsibilities later.

In terms of the chronology for the parent interviews, I began the interview by asking parents to tell me about the delivery of their child and their journey to ACH and then
attempted to proceed in a sequential order of the events they had experienced in touching their babies. I included questions that progressed in time until their current experiences at the time of our interview and even about their hopes and plans for their baby in the future. The stories shared by parents did not follow a chronological order. Parents would begin to answer a question, and then they would remember something they wanted to tell me about a previous question, or they would begin to tell me about something that we hadn’t discussed yet. I allowed parents the freedom to tell their story however they needed to and made attempts to retell their stories in chronological order as I coded data and prepared it in this document.

Triangulation

Triangulation was used in this study. The purpose of triangulation, as explained by Patton (2002), is to test for consistency from different sources of data collection. Studies using only one data collection method are more vulnerable to errors (e.g., loaded interview questions and biased responses from the researcher). Although different types of data collection may yield different results, this finding should not be viewed as weakening the study, but rather offering opportunities for further insight into the phenomenon. The sources for this study were the parents, the nurses, and myself. The methods that supported the triangulation were the parental interviews over a 4- to 6-week period, the nurse interviews for anecdotal observations, personal perspectives of parental touch, and the journals over an approximate 4-week period parents would keep during the study. I also had field notes and observations that added an additional perspective.

Research Questions

The overall research questions that this study examined were: What are the experiences and perceptions that parents have surrounding touching their infant in the
Questions were generated that would elicit meaningful responses from the parents through the semi-structured interviews. I made an effort to be attuned to body language and verbal responses to determine the best approach to facilitate each interview.

**Parent Interviews**

The following questions provided some structure to facilitate the parent interviews:

1. What are the experiences, perceptions, and feelings of touching that parents have in the NICU?
   
   a. How do you feel about being in the NICU with your infant?
   
   b. What sort of touch experiences are parents anticipating most?
   
   c. What were the ways that parents had physical contact with their infants? (kangaroo care, massage, breastfeeding, containment hold, or other)

2. How do parents feel after touch experiences?
   
   a. What staff were near you during this time?
   
   b. What was the environment like during touch interactions?

3. Tell me about how you feel bonded to your baby?
   
   a. What sort of things make you feel closer to your baby?
   
   b. Do you think touching your baby makes you feel closer to him/her?

4. What is your relationship like with the nurses?
   
   a. What sort of things does the nurse do before you get to touch the baby?
   
   b. What sort of things was the nurse saying before, during, and after these times?
   
   c. How do you feel about being involved with your baby’s care?
   
   d. How does staff respond to your presence?
Lincoln and Guba (1985) suggested detailed phases of inquiry that become more focused as the study progresses. This study began with the initial interviews of parent perceptions of touch experience with their infants. The second phase began with the journal process. Verbal and written directions were given to parents on guided journaling to facilitate reflective responses. During this time, I also met with NICU nurses to gain their observations and perspective. I transcribed the interviews and then mailed a summary to the participants for member checks. At that time, I invited their feedback and requested they send their journal to me for collection.

I anticipated that the parent interviews would be emotional for the parents. The consent forms detailed the risk of strong emotions resulting from answering the questions. I reassured parents they had the choice to refrain from answering any of the questions and had the option to stop the interview at any point for a break or for termination of the interview if they felt it was needed. Contact information was given for both IRBs as well as myself and the major professor should they have chosen to withdraw from the study at any point.

Although I had had a son in the NICU, the conditions of his birth were not shared directly in the interviews. Only one mother asked if I had ever experienced having a baby in the NICU. I briefly told her my story and she seemed satisfied with my response. I realize and note in this study that having had a similar experience with unexpected complications at birth and a child in the NICU, I openly acknowledge that, to some extent, I was not an objective interviewer.

Nurse Interviews

An interview was held with four NICU nurses. All nurses received notification of the current study and their responsibilities (Appendix E) prior to the data collection. All
interviews were recorded for later transcription. The questions used to guide the nurse interviews were:

1. What sort of touch interaction do parents typically have with a baby at this gestational age?
2. What is the typical comfort level of the parents before the touch interaction?
3. What are typical things parents say during touch experiences?
4. What does their comfort level appear to be during the touch interactions?
   a. What sort of emotional responses do parents have when touching their babies?
   b. What sort of things were they saying during touch experiences?
   c. What was going on during this time in the environment?
   d. What were you during this time?
5. What is their typical mood like following the touch?
   a. What sort of things were they saying or asking?
6. Do parents ask to touch their baby?
   a. Who is usually the one who initiates touching the baby?
   b. What sort of questions do parents ask about touch experiences with their baby (anticipation)?
7. How do you feel about parents touching their baby?
   a. Do you think they should do most of the routine caretaking?
   b. What is your role in helping families bond with their babies?
Journals

Bolger, Davis, and Rafaeli (2003) argued that one of the greatest strengths of diary designs is their ability to characterize dynamics such as the effect of time leading up to or since an event. Journaling may help determine antecedents, correlates, and consequences of lived experiences of touching and bonding with one’s baby. They can be used to evaluate whether individuals differ in the processes being studied as well. Obtaining sufficient journal entries can enable the researcher to address questions and aid in the development of themes.

Bolger et al. (2003) argued that asking participants to recall their experiences will often bring biases. Participants’ limited ability for retrospection may result in faulty reconstruction of the phenomena. Parents may remember only intense “peak-end” experiences, and other portions of the experience may be lost (Stone, Smyth, Kaell, & Hurewitz, 2000). Journals may also be difficult for participants to keep up with as well as to remember to do daily. Despite these difficulties, journals appear to be more successful for recalling experiences during times of change (Bolger et al.).

For the purpose of this study parents were asked to keep a weekly pen and paper journal over an approximately 4-week period. Parents were asked to journal at least once a week each week following a touch experience with their baby. A variable schedule, as detailed by Bolger et al. (2003), allows individuals the opportunity to journal when it is convenient for them. Parents were asked to journal following touch interactions whenever possible. I told them, “When you’ve been able to hold or touch your baby, please journal so I can understand better what that was like for you.” I hoped to gain the most authentic experiences by having them journal soon after the touch interaction. An event-based design avoids biases that later entries may have. This form of journaling has been successful for
numerous qualitative studies surrounding a pre-established definition of an event (Bolger et al.; Jensen-Campell & Graziano, 2000; Laurenceau, Feldman Barrett, & Pietromonaco, 1998).

Parents were encouraged to keep the journals with them. I was concerned that parents would feel uncomfortable leaving journals at the bedside for fear that staff might read them. This fear may further inhibit their journaling of emotions and frustrations. The journals were also a form of data, so they could not be left unsupervised at a bedside. Asking parents to keep the journals with them was selected in an effort of convenience for parents as well as to secure data. As previously mentioned in the literature review, parents sometimes fear that offending nursing staff could result in lower quality care for their infant. I assured parents that the journals would remain confidential and the original would be returned to them following my later review.

I attempted to collect the journals through the mail approximately 4 weeks following the initial interview. A postage-paid envelope was provided for parents to mail the journal directly to me so that I could copy their journal notes. I then planned to mail summaries and portions to the parents for review and clarification accompanied by a letter to explain the process (Appendix F). I planned to then seal the journal and mail it back to the parent. Sealing the journal with a taped signature would have provided increased security of their confidentiality. However, no journals were ever returned.

In my exploration of the possible contributing factors to the loss of the journal data, I reflected on their stories and my previous knowledge of this population. These parents were in a transient state where they were sleeping in multiple locations, were living out of their suitcases, and had limited space to store belongings. The extreme emotional stress and sleep
deprivation could have contributed to a lack of writing in that parents seldom remembered to journal. The movement of families between hospitals and other locations could also have contributed in that journals could have been lost or left at other locations. When the time came to send the journals back in, they could have been at another location and the journals may have appeared more a hassle than a benefit to them at that point.

Perhaps, for some parents, the expressions in their journals were much too powerful for them to share at that point. I realize that sometimes individuals may become so involved in writing that they express things that they do not wish others to know. Perhaps, the sensitivity of the situation contributed to the hesitancy by some parents to share their written stories. I, too, in the writing of this report meticulously examined how much of “me” I could allow myself to share. I reviewed my own personal journals during the delivery of Aidan and Eli and determined what my readers needed to know in an effort to reveal my own biases and lived experiences. I had the privilege of omitting some things that I did not feel appropriate or relevant, but the parents in this study did not have this liberty. Mailing in the entire journal would have resulted in a lack of a filter for them, which could have resulted in embarrassment or disclosure of private information. Although this would have greatly contributed to my understanding of their story, I respect their choice not to return the journals. As previously mentioned, this is all speculation based on my experience with these families and the dynamics involved in their experience.

Reciprocity is important in showing respect for families’ time and participation. Researchers Lincoln and Guba (1985) stressed the need for continued reciprocity. To show appreciation for their time and participation, a gift bag was provided that contained books for
their baby. I also provided a letter of gratitude for each parent. I provided a thank you note and a small box of chocolates for each of the nurses who participated.

Analysis

Following all data collection, I personally transcribed each interview. I transcribed the interviews verbatim with the use of a transcription machine. I then began the coding process as follows: (a) writing synthesis statements in the margins, which helped me summarize what I thought participants were communicating; (b) using the statements to develop common categories; and (c) typing categories/theme names in front of excerpts of the transcripts and using the “Find” function in Microsoft Word to easily access the coded narratives as well as highlighting those sections that corresponded with the themes. I then cut and pasted those sections into separate word documents for easy reference in reading and making additional notes as needed. During this entire process I kept a methodical log of my thoughts and questions pertaining to the data analysis, which will be discussed more in the following section.

I identified and assigned names to the conceptual categories by segmenting the data as described by Strauss and Corbin (1990). These descriptive categories provided the preliminary framework for the data analysis. Grouping of words, phrases, or similar events provided the basis on which later modifications were made as the analysis evolved (Strauss & Corbin, 1990). This helped me make meaning of the experiences of the parents and nurses. I wrote comments and questions in the margins to further my exploration and synthesis of the data. I began highlighting common phrases and color coding them within each transcript to look at commonalities between the transcripts. I then began to narrow the statements and label them with a single word or short phrases.
The next stage of the analysis involved an examination of how categories were linked. Previous grouped themes were compared and combined as I looked for larger themes. Coding allowed me to better understand the touch phenomenon of parenting and bonding with a baby in the NICU.

Finally, I attempted to develop a story line understandable by others and to follow a fluid revealing of themes that emerged. I then examined how certain factors influenced the phenomenon leading to specific parental experiences. Following the suggestions of Charmaz (2000), I was interested in the views, values, beliefs, feelings, assumptions, and ideologies rather than describing mere facts. Polkinghorne (1998) described narrative research as telling a story. He explained that the events and actions of the participants are collected and organized to develop a plot for their story. This allows for greater understanding of the contexts and relationships between their reports (Hatch & Wisniewski, 1995, p. 162).

I utilized a peer as an external auditor to review the transcripts to see if there was agreement with the coding and conclusions I had drawn following my preliminary conclusions as well as during each grouping. This auditor was a 40-year-old woman who was working at the same university as I was. I also utilized the NICU CLS as an auditor. She had had many years of experience as a CLS and as a social worker in the NICU. She also had conducted and worked with research groups collecting and analyzing qualitative research collected in the NICU. I provided her with copies of the transcripts (no names provided to maintain confidentiality) and asked her to read Chapter 4. Neither auditor had any disagreements with my findings.
**Issues of Trustworthiness**

To ensure rigor and trustworthiness, I considered Lincoln and Guba’s (1985) four proposed criteria for judging the soundness of qualitative research. Prior consideration of these four criteria provided assistance in designing the study and served as a reflective agent as well as the data were collected, analyzed, and reported.

**Credibility.** Credibility of this study was increased by developing a prolonged relationship with the participants seeing as I had the opportunity to collect multiple forms of data and member checks to better ensure that I had understood their experiences. I had worked with NICU parents so I understood some of the dynamics and considerations for working with this population. I was available for families at any other time they attempted to contact me. I had ongoing communication with the NICU CLS, nurse research director, child life director, and nursing staff working with these families to keep them posted of the research status. My methodological approach utilized triangulation to strengthen the trustworthiness of this study. Triangulation of the data occurred through my personal field experience with the phenomenon, data, and participants; the reports of parents I interviewed; and the perceptions of the parents’ experience by the NICU nurses.

**Transferability.** Through a description of the time and context of the research, I established some transferability. Lincoln and Guba (1985) said, “He or she can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility” (p. 316). They further explained that a “thick” description is difficult to assess but should provide potential individuals using this research a sufficient database that makes transferability judgments possible. The goal of this transferability is to apply some of the understanding gained from
this research to other families experiencing similar situations. I realize that this research is limited in transferability in respect to the varied complexity of each delivery, family dynamics, and complications of the babies.

**Dependability.** Dependability emphasizes the need for the researcher to account for the ever-changing context within which the research occurs, as described by Trochim (2006). Through the use of my own field notes and research documentation, I attempted to increase the dependability of my research. I worked closely with my major professor and committee members and the individual serving as an external auditor to provide a rigor to the analysis and understanding of the data. The strategies employed in this study strengthen the study’s trustworthiness. The field notes I kept give insight into my own experiences of conducting the research. This reflective exercise helped me gauge my own position throughout the study to limit personal input or persuasion. I also kept notes in a journal to record methodological decisions and rationales (Lincoln & Guba, 1985, p. 327). I placed post-it notes and wrote down different ideas that emerged during my analysis of the data. As I transcribed and coded data, I often wrote down ideas and questions I had in regards to sections of the transcripts and my personal field notes. These allowed me to reflect back on understanding why I coded certain segments of the data the way I had and facilitated my ability to present it in a logical way.

**Confirmability.** Qualitative research tends to assume that each researcher brings a unique perspective to the study (Trochim, 2006). Confirmability refers to the degree to which the results could be confirmed or corroborated by others. To establish confirmability I again utilized the triangulation components and reflexive documentation that I had collected. The audit trail and processes strengthen this study. Because I work at the hospital where the study
took place, I had ongoing access to other NICU CLSs, nursing researchers, and educators
with which to work. I have revealed all potential biases in this report and have discussed
them with those with who I was working and with who influenced the reporting of this study.
CHAPTER 4. FINDINGS AND DISCUSSION

Introduction

The purpose of this qualitative study was to examine the role of touch in the parental experience of having a baby in the NICU. This chapter focuses on the findings of the qualitative data that I collected through multiple strategies. Data methods were to include nurse interviews, parent interviews, researcher field notes, and journals that parents were to write in following touch experiences, as described in chapter 3. However, no parent journals or member checks were returned to me, which will be discussed later in chapter 4.

This chapter is organized and presented to allow one to see the emergent themes and subthemes for both parents and nurses. Following the presentation of the themes, there is a comparison of where nurses and parent perspectives overlapped as well as where they differed. The discussion section gives further insight into the findings from the current study, linking the results to current research and practice. The themes and subthemes revealed in parent interviews were:

- Touch Experiences
  - Positive touch experiences
  - Negative touch experiences
  - Communication

- Losses
  - Control
  - Expectations
  - Separation
Nurse interviews revealed the following themes:

- Touch Responses
  - Overwhelmed with Emotion
  - Grief and Loss
  - Comfort Level Attained By Parents

- Types of Touch

- Barriers to Bonding
  - Environment
  - Communication
  - Presence

- Protection

**Emergent Overarching Themes and Subthemes for Parents**

Initially I visualized that interviews would follow a logical sequence from the birthing experience to the time of the interview. I also expected that parents’ responses would be similar to the nurses’ reports of this phenomenon. Much to my surprise, parents revealed their stories in a nonsequential order. Although all the interviews began with the delivery of their child and their journey to ACH, I found that parents would begin to answer one question and then begin to talk about something different. They would suddenly remember something of significance and stop their comment to go back. I believe this provided rich data, as the parents assumed more control over the interview and were able to communicate
issues and experiences of great significance to them. Although the interviews did not proceed in the same order, all interviews revealed the reported themes.

As I began the interviewing process, parents who I contacted asked that their partner or spouse be present as well. After consulting the IRB and verifying that this was within the protocol limits I had received, I agreed to meet with couples at their request. However, as time for the interviews came, most of the fathers did not show up for the interviews. That provided me with five mothers and one father for interviews. Although many of the parents failed to show up to meet me when it was time for their interviews, all the parents told me how wonderful they thought the study was and how they would like to participate, but only these six parents followed through.

All these parents had normal pregnancies until the point of their unexpected and emergent deliveries. Although the situations varied among individual families in terms of number of children, family composition, demographics, and complications for their preterm infants, it turned out they all were experiencing similar emotions and perceptions. All parents had touched their infants in a variety of ways that spanned from reaching in to touch hands and feet through the port holes of the bed, all the way to holding and kangaroo care. No mother in this study had breastfed her infant, although all but one were currently pumping milk to stay prepared for upcoming opportunities to nurse. Multiple examinations and tests were conducted on all the infants in this study, revealing serious complications for some of the infants and hopes of anticipated homecomings in the near future for others.

Touch Experiences

As this study centered around the phenomenon of parents’ first touch experiences with their baby, it was the most commonly discussed theme. All other experiences reported
in the emerged themes could be tied back to the experience of touching their baby. I anticipated that touch experiences would be positive for parents and would offset their negative emotions. However, my analysis revealed that there were negative emotional responses from parents in regards to touching their infants—emotions that typically resulted from fear. The emotional responses overlapped greatly in that, although parents were scared in touch experiences, most still felt extreme joy in reflecting on those experiences and desired more touch interactions.

Positive touch experiences. Mothers all expressed the powerful impact of touch for them. The power of touch as the means by which mothers perceived bonding with their babies was a theme referred back to over and over. For the purpose of this study, bonding is defined as the positive feelings of closeness parents feel towards their babies. Michelle said,

Until I can put my hands on him, and show that mommy is there, I feel like I can’t bond with him, but he can’t bond with me, ‘cause he don’t know where I am. He don’t even know I am in the world right now. . . . I think that’s the hardest.

Kate shared a glimpse into the moment she first felt bonded with her baby. This mother was very emotional because her son had experienced many difficulties during his short life. Holding her son was something that she did not anticipate would happen for a long period, and she was excited to have had that experience with her baby. She told me the story of the first time she got to do kangaroo care with Luke: “The first time I felt bonded to my baby was during the kangaroo care. I knew then it was going to be alright. Kangaroo care was awesome!”

All parents in this study had experienced some form of touch interaction with their baby. Overall, mothers all reported excitement and desire to touch their babies. Yolanda, the
mother of twins, discussed the first touch experience she had with her son, Tyrell: “Yea, he grabbed my finger and held it. . . . I was just sayin’ I was happy about dat.” Yolanda smiled and giggled a little during this portion of the interview. Her interview was very emotional in that she expressed much anger, fear, and frustration. The only times in the interview when she displayed moments of happiness, such as smiles or giggles, were when she was discussing touch experiences. She further described happy feelings in connection with touch: “I feel a little better . . . happy . . . being happy just to touch dem.”

Touch interactions with their infants were paramount moments that parents reflected on with mixed emotions. Kate’s son was born unresponsive and, after the medical staff resuscitated him, they brought his isolette to the edge of her bed so she could touch him through the port hole before they carried him off to the helicopter:

The first time I saw him move was when he grabbed my finger. It was right before they were taking him away on the helicopter to the hospital. . . . I didn’t know what would happen to him, but I got to touch his little hand.

I found this statement very powerful. In trying to understand her experience and imagining myself in her place at that moment, I cannot fathom the power of that moment. Kate stated she did not know what would lie ahead, but she shared in her story: “but I got to touch his little hand.” It appeared to me that that touch experience was at least something she had to hold on to. She did not have a baby to hold in her arms like most mothers anticipate. She had to watch her son be “swept away” and did not know if she would ever see him alive again. Yet, she appeared to have hope at that moment, holding onto the thought that she touched him.
Yolanda described her first touch experiences resulting from the nurse’s invitation to touch her babies. In the two days since the initial touch experience, she had gone and touched them each as soon as she arrived in the NICU. She didn’t ask permission to touch her babies and laughed as she explained it to me:

*Interviewer:* “So yesterday and today did you go in . . .”

*Yolanda:* “And touch dem?’ [she turned her eyes up toward me as though she were hiding something]

*Interviewer:* “Yea. Was that the first thing you did?”

*Yolanda:* “Yea, touched dem. I didn’t ask [laughed]. . . . [The nurses] looked at me. I guess dey thought some of dem didn’t want me to touch [my babies]. But dey didn’t say anything . . . turned dey heads.”

Yolanda also expressed much insecurity in the setting of the NICU. She explained that she did not feel comfortable back there and spent minimal time “just looking” at Tyrell and Monique. However, when it involved touch she exerted more independence and interest in being in the NICU, as described above.

It was interesting that as parents were asked about various aspects of touch and bonding with their baby in the NICU, they often came back to the specific topic of touch. As I attempted to explore the role the environment played in influencing those touch experiences, I asked parents to describe the surroundings during the times they got to touch or hold their babies. Mothers reported minimal distractions from the environment, and their comments often related back to the touch experience itself. For example, Jennifer responded to a question about the environment in the NICU by describing the surroundings and then ending with:
So, it’s a pretty calming environment. You know while you’re walking him and sitting there, it’s like I want to go to sleep too. It’s like relax with him. So yea, it’s pretty relaxing, once you get to hold him.

That specific comment referred to the environmental sounds and sights that she saw at times when she got to touch her baby. I found that most parents briefly answered the question about environmental surroundings, but then returned to talking about the specifics of the touch interaction itself. Kate reported almost the exact same way that Jennifer did by following her description of touch with that of the environment with: “So it’s really, really good . . . to be able to hold him.”

Mothers reported that holding their infants was very important. The two mothers who had held their infants shared how special those moments were and how it had made an impact on them. Jennifer described how touch allowed her to feel it was going to be “okay,” and it gave her hope. As she explained what it was like to hold Skyler the first two times she reported:

Whenever you can hold him and put him up next to you, I know my body heat is warming him up, it makes me feel like he’s gonna be okay and he’s gonna get out of here and that he’s gonna be.

Hope was a dynamic feeling connected to the positive aspects of touch. Later, Jennifer went on to further describe her favorite ways of touching Skyler:

It’s my favorite thing to get to hold his hand, and I love holding him now. Anytime they will let me hold him, I will hold him the entire time until I have to go pump, and then I will go pump and eat and then go back and hold him more if they will let me.

And they don’t have to do anything to him. I will just sit there and hold him if they’ll
let me. But holding him is definitely. I would love to do kangaroo care, but I think once his tube comes out, if we can, we can do that. That would be really special I think.

After the interview had ended and I was thanking Jennifer for her participation and wishing she and Skyler well, she made this unsolicited comment: “I am really glad I got to hold him. It’s been a very therapeutic day for mom!”

A side note about Jennifer is that during her interview she appeared hyper by talking fast, bouncing around, her voice reflecting much excitement. As I reflected on my field notes and the transcripts, it occurred to me that, prior to the beginning of the recording, she stated she had just left the NICU where she held her baby for the second time. It is interesting that her interview was different than the other five parents I interviewed. Their interviews were calmer and parents spoke at a slower pace. In those interviews there were more emotional moments when the mothers cried than there were with this parent.

Upon reflection, it would be interesting to see what effect the dynamic of touch played in her interview. It appeared to me that she was happy to have held her son and that was reflected in her attitude and perceptions at the time of the interview. None of the other interviews involved the dynamic where they had just had a touch experience. I had never met this mother before or since, so I cannot totally attribute this phenomenon to the touch interaction. Perhaps she usually has an upbeat attitude and expresses a lot of joyful emotions. This is important to share and explore as a potential part of this data collection.

Saturation was reached in respect to mothers expressing their desire to touch their baby in any way possible. However, the father who participated in this study did not express the same perspective. Jim did not report any positive aspects of touch. The only aspect of
touch he described to me I coded as a negative aspect of touch, which I will present later. Jim explained how he perceived a mother’s role and his own acquisition of his role as a father by saying:

Because [mothers are] more nurturing and [fathers are more] “do what you gotta do to get it done,” you know. Just take care of them type. So that, the touching really don’t bother me because I don’t. Just let him do his thing right now.

He also discussed his role in supporting his wife and son by saying, “I try to be there as much as I can so I guess it’s a little different than mom and dads.”

As I reviewed Jim’s transcript and listened to his interview, I began to see a more protective element from him. He mentioned “fixing” things and “taking home” as important recurring terms in his interview. He even critiqued the hospital and attempted to justify his overall goal of going home saying:

I mean it’s nothing against the hospital. They been real good here as far as I know.

But . . . that was an important step for us when we brought our daughter home. I want it all said and done and I want out of hospitals. . . . I know when we can get him home, that’s when, um, I’ll relax a little bit . . . when I get him home is where I am looking forward to, having us all under the same roof again.

It appeared Jim differed from the mothers in that his goal was to fix the situation and have his family back together. Mothers appeared to be focused more on the next step of holding their infant and saw going home as a distant second. Mothers all discussed their primary goal was to hold their infant. All mothers who participated referred multiple times to their anticipation of being able to finally hold their baby. Only two of the mothers, Kate and
Jennifer, had been able to hold their baby at the time of the interviews. Kate told me she had done kangaroo care a couple times, and Jennifer had held her son twice.

One of the questions asked in each interview was what the parent was looking forward to most. This was chosen as a question to explore if parents would go back to some form of holding or touch, or if something else dominated their anticipations. Every mother said “holding.” Michelle gave a glimpse into her longing to hold Jett:

> It makes it hard because I just want to grab him up and scoop him up and hold him and kiss all over him and tell him it’s all gonna be okay, but I just can’t right now so.

> You fight with that every day. But you know it’s the best for him right now.

When I asked Yolanda what she was most looking forward to, she also discussed holding her twins, but then described her feelings of disappointment because it would be longer than she had expected until she would get to hold them: “Sad. ‘Cause I thought it’d probably be sooner. I guess they know best.” This comment from Yolanda appears to communicate more than just the desire to hold and the disappointment from waiting; it also appears to communicate a lack of control and knowledge. As she said this, I remember her looking down and shrugging her shoulders as if in a state of defeat. Her voice sounded exasperated and I felt deeply sorry for her at that time. Yolanda appeared to have the most difficult situation presented by her babies’ NICU stay. She told me the hardest thing for her at that time was not being able to hold her babies and how that lack of holding influenced her emotions and comfort: “Not bein’ able to hold dem. Dat’s the only thing. I just want to hold dem. I guess it’d ease me better.”

Jim’s responses yielded an interesting facet regarding this experience. As mentioned, his perspective differed from that of the mothers. His interview and his wife’s interview were
done simultaneously per their request. The dynamic of interaction during the interview was what I would refer to as a delicate balance of taking turns in answering questions and a respectful pause to see who felt most strongly about answering each question, allowing that partner to answer first and letting the other partner process a bit more. However, in response to the question about what parents most anticipated following the interview, they both abruptly answered simultaneously with strong body language that became more erect and almost seemed a sigh of relief for them. When asked what they were most looking forward to, the interesting thing was that the mother said, “Holding!” and the father responded with, “Taking him home!” The father was the only one who had this different perspective. I cannot be sure if this was due to his perspective as a male or to his own unique experiences up to that point, so it cannot be assumed that other fathers would respond the same. Michelle continued her statement after they both looked at each other a bit surprised:

Holding him. I know that’s a long way down the road so I accepted my next step is just to hold him. I want to hold him. I want him next to me. The way, I don’t care about [taking him home] right now. I might care about it later, right now I just want him up against me and I just want to hold him and let him know that mommy’s here. And it’s gonna be okay you know.

Even with respect to touch discussions, holding seemed to be a theme that stood out. When I asked Michelle whether or not she got to touch her baby at birth her response was: “I didn’t get to hold him. I got to touch him. I got to see him. They just put him in the warmer.” The language used in her reply conveyed to me that touching her infant was important, but that she desired most to hold her baby. She told me what she did not get to do before she actually told me what did happen.
It’s also noteworthy that she differentiated touch as being separate from holding. This again led me to see that holding was significant even compared to touch. Even though Yolanda had already been able to touch her babies through the port holes, she described the only way she could feel close to her babies as: “If I got to hold dem. I think dat’s the only thing right now that would make me feel closer right now, if I could hold dem.”

Holding appeared to be a powerful way that mothers perceived their ability to “be there” for their babies as well as a sense of security for themselves. The two mothers who had the opportunity to hold their babies revealed much excitement and happiness in those experiences. Jennifer discussed her excitement about getting to finally hold her son: “I am excited to get to hold him!”

Another form of touch discussed was breastfeeding. All the parents in this study briefly discussed breastfeeding at some point during the interview. Even Jim included a short discussion about the hospital providing meal cards so Michelle would get the nutrients she needed for the milk she was pumping for Jett. Michelle actually explained to me that if she got a message from the nurse that the doctor was in the unit, she would have to leave the interview, because it was the day they were to learn if he could start getting Michelle’s milk and she did not want to miss talking with the doctor. I explained my full understanding of her excitement and anticipation and my willingness to accommodate her in any way, offering to pause the interview until she had another opportunity to meet me following the visit with the neonatologist. Michelle told me: “Like breastfeeding, um, I don’t care how much it puts me out, it’s important right now, so that’s what I am going to do.”

At the end of our interview, when I asked Jennifer if there was anything else she would like to share with me, she responded:
I love the whole lactation thing you guys have here. It’s been kinda therapeutic for me. I had my pumps and stuff at home, but the first night we were here and I had all our friends here and I was like, “I need to start pumping for him and they told me I need to start right now.” And I was going to send them home to get my stuff and bring it up here and [the front desk personnel] said, “We have everything here for you.” And that was a huge relief . . . it’s been wonderful . . . it’s a great thing that I really enjoy that back there and it makes me feel like I am doing something. So tell them “good job” about whoever thought about having that. Way to go! Yeah!

Lori and Kate also made similar comments about their appreciation for the services the hospital provided for them to be able to breastfeed. They also reported the significance of their breast milk in helping their babies get better. Kate even said: “[Pumping] is something I can do for now. Then later he’ll be able to actually breastfeed. It’s just a step at a time.”

Yolanda was the only mother who had chosen not to pump milk for her babies. She did not disclose the reason for that choice. All other mothers proudly and excitedly shared their anticipation of upcoming opportunities to start giving their babies their breast milk.

Overall, the parents in this study reported that their touch experiences had been positive. Although all the mothers shared a range of emotions in their NICU experience, they all agreed that touch was a positive thing that they desired more of as their baby progressed toward good health.

*Negative touch experiences.* All the parents expressed a fear of touching their infant at first. Similar to other studies, such as Pohlman’s (2009) study of fathers in the NICU, I found parents were hesitant to touch their infants at first. Some did not even know that touching their infants was an option until days had passed. Parents also voiced a concern
about touching in conjunction with hurting the baby. It is unclear exactly what caused this common fear. It might be their own perceptions of how fragile their infant was, messages the medical staff had conveyed, or in response to the environment. Although mothers expressed the common desire to touch and hold, they coupled that feeling with fear of hurting their infant and causing them additional undue pain. Michelle described what appeared to be her resistance to touching Jett too often for fear of hurting him: “They say I can [touch him in the bed] more often but I choose not to because I don’t want to be play a role in causing any problems for him.”

That feeling of fear was shared by all the parents in the study. Terms such as “little” or “delicate” were often associated with describing their babies as well. Jim stated:

I am still just worried that I am fixing to hurt him so if I ain’t got to mess with him right now, I choose then you know . . . I try not to mess with him, I’ve touched him once or twice but I don’t like, he’s so delicate, he looks so delicate right now that I don’t want to touch him ‘cause I feel like I’m fixing to hurt him.

As I tried to make meaning of his comments, I attempted to summarize his comments by asking if the discomfort in touching Jett at this point was stronger than the good feeling of bonding. I asked Jim to tell me more about how he felt about touching Jett at that time, to which Jim responded: “Right, right. I just right now, you know the doctor says he needs his rest so that’s what he needs. I don’t want to mess with him.” Jim further described his desire for his son to be healthy and the need for minimal stimulation, as explained by the nurses and policies: “Yea, we just want him to be healthy and if you know they say the minimal . . . then we just try not to mess with him.”
Lori also felt a strong desire to touch James, but feared all the medical equipment, tubes, and wires she saw. She explained how she wanted to hold and touch him, but worried that she “might hurt” him. She told me that the nurses had explained the dangers in touch, so as a precautionary measure, she was limiting her touch experiences with James in an effort to better protect him.

Yolanda described a touch experience with her daughter that resulted in a poor physiological response in which her daughter “desated” (a condition in which desaturation occurs in the lungs and they do not properly oxygenate, which results in abrupt loudly beeping of monitors). The first time she touched her daughter, she reached through the port hole and touched her hand: “She was calm at first, but den I guess she just started I guess desating, acting a fool. So dey told me I had to take my hand out.” She expressed anger in response to the nurses telling her she couldn’t touch the babies. I did not sense from Yolanda that she was concerned about Monique’s physiological response, but rather the nursing reaction. Her body language appeared to communicate the message of “oh well.” She raised her eyebrows at me and shrugged her shoulders. She cocked her mouth to the side and then began to talk about later touch interactions. This negative experience, however, did not keep Yolanda from touching her daughter again. The next time she did not ask to touch her daughter. She took the initiative herself. She described her emotions when touching her children as: “Happy. Sad. Scared. Then I’m gonna touch them the wrong way and den dey gonna have to be in here even longer.”

All six parents had witnessed critical conditions for their children during which they feared for their children’s lives. They all reported how thankful they were for their children’s survival. I could understand their hesitancy to do anything else to further complicate the
matter. Yet, it presents a difficult combination, because mothers, particularly, strongly desire to hold their babies. In an effort to protect their children, they are forcing themselves to do without something they reported so strongly needing.

*Communication.* Mothers discussed how they wanted to communicate to their babies that they “were there.” This was a common discussion point for all the mothers. Mothers also saw touch itself as a pre-eminent way for them to communicate their presence to their babies. For example, Michelle said:

I do touch him once a day, just to. I don’t know if he knows I am there. You know I wonder if he knows it’s me ‘cause I just don’t know, but I try to touch him at least once a day. You know?

Mothers frequently described their attempts to “be there” despite the limitations of the NICU setting. Jennifer described looking at Skyler and positioning herself in the direction he was looking so he saw her as much as possible. Lori described trying to be at the bedside so she could be there if James needed her. Kate and Jennifer were unique in that they had recently started doing some limited holding experiences and their babies were able to handle more touching and sensory input. However, Michelle and Yolanda still were under minimal stimulation protocols that greatly reduced those touching interactions. Yet, touch still emerged as a way mothers reported “being there.” Yolanda further explained:

If I got to hold dem. I think that’s the only thing right now that would make me feel closer right now, if I could hold dem. . . . I just wish dey kinda knew who I was. I’m not sure dey know who I am.

I think the most powerful portion of this statement is Yolanda’s perception that she viewed holding them as the way to let them know she was there and develop that bond. Yolanda also
went on to discuss her reactions to Tyrell’s medical care and the amount of touch her babies received from the nursing staff:

I don’t know dey sense who I am. Dey got everybody touchin’ dem, so dey used to people touchin’ dem. And I want to just have dem know when I’m touchin’ them.

And I don’t think dey know dat. So dat kinda make me mad right there.

These intense desires revealed by mothers to touch their babies in an effort to communicate their presence presents a gap in the current situation. If mothers perceive touch as the primary communication method for conveying this powerful message and they cannot touch their babies or have minimal touch interactions, a barrier is present. Further investigation into parental perceptions of ways they feel they are “being there” for their babies would assist medical staff in meeting this need reported by the parents in this study.

Loss

Themes emerged throughout the interviews depicting messages of loss. The major forms of loss described by the parents were the loss of control, loss of expectations they had for their child, separation, and grief issues.

Control. Parents all experienced a loss of control on many different levels and areas surrounding their children’s hospitalization. One of the first overt comments that struck me was when Kate was telling me her story of Luke’s birth and his unresponsiveness. She shared:

He wasn’t breathing so they had to work on him right away. They held him up above the curtain so I could see him when he was born and then they rushed him away to work on him. I kept asking over and over how he was and what was going on, but they were trying to hide it from me.
Her perception of the hospital hiding information regarding her child was very upsetting. It leads one to wonder how those experiences then shape how parents perceive later negative experiences. Kate later described her current experience with nursing staff: “Some nurses try to make me feel like it is touch and go, but I know better because I am involved and know how he’s doing.”

Kate told me that she had generally experienced positive interactions with nursing staff and had actually nominated one nurse for an award. However, she reported there had been a few nurses she “didn’t like.” I am not sure to what extent that initial experience at Luke’s birth had influenced her experience and perception of nursing communication and attitudes.

Kate was not unique in her concern that nursing staff may “hide” information. Yolanda stated her concerns at the birth of Tyrell and Monique. As previously mentioned, Yolanda had an emergency C-section, and she was sedated during the delivery. She didn’t remember anything until she started to wake up. She began to tell me what it was like as she came to: “I was too drugged up. I couldn’t see dem. But I was up, asking dem, ‘where da girl was at,’ but [the nurses] wouldn’t tell me nothing. So I ain’t get to see them till the next day.” She told me that she did not know what was going on and did not understand what the medical conditions were that her children were facing. Yolanda later discussed her frustrations with everyone touching them now (as needed for medical care) and viewed that as contributing to her feelings of Tyrell and Monique not knowing who she was. This contributed to her feelings of helplessness as she stated: “Causes I can’t do nothin’ bout dat right now.”
I personally could identify with Yolanda’s lack of understanding. Although I have medical training, as well as extensive child development knowledge, the experience of suddenly being told, “Your baby is very sick,” is overwhelming and a sudden sense of confusion sets in. I can remember, in my own experience, calling friends to bring my textbooks and professional resources to the hospital immediately so I could read about Aidan’s condition to be better prepared to ask questions of the doctors. Suddenly, within 24 hours, Aidan went to being bottle fed with formula, as prescribed by the doctors, with no prior notification to us. I arrived to give my milk and they had already fed him. There I was pumping milk every two hours and had arrived fully prepared to give Aidan my milk, only to have lost control of the situation. I had knowledge but no access to a doctor to better understand and clarify for me why that decision had been made without me. Unfortunately for Yolanda, she had limited education and no medical or child development training to give her even a basis from which to build. I can only imagine the degree to which she was feeling that loss of control and lack of understanding.

Michelle also described her loss of control and helpless feelings:

I guess the fact that I can’t do anything. There’s absolutely nothing I can do. And that, that’s the real problem right there. ‘Cause I can stand there and look at him, I can even touch him some, but there is absolutely nothing I can do to make him feel better. And that makes it hard right there. So helpless.

Jim voiced the same experience as the other parents saying it was difficult to not be able to do anything to help. He also discussed the medical terminology and confusion about the equipment. Following the previous statement from Michelle, I asked Jim if it was the
same or different for him. He answered: “Yea, pretty much. Not being able to do anything to help.”

A recent study on the father’s experiences in the NICU revealed the overarching theme was a sense of lack of control (Arockiasamy, Holsti, & Albersheim; 2008). It would be a valuable component of our FCC practices to empower parents to take more control and help them feel they were in the role of parenting. Further exploration of parents’ rights and interactions with the medical staff should be conducted so those involved can better see how to empower parents during this critical time. Pohlman (2005) reported that fathers’ stressors often lie outside the NICU, such as with work and financial responsibilities, resulting in an invisibility of their stressors to healthcare providers. Other studies have reported similar findings that support the experience of the father in this study (Arockiasamy et al.; Haut et al., 1994).

Jennifer reported her attempts to gain control by providing for Skyler’s routine care needs:

I’m begging them, “Can I check his diaper, please, can I?” . . . It’s like you know the emotions say I shouldn’t have to ask, “Can I come back and see my baby,” and I shouldn’t have to ask, “Can I check his diaper?” He’s supposed to be home. I should be able to feed him when I want to and hold him when I want to and change his diaper when I want to. It’s like you have to go through a third party to be able to bond with your baby. That’s been hard.

It is important to note that Jennifer stated to me that she felt the nursing staff were in favor of her participating in her son’s care, although her comments, such as the previous one, may lead one to question her acquisition of the motherly role she was desiring. Previous
studies have also reported that parents described feelings of being unable to parent as they would like and felt inadequate compared to the level of care provided by the NICU staff for their infants (Haut et al., 1994). Jennifer also discussed rumors she had heard about NICU staff and her experience in relation to those:

I’d always heard before coming to the NICU, “Those nurses are really possessive of their babies,” “Don’t touch them before you ask them,” say “May I touch my child,” or whatever. But they’ve all been like “whatever you want to do. If he needs something just call me.”

It is interesting to note the control language. She said the nurses said, “If he needs something just call me.” Although the nurses’ statement appears to be intended as supportive, it could convey the message that if her child needs something, the nurse is the primary caregiver who will provide it. Do statements like these convey that parents are empowered to be providers of their child’s care while in the NICU? Perhaps rephrasing that questions as to “If you need anything, just let me know” would convey that the nurse is there to assist the mother rather than take her place as provider of care for her infant.

Parents differed in their sense of personal control throughout their NICU stays. Jennifer voiced much more control in feeling comfortable in asking to do things, saying me, “I am his mother.” Whereas the other parents seemed to follow the nurses’ lead as to what options they had, Jennifer appeared a bit more bold. It must be noted, however, that this mother had a husband who was a resident at the same hospital where her son was being treated. She had access to a doctor 24 hours a day with a husband who is a doctor. He could also help her understand medical issues and terminology. This may have been a contributing factor to her increased understanding and medical explanations to me. This may also connect
back to the previous discussion on education level and access to medical knowledge as I examined the different dynamics between my and Yolanda’s medical understanding.

Yolanda reported feelings of fear that appeared to originate from the doctors asking her to consider removing support from Tyrell. She also appeared to have a poor relationship with the nurses, as she told me they gave her “dirty looks” and “turned dey heads” so they did not have to acknowledge her touching her babies.

Jennifer later discussed both her understanding and frustration about the dynamic that doctors “have to learn,” but that she didn’t want to be present during those times of discomfort for her child. Jennifer described how helpless she felt during his last extubation:

I’ve been back there when they intubated him and it’s kinda hard to watch that kind of stuff when, and I understand with it being a teaching hospital and my husband being here and I understand having to learn, but when they had to reintubate him they actually did that three days ago. He had to be reintubated. And the resident tried three times before the attending had to step in. And that was really hard watching the resident not get it three separate times and his little face squirming. It was my option not to be there tomorrow when they extubate him again and just let daddy handle that . . . because I don’t want to go there again.

It is incredibly difficult to watch your child suffer through procedures. I have lived this experience a few different times when I chose to serve as an emotional support while Aidan underwent different medical procedures. The choice to stay or not to stay should not be judged with a value of what is right or wrong, but rather what is right for that family in their own lived experience and capacity to handle what is presented. I respected Jennifer’s
choice not to be present during the extubation. She expressed that she would allow her husband to handle that because it was something too difficult for her at that time.

In further exploration of this issue as it relates to touch, Yolanda discussed how she didn’t even know that she would be able to touch her twins while they were in the NICU until one day a nurse mentioned it in passing. She explained:

I didn’t even know I could touch dem. [The nurse] was like, “Do you wanna touch dem? Do you wanna clean dey mouth?” . . . and I was like, “Can I touch dem?” and she was like, “Yea. You could’a been touchin’ dem.” ‘Cause I didn’t know. Nobody told me dat. ‘Cause at UAMS you couldn’t touch dem. She was like, “Yea, you can touch dem”

I perceived this as a form of loss of control because Yolanda had been grieving the loss of touching and holding her babies. It was not until the day before the interviews that she had been able to finally touch Tyrell and Monique. She had previously been told by doctors at the delivery hospital that she could not touch her babies. She assumed that was something she would not be able to do until the nurse mentioned it in passing. She also reported that the nurse told her that she “could’a been” touching her babies. She had lost days of that desired contact all because it was not communicated to her.

Over all, parents verbalized through their interviews that they were getting more comfortable asking questions and doing things for their infants. Michelle explained her rise in comfort level:

I ask a lot of questions so they kinda sit with me. Because I am constantly asking questions about him, what to expect you know. You know what has changed, what
does she think, you know, what’s gonna happen. . . . They say too much information is not good, but I can understand better if I know everything.

Parents appeared to perceive the hospital staff as a powerful entity who were providing so much. As Kate described her experience of having almost lost Luke, she began to cry. She talked about the hospital staff and stated: “I owe them everything I will ever have because my son wouldn’t be here if it wasn’t for them.”

It was interesting to me that, in many of their comments about interactions with nursing staff during touch experiences and perceptions of support from nursing staff in regards to touch, all parents voiced to some level that they saw the nurses as supportive of them touching their child. However, as I looked for common phrases among the transcripts, I noticed that all the comments frequently had what I labeled “control language.” Phrases like, “she let me,” “they told me I could,” or parents asking for permission to do things that would be perceived as a parental right were frequent in all the transcripts.

Kate described the catalyst for her empowerment resulted from two “bad experiences” she had had with nurses. I asked Kate to tell me more about those bad experiences, but she said she did not want to. I wondered if that motivation was linked to previous studies in which parents have reported the fear that upsetting the nurse would result in less quality care for their infants. When I asked her how those experiences made her feel, Kate responded: “It actually made me feel closer to him. I knew I had to be the one to stand up for him and started asking to do more things for him.”

During this portion of her interview, Kate’s body language appeared more erect and strong. Her voice was sterner and she had a determined look on her face with somewhat of a frowning expression. Overall she discussed how she had positive experiences with most
nurses, but that those challenges only made her stronger and closer to Luke. It appeared to me that she was taking back some of the control that had been previously lost. This discussion closely aligns to Fenwick et al.’s (2008) finding that as parents began to take on more initiatives and develop more comfort and competence, they began to voice their own views and desires to nurses. In that study the authors cited one father who said almost the exact same thing Kate did in the above comment. Other studies have had similar findings with parents assuming a perceived control over their baby; Aagaard and Hall (2008) reported “from their baby to mine” and moving from “silent vigilance to advocacy”.

Control was an important theme that emerged. As I reflected back on my understanding of FCC, I began to question what role nursing staff had in the control of what touch interactions parents had. The question came to my mind: “Who has the right to put parents in a submissive state where they must ask permission to do all the things most parents do as the primary caregivers of their children?” I also wondered if parents felt this way naturally due to the situation or if there was an unintentional phenomenon that was occurring to place parents in this role. I wondered if, as parents became more comfortable over the weeks and months, they would then enter the room and say, “I want to” rather than “Can I?”

The parent reports in this study were similar to those in Fidler’s (2002) study, which found fathers reported staff as being seen as parent-like, resulting in important milestones being lost (e.g., cutting the cord, holding the child right after birth). Kenner and McGrath (2004) reported that parents perceived nurses as having control over them and used coercion as a way to motivate parents. However, because parents depend on the nurses for access and assistance, the control dynamic presents a difficult boundary within the parent/nurse relationship. They reported the rules established by nurses made parents “obey” them,
resulting in a continued loss of control. This will be discussed more later in the comparison with the nursing reports.

Both Kate and Jennifer talked a lot about all the precautions they took during pregnancy to avoid complications. They discussed their diets, vitamin intake, their choice not to take medications, and other health precautions that were recommended for their pregnancies. Jennifer described her preparation for her son:

I just didn’t expect this at all. I hadn’t had any problems. I didn’t even drink caffeine or anything. I took prenatal vitamins, I didn’t even take one Tylenol . . . [laughs]. There was nothing other than my high blood pressure that was wrong. His heart rate was always good and his ultrasounds were always good and he was perfect size and you know. . . . We didn’t expect to be here . . . it’s not supposed to be this way.

I wondered if their insistent messages of all the reasons their children should have been healthy were a reassurance to both themselves and me that it was not their fault their baby was in the NICU. Lori revealed that a nurse had told her that her son would not be here if her body had “kept him longer.” This language was very powerful for me. It could be perceived as conveying the message that these mothers either chose to or unintentionally failed their babies. Although Lori reported she did not feel the nurse intentionally meant to hurt her feelings, she expressed that it bothered her. These experiences could manifest as a form of guilt of their body, in essence, failing their baby. Although they had had no control over the situation, I wondered if it was perhaps the catalyst for this portion of their interviews. Neither Michelle nor Yolanda discussed this during their interviews, however, further studies that could explore the psychological guilt associated with preterm deliveries is
needed to better understand and serve these mothers in providing the appropriate amount of emotional support regarding these issues.

Kate described how being able to do kangaroo care made her feel more empowered. After we discussed touch experiences revolving around kangaroo care, she said she started asking to do more necessary care routines for her son such as: “Can I change him, can I bathe him, can I change his clothes. Because he is my baby and I guess I like doing those things because he’s mine.” She discussed how she felt powerless and scared prior to the kangaroo care experience she had had.

One must consider that as each day passes, parents have more and more opportunity to raise their comfort level; however, it is interesting to note that the feelings of empowerment most parents described were somehow connected to a touch experience. Kate didn’t mention kangaroo care until I specifically mentioned it, and then she began to tell me how powerful it was for her. I wondered if it was because she did not think I would know what it was or if she was speaking in general terms for another reason. It was interesting to me that she viewed that moment of skin-to-skin contact as the turning point in her experience and yet didn’t specifically mention it until I asked for clarification of the type of touch.

*Expectations.* All parents had experienced a loss of expectations. Although they had little control over the things currently happening in their child’s life, they all had anticipated taking home a healthy baby at full term. For some of these mothers, their pregnancy was cut almost in half. Each of the parents in this study had had no reasons prior to delivery to expect having a baby preterm. Kate discussed early in her interview the loss of what she had planned as the ideal birth for her son: “It just wasn’t supposed to happen like this. I had plans. I don’t even have stuff for him, yet. We haven’t had showers. We haven’t even
finished his room.” Lori expressed the same message: “It just wasn’t supposed to be this way.” Jennifer gave a powerful description of the loss of control as previously mentioned when she described having planned to breastfeed, change him when she wanted, and hold him when she wanted to. She commented: “We didn’t expect to be here. It’s definitely . . . not supposed to be this way.”

Yolanda discussed a bit of a different perspective, although it was still a loss of expectations. She described all the things she had purchased for the babies and felt they would go to waste: “It’s quiet . . . It ain’t what I thought so . . . first thing ‘cause you want to see day first babies. ‘Cause I done had all these plans for ‘em. I guess I call it a little cage” (referring to their isolettes and the environment). As I further investigated the plans she mentioned, she began to talk about the clothes she had purchased for Monique and how she perceived they would not be used:

But den I really take dem home and start dressing dem up. Now I can’t even put em on clothes yet. Dat make me mad . . . I bought a lot of stuff. Family been buyin’ thangs. Trying to buy stuff. Everything. All kinds of. I been wanting to put on these little dresses my auntie bought. And all these head bands and stuff so, not being able to put on all that, then you feel like it’s going to waste . . . ‘cause by the time she be get out of here, it ain’t gonna fit.

Something interesting I noticed about Yolanda is that she often referred to future plans for her daughter, such as in the previous passage where she was anticipating her daughter would come home, but that the clothes and items she had planned on using would be useless. She never mentioned in her interview anything about her son’s future. There was no discussion about his clothes or toys. She didn’t even mention asking for him at the birth
like she did her daughter. I am not sure as to the dynamics regarding this, but it made me wonder if her anticipatory grief in potentially losing Tyrell and the projected outcome for his quality of life had caused her to briefly distance herself from him. Her focus was on her daughter.

*Separation.* Parents all reported similar experiences that influenced their ability to bond with their babies. For the purpose of this study, bonding was defined as the closeness perceived by parents toward their infants. Barriers to bonding that occurred most frequently were parents’ closeness to the hospital, their communication with medical staff, and primary nursing.

All the mothers in this study were staying close to their babies by remaining at the hospital. Jennifer described her feelings of needing to be as close to her baby as possible. She explained how she sat at his bedside most of the day and just looked at him and talked to him. She described those experiences as “being right there” should her son need her. Jennifer explained her few experiences of leaving the hospital as stressful times:

[I] go home to shower and I’ve taken a couple of naps at home, but I don’t sleep well when I’m at home and just worry about him being up here. My husband and I have both left twice, and that’s the hardest part whenever that there’s not one of us here.

Mothers often returned to the idea of closeness to their babies, as Jennifer did in the above quote. Michelle explained her experience when she spent a night at the hotel and her difficulty in being away from the hospital:

I guess just being close to him makes me [feel close]. Because when I leave the hospital . . . it really bothers me, to the point I can’t rest well because I want to be right here. And if it means that I don’t sleep because being in the ICU then that’s
what it means because it’s like, it hurts, physically hurts me. ‘Cause I don’t know if he’s okay if I am not here. So I don’t know. I am trying to do my part the best I can.

Lori and Kate felt the same way in that they reported needing to be near their children. Yolanda did not directly refer to closeness as a desire in her interview. She revealed that being present in the NICU was a stressful experience, as previously reported. Seeing her twins in their present condition appeared too difficult for her and she chose not to be near in that respect. Although she did visit a few times a day, she had a different experience than the other mothers.

Jim expressed a desire to be near Jett. Distance was a factor that had kept him from being able to be as near as he wished to Michelle and Jett. He described constraints due to the distance of separation, money, and other resources like time:

With our daughter, just as a comparison, the NICU that she was in, the waiting room was smaller than this room, so, there wasn’t nothing for the parents. So if you didn’t live close, you either drove it all day or you stayed in the motel. You didn’t have any other options . . . ‘cause you couldn’t afford it, and you know, you picked your times to come up. . . . So you know we been lucky in that sense . . . throughout the week she has been able to, um, stay in the waiting room and stuff like that. . . . It’s too far . . . to drive every day.

Haut et al. (1994) described bonding attempts in the NICU as hindered by multiple things including the length of time parents are separated from the infant. The parent reports from the current study appear to support previous findings.

_Grief:_ All parents described feelings of loss of their baby to some degree. Kate’s experiences involved having seen Luke lifeless and at that moment having little hope of his
survival. Her interview was a very emotional one in which she showed more overt physical responses, such as crying, more often.

The parents in this study all had unexpected traumatic deliveries that allowed no emotional preparation time. Michelle described her anticipation of her son’s birth: “They actually told me that his chance of survival was very, very slim. I didn’t expect him to survive the delivery. Neither did anyone else really. And he survived it and he’s here.” Her husband, Jim, described his experience with the unexpected survival of their son:

I mean when I guess when they sat her up to do [the epidural], I guess being like that triggered everything else to kick in ‘cause they got her you know in position or whatever and they were already seeing the head. And it was like, you know, it was a mad house at that point, and like you said, we wasn’t expectin’ him to survive the delivery. And so you know, when he came out and he cried, you know it kinda I don’t know just said well, “Okay.” We are going to do more now, it ain’t just a still birth or nothing like that. ‘Cause that’s the way everybody, you know, we took it. It was that the baby was not going to survive the delivery and so when he cried when he was out you know [he paused].

And Michelle finished his paused comment with: “Hope.” Then Jim nodded in agreement. He looked at Michelle and then the ground. He pressed his lips together as so to maintain his composure and prepare his thoughts. He then continued:

Yay, almost a sense of normal. We knew it was still a shot in the dark, but you know when he cried it was kinda a normal sense. That right there made me feel a whole lot better. Because we were pretty much told the chances of him surviving was slim to
none. And we had pretty much come to terms with that. . . . I mean we don’t [he paused].

Jim paused with an emotional look toward the ground. It appeared he might cry so Michelle quickly took over and continued where he left off:

I think that is why we’re so calm about it. Because . . . he’s here and he wasn’t supposed to be. And so. I think that’s why the doctor is like, “Don’t freak out,” and we haven’t. Because if it wasn’t for them doing what they’re doing and him being a fighter like he is then we wouldn’t have him right now. So I am blessed to have him for whatever, however long God lets us have him.

Jim regained his control over his emotions, and he continued:

But, really, I mean we just you know . . . we’re taking it one day at a time and we don’t want to get our hopes up too much you know. Still the doctors are telling us there can be major complications. We try to prepare for that because you know. We are still hopeful and hope for the best. And he can’t be doing any better than what he’s doin’, so you can’t ask for anything more.

Michelle then followed him with these thoughts:

So I mean, we try not to be too optimistic, overly optimistic about his condition. We know there is still a lot of milestones he’s gotta clear, but he survived delivery, so. He survived the first 48 hours and his lungs are developed enough that they are working, maybe not at full capacity, but they are working.

And then they took turns listing all the major organs that had been examined and appeared to be functioning properly, followed by a list of major organs that tests were scheduled to examine. Then Jim gave some glimpse of hope and joy he had by adding:
So we’re just playing the waiting game and let him kick butt. So I am really happy. And you know it’s not all doom and gloom. I know there’s babies that don’t make it, and I know there’s still a lot of stuff that can go wrong . . . but we’re really trying to stay optimistic about the whole thing and you know as of right now in the way he’s going . . . you can’t help but be optimistic.

Then, as it appeared that although Michelle agreed to some extent, she brought up a more heart-tugging thought. She discussed her choice not to purchase any clothes yet given that the future was still so undetermined:

We’re happy about it and it’s going great, but I’m not out there buying clothes yet. . . . ‘Cause at any point and time it can go wrong. So I mean, I still got that in the back of my mind. He’s doing well. But in the back of my mind, I’m happy that he’s doing well, but I got [his possible death] in the back of my mind.

She needed a break because the emotions were becoming too strong to hold back, and she cried for a moment. Even though neither of these parents specifically used the word “death” they referred to it with pseudo words like “that,” “it,” and “you know” with an upcast eye so as to communicate they didn’t want to say it. They continued to discuss the choice not to purchase clothes and the emotions revolving around these fears.

Yolanda had a different experience in that her hope was cut short for her son as they arrived at ACH. She told me her experience when the doctor discussed removing life support from her son:

Then when I first got here, der dis doctor, well, one of ‘em were at the other hospital and one of ‘em was here, and one doctor askin’ me did I want to pull the plug on my little boy. ‘Cause he said he was gonna be mental and a lot of parents pull the plug.
When I got here . . . dey told me his brain couldn’t get no better, it was at a grade IV.

But today, they did another ultrasound and it was a grade III. So, it done got way better.

Yolanda then continued to explain how upset she was with the doctors who had presented this option. The thought of removing support angered her so that she then discussed fears that medical staff would do something to hurt him.

And I kinda, kinda don’t want him to be here. I just don’t trust people like that. I don’t know what they gonna do. Say dis woman came to me, ask me do I want to pull the plug and she seem like she’s a little upset ‘cause I wasn’t gonna pull the plug. Sayin’ it wasn’t gonna get no better, but now it gettin’ better. So made me kinda frustrated to even have ‘em at dis hospital, knowin’ what gonna go on. Is it gonna be what God intended or somebody else gonna go and do somet’in? Dat’s frustratin’.

Yolanda repeated the above statement multiple times using almost the exact same sentences. She frequently referred back to the doctors talking about “pullin’ the plug” and to her discomfort with nursing staff and what they might do to him. I believe that repetition was her way of communicating its significance for her. Yolanda appeared to have limited communication skills and a difficult time communicating her understanding of the medical conditions. Again and again she reassured me her son was doing better and that he was better than the medical staff had thought. She appeared to equate that with the hope that he would continue to get better, although she made no reference to his future as she did with Monique.

Kate had experienced first-hand grief with the birth of her son in that he was lifeless and nonresponsive at birth. She expressed much gratitude toward the hospital and God for the survival of her son. She cried and showed deep emotion as she told her story: “I didn’t
think he was gonna make it. I just didn’t. I only got to see him for a second and then he was gone. And I was like . . . Is [when they held him over the curtain] the only time I’m gonna ever gonna see him?” Kate repeatedly assured me that her son was doing much better compared to other babies in the NICU:

I am truly blessed. They call him a “whimpy white boy” because he was born so healthy, just early. There are so many out there who are sicker than he is. We turned down a room at Ronald McDonald because we’ll be going home soon and there are other people who need it worse. We are doing really well.

All parents reported concerns for their child’s progression in health. The severity of each baby’s condition varied, with some of the parents expecting to go home sooner than others. Yolanda made no mention of the length of time she anticipated to be there. With little understanding of Tyrell and Monique’s condition, I can only imagine the confusion and frustration she must have been experiencing. All parents discussed the common tests that all babies in the NICU experience. They reported progress as well as those areas still to be determined.

Jennifer described how the doctors could not find out what was happening with her son:

They can’t find out what’s wrong with him . . . nothing that could be causing the problems . . . we just don’t know. We don’t know how long he’s gonna be here, . . . what’s going on . . . and they are like, “I’m sorry we don’t have an answer for you on what is going on.” We just want someone to say, “He’s going to be okay, and he’s going to be okay.” But they can’t. Because that would be false hope because they don’t know what’s going on. That’s kinda hard.
Jennifer continued to describe her anticipation of breastfeeding him and providing her breast milk for Skyler. She then explained the process of intubation and how she had seen the doctors attempt to reintubate him because the extubation failed, and it was evident her son needed to continue to be on the breathing machine. This caused much concern and disappointment because his condition was not improving as anticipated:

I am just really hopeful that everything goes okay tomorrow. And if it doesn’t . . . I know it will be really hard, because when they had to reintubate him it was just, he didn’t take it real good . . . which is hard because when you take a step in the direction of recovery and you have to take that step back it’s hard.

Parents all felt that progress was an up and down battle. They described the feelings of joy when their children made progress, but often referred back to the anticipatory grief that loomed in their minds. Jim said: “There’s a reason why they want to keep him up here, so you know that’s always playing in the back of your head, what kind of serious problems can occur.”

Jennifer later discussed Skyler’s medical concerns and his journey to recovery through the use of an analogy:

It’s like a roller coaster that whenever you are about to take the next step forward it’s exciting and nerve wracking all at the same time. But you just have to be hopeful and say my prayers and hope he’ll be okay and that tomorrow and if he doesn’t . . . we’ll get through it. It’ll be hard, but.

I found it interesting that Jennifer, as other parents, stopped her sentence before she said the words that all the parents appeared to avoid. I cannot be sure what Jennifer would have said if she had finished her sentence, but as previously stated, other parents stopped sentences
before they said things like “that he won’t make it” or “if he dies.” As discussed previously, parents appeared to avoid the death words, but communicated the emotions they were anticipating such as when Kate said, “It’ll be hard, but.”

Lori also experienced the powerful feelings of fear as each test brought new anxieties. They had been doing routine scans and exams of her son’s heart, brain, and other organs. She described those moments of waiting for results as emotional and scary. The results had the potential to be a step closer to home or to bring anticipatory grief if the results were not positive. Jim expressed the same experience as he described Jett’s progress:

They’d done scans of his heart and brain and all. You know this is all really important information for us, important milestones and all. ‘Cause you don’t have a heart murmer and his brain ain’t bleedin’ those are good things, but if they are, then we need to be prepared for that.

It appeared that, although Lori and Jim had hope, they too still had those feelings of fear that something could still be wrong or go wrong with their children’s recovery. That emotional distance was evidenced in all the interviews, where parents described those feelings as “in the back of my head.”

All the parents interviewed expressed comments of hope to varying degrees. Although they also expressed anticipatory grief comments, it was encouraging to hear them talk about their anticipations for recovery, homecomings, and introductions to other family members. The term “hope” was used extensively throughout the interviews. Michelle even described Jett’s first screams at delivery as, “Hope.” He was not expected to survive the delivery so his voice alone was the first glimpse she had at hope.
Touch also was heavily involved in how parents expressed significance for hopeful feelings against the grief and loss issues. For example, Jennifer said:

It was just, makes me feel like it’s gonna be okay. I mean even though we can hold his hand and see him, whenever you see him laying there, and whenever you can hold him and put him up next to you . . . it just makes me feel like it’s gonna be okay and he’s gonna get out of here.

Support

Each of the parents discussed the support they currently had. I found this closely related to each of their experiences with the other themes of positive touch experiences, separation, and primary nursing that emerged in the study. For example, in relation to the previous discussion on separation, families described who “was there for them” or provided for different needs. Both Lori and Kate described their families as a source of support during their separation from home and in meeting their needs at the hospital.

Kate emotionally described the role and support of her husband as she cried. She told me that he stayed with her the whole time during the delivery and that she “couldn’t have done it without him.” Jennifer described her husband and how his supportive role has helped her in so many ways:

My family and my husband have been there for us. My husband has been wonderful and when he breaks down, I can be there for him, and when I break down he can be there for me. And you, know, we’ve broken down a couple times together. It’s been pretty good with one of us being able to hold the other one up. So I’ve got a really good support system.
Jennifer also described the nursing staff as a great source of support for her. She reflected on the stories shared by medical staff and how those stories and encouragement have helped her during this difficult time:

The hospital staff has been a huge part and the nurses really. It’s been amazing to hear how many of them have gone through this type of experience with their own kids or known somebody, so they’ve been a really big support saying, “I’ve been through this, too.” Or they’ve been encouraging to take care of ourselves because whenever we do go home, we’ve got to be there for our son and for us to go to sleep, so they’ve been really great.

Michelle and Jim had different perspectives on their support systems. I found it interesting that each reflected their current lived experiences. For example, when I asked Michelle who had been a support for her during this time, she responded:

Actually, the doctor. Every time I go in there and she’s talking to me about it: “Do you have any questions? What can I do to help you understand anything more?” in a sense of trying to understand my child. Emotionally, it’s been my family. It’s been great.

Jim was living with his sister, and she and her husband have helped with their daughter, so Jim’s response was:

Mine probably, I been . . . you know I can’t stay up here so she pretty much fills me in on the day’s progress and what’s happened throughout the day, but um, probably I’d have to say my sister because she’s watching our daughter for us while she’s up here and I got to work, so I mean between her and my sister . . . them two is where I’ve gotten most of mine.
I remembered the same experience as Jim and Michelle in having my own baby in the NICU. I cannot imagine what would have happened if I had not had a mother who cared for our daughter and drove her to see me each day. It was so painful to make those choices as to allocation of time and attention having children in multiple locations that are an hour apart. I also had the wonderful experience of a husband who drove back and forth to bring me items that I needed and provided emotional support through frequent phone calls during that week.

Yolanda had a different experience than the other families. Although she did mention an aunt who she stated had been supportive of her pregnancy, she had little access to family at the hospital. No one from her family had been to visit at the time of the interview. When I asked her about support, she responded:

Somewhat . . . It’s kinda a mixture. I don’t know how I truly feel about it. I got da dad here with me now. But I understand dat dey got things dey gotta do deyself. It’s ok. I guess. I feel like I got one auntie. She always dere. She been helpin’ me get back and forth so all dat.

Yolanda then described the presence of the father as “frustrating” because they were fighting with each other. I am not sure if she was angry with him because he had not been there for her during that time, if it had to do with their past and the current status of their relationship, or perhaps something else. She described the dynamic of support from her perspective:

It been difficult [being alone], but den I think time get better, like this weekend get here. It’s just he’s frustrated ‘cause he can’t get here. Then I frustrated about it. I ain’t gonna say we fight over it, but I kinda bicker at him, he bicker at me. He bein’ mad, then I get mad. It’s all kinda worse. I think it makes everything more frustrating.
Yolanda added a rich perspective on the role of peer support from other parents who were experiencing similar situations. Yolanda told me the progression of her experience with sitting in the waiting room and how talking to other parents had been helpful to her. None of the other parents mentioned this dynamic. However, all of the other parents in this study had other sources of support of which they spoke highly. It appears that Yolanda had had no one else available, and perhaps the other parents in the waiting room were serving as a pseudo support group for her until her family could later assume that role of support for her. She ended her description of the other moms with: “It make me feel better.”

At the end of each interview, I invited the participants to share anything else they would like to talk about. I felt this opened the interview to any area that we had not explored but that parents felt would be of interest. As Yolanda responded to this question, she described communication as it related to understanding the medical aspect of her children’s health as well as the emotional implications. As previously mentioned, Yolanda did not have access to a good support system. During this portion of her interview, Yolanda explained to me the dynamics of understanding and support within the context of other mothers and their stories, which I felt brought an interesting facet to her experience:

When [the other mothers] come to a place like this, and they see the other people sitting around out there. . . . Well, when I go dere, I was kinda like stuck up with it. I didn’t want nobody to say nothing to me, and I was scared to move and the waiting room got a lot of girls . . . some of dem force dey self on me to talk to dem. But then after dey’d talked to me, tellin’ me dey stories, how long dey babies here . . . some of the girls babies younger than mine, she was tellin’ me how better her baby is doin’ now. . . . The doctors get you information and you probably think the worse of it, but
as you listen to other people that just ‘cause the doctor says it, even though they doctors, don’t mean it gonna turn out like dat. Don’t just sit up in a bundle, talk to somebody about it.

I thought this aspect of Yolanda’s story was significant because it revealed her use of a support system to make sense of the communication and provide support for the hope she had despite some of the news the doctors had given her about Tyrell and Monique. Communication with others about the information from nurses and doctors allowed Yolanda to make meaning of her experience and to develop a greater perceived understanding of what was happening in Tyrell’s and Monique’s treatment.

It was interesting that the location of the parent appeared to play a role in where they viewed support coming from. Yolanda utilized available peer support and Jim referred to the sister he was currently living with. The couples all referred to their spouses and families. The two mothers, Michelle and Jennifer, who spent the most time at the bedside, referred to the medical staff in their discussions of support. This information has important implications for professional practice. Additional support groups should be considered as support for those who have no family present, and medical staff must closely examine their role of support to families who are often at the bedside. It also opens up the possible need for additional investigations into the perspective of sharing personal information with the families being served. Further deliberation into the amount of professional distance and barriers to personal information should be further examined. In this report parents shared the value of hearing the lived stories of staff members, so perhaps learning more about this phenomenon would better assist medical professionals in providing that level of support.
Primary Nursing

Primary nursing is described as a nurse assuming “primary” responsibility for a specific patient. That means whenever an individual is working a shift, he or she will typically work with that specific patient. At ACH, nurses typically work 12 hour shifts, so the parents in this study typically had two nurses a day, which adds up to 14 different nurses a week with whom they could be interacting. That does not account for staff rotations for lunches and breaks, all of which contribute to additional nursing staff with whom they are interacting.

Comfort levels with nursing staff and the neonatologist were linked to primary nursing themes. There were no specific research questions to explore this topic, but this theme emerged in both parent and nurse interviews. Although parents did not know the technical term, they described developing rapport with the same nurses and doctors. Jim described his experience:

I think it’s easier if you know the same nurse. . . . It’s just an easier transition if he has the same nurse. If you know the person taking care of your baby, it just ain’t another stranger. I don’t know. I give a lot of props to the nurses to the stuff they gotta see and deal with. I am sure it’s hard and I’m sure a lot of them don’t want to be attached, but you know I can kinda see where they’re coming from, but the same sense, you go over at night and you got a nurse, and you go over the next morning and you got a different nurse, so you never know from one day to the next who you got.

Consistency with the nurses, you know.
He went on to further describe feelings of being “really, really scared” and the possible security he would feel if there were more consistency in nursing staff. His wife continued his comments, saying:

Like you say, you get rapport with them, and then you can actually ask the nurse questions, rather than like say, “Okay, how’s this nurse gonna act with me? Am I gonna bother her if I ask all these questions?” that goes every single day when you have a different nurse.

Michelle discussed a positive experience she had with the doctor to illustrate the connection to primary nursing:

Like, uh, we have her neonatologist and I have seen her for several days now and I feel comfortable with her to where I don’t have to sit here and oh yea, let me ask her this. I am comfortable enough with her at this point now where I can ask questions and I’m not hesitating, I don’t feel stupid. I feel like she’s comfortable enough to be able to talk to me about it so it’s different if I don’t know the nurse or he has a different nurse every day.

Jim and Michelle continued their conversation by explaining the comfort they believed they would feel if Jett had a consistent nurse caring for him. Jim then told me that he hoped Jett would get a primary nurse in a couple days. He explained that because parents are scared during those first few days, that it would be helpful to get one as quickly as possible. Michelle continued with this description of her comfort level with nurses:

A familiar face is . . . easier to handle when you have a baby in the ICU than it is to see a stranger’s face every time you come in there and you have to feel that person out to see if you are gonna click with that person in the first place. Because if you
aren’t comfortable with your nurse then you can’t get comfortable with your child.

Because you feel like you’re in that person’s way.

Here one can see Michelle directly state those feelings of discomfort with nursing staff keeping her from feeling as close to Jett as she desired. Then Jim and Michelle began to give me examples of experiences that posed difficulties. Jim described Jett’s nurse from that morning: “She wasn’t bad, but you kinda felt like you were in . . . her way.” He followed with a description of various reasons why one might not “click” with a nurse due to her personality, her being busy, or that she just might not be a morning person. He was specific to make it clear that he tried his best to remain out of the nurse’s way and knew the nurse had a job to do. I believe he was referring to the nurse’s job of taking care of Jett, but he didn’t realize that in an effort to provide FCC, the nurse’s job was to include him and Michelle and make them equal partners in their son’s care. That may manifest in different ways for different families, as each family brings a unique set of experiences and dynamics that reflect their own values and belief systems. I felt sad that Jim expressed his presence as problematic and bothersome to the nurse:

You kinda felt like you were in, to me, I felt like I was in her way. . . . I’m always conscious about trying to make sure if they need to get over there, then they need to get over there. They don’t need me in their way. They’re trying to do their job.

This situation could have presented an atmosphere in which Jim didn’t feel welcome or began to resent the nurses’ reaction to him. Michelle then began to describe how comfort levels with nurses influenced her perception of medical care and Jett’s health status:

For example . . . you walk in and you know, “How’s he doin’ this morning?” And you ask about labs, and “I don’t know, let me go look.” And . . . they’re real nice
about it. Or you ask them how he’s doing this morning, and they look at you like, you know, “Pretty good I guess.” Not really saying that, but you just get the sense, “Well you don’t really know what’s going on” [referring to the nurse knowing their son and his conditional status].

It appeared to me that Michelle was communicating distrust in the nurses because she did not feel welcomed or that her presence was accepted. I believe she was expressing insecurity in Jett’s medical care because the nurses seemed “put out” with their questions. To see if I was understanding her comments, I then attempted to summarize this for Michelle by asking if it was the way the nurses were giving the information that affected her feelings toward the nurses and feelings about Jett’s care. She then summarized with: “It’s the way [the nurses] perceive it, you know, and react to you.”

Although all parents spoke about the concept of primary nursing, their motivations for such differed. For example, Yolanda discussed her concern of having so many nurses with not being able to blame someone if something happened:

You just never know about people nowadays. And what people would do. Rather have just one nurse or two nurses, where you know it could be this person, but five or six of them all doin’ different kinda stuff to dem. But some can’t just point no finger ‘cause you don’t really know.

Yolanda voiced much concern about the medical staff. Remember that the doctor had discussed end-of-life issues with this mother concerning her son, Tyrell, which she termed as “pullin’ the plug.” She further described that experience with the doctor as him “giving me a dirty look and gettin’ upset.” She ended by commenting on how she didn’t know who he was. Yolanda could not tell me who any of the doctors were who were working with Tyrell
and Monique. Nor could she name any of the nurses she had met. Jennifer, Kate, and Lori also voiced their desire to have more consistent nursing care for their children. The comfort level desired by parents in regards to consistent nursing staff presents a unique problem. Later discussions comparing views on primary nursing will be presented in the section on comparisons for nurse and parent interviews.

Parents reported that communication was an important component of their comfort and understanding in the NICU. Positive communication interactions appeared to facilitate open exchanges in which parents felt more comfortable asking questions and gaining medical information on their children. Jim shared his positive experience with the nurses explaining the medical equipment on Jett:

You know the nurses are real. They let you know what’s going on. We talked to . . . well I just came up last night. . . and I was asking questions. [Michelle’s] telling me the stuff on the phone throughout the week, but you know until you get up here and you say, “Well what’s that and what’s that,” I mean [the nurse] spent probably 30 minutes kinda going back over everything for me. That . . . was kinda nice.

Communication appeared to be a strong influence in the comfort level of parents as evidenced in the transcripts. The previous section on control issues revealed a different contribution to communication. Although communication and control emerged as separate themes, they are connected. If parents perceive medical staff as controlling, they perhaps view the nurses as withholding information or creating an uncomfortable setting for communication exchanges. Kate described the withholding of information during Luke’s delivery when he was in such critical condition as “they were hiding it from me.” This overwhelming and emotional experience then may have contributed to her later distrust of
some of the information presented from nurses her son currently had. Kate described, “Because I know,” in response to information that reflected a more dim outlook. I cannot be certain that Kate’s resistance to “bad news” is influenced only by the control of information she experienced earlier. The hope of her son’s recovery is a powerful catalyst in confronting poor news as well.

As evidenced by the research and the experiences shared in this study, parents are in an emotional period, trying to understand what is happening with their baby. Jim described a situation and his feelings of discomfort with something that had happened the night prior to the interview when information was not available. Jett had had some tests done on his heart and brain and they had been waiting for the results that afternoon. When Jim arrived, he and Michelle went to the bedside and asked the nurse, and the results were not in his file. They reported that the nurse did “a good job” and tried immediately to locate the missing files; however, the doctor was busy with another patient so the nurse could not ask at that time. Jett’s nurse called them later that night when she located the information. They had gone to the store to pick up a few items and received her call. Jim described this experience as: “That was as best as it can be, but then you get some that come in and say, ‘Well, that information ain’t here.’ And just you know, leave it at that. Well, [the nurses] kinda stand in the way.”

I found it interesting that Jim phrased the nurse’s slow response to locate information as a barrier in this situation. He then told me that when nurses have responded as illustrated in his previous statement, they sometimes just assume the best and try to go on. It is difficult to imagine not knowing information about your child that is critical for his or her survival, and just assuming because you perceive that nurses are not going to take the time to find out or appear apathetic in locating that information to you.
Michelle reported that even the conciseness of a nurse’s response can communicate that “you are a bother.” She gave an example of asking for the doctor so she could find out more about Jett’s results:

You say “When is a doctor going to make their rounds?” Some of them are like, “Well, it’s probably going to be an hour or so, and it varies every time.” But, [the nurses] try to give you as much information. . . . Or you’ll ask a nurse, “Has the doctor made rounds?” and they say, “No.” . . . “Well do you know when they will?” . . . “No.” That makes a difference in how you interact with your nurses. They give just direct short answers instead of you know, “They usually make their rounds around this time if you want to check back.” I mean, just that little bit of tiny information makes the biggest difference.

Jim and Michelle then began to tell me a story about a rash that had appeared on Jett’s neck. It is possible for babies in the NICU to have skin irritation or break down as a result of tapes and medications placed on their delicate skin. The new nurse had just arrived on shift and Jim and Michelle came in to visit Jett. The nurse asked them if they knew anything about the rash on Jett’s neck, to which they reported being very surprised. Michelle had been staying at Jett’s bedside most of the time, so she reported feeling concerned and surprised that it had not been noticed by the previous nurse. She described her concern about the lack of communication between all the different nurses Jett had had since he has been here with: “Somebody’s not passing on information.” Jim then followed her comment with:

Yea, are you not paying attention? Are ya’ll not paying attention? Which, I don’t know that she’s not seen him before. And I kinda thought in the back of my head, “You’re really not paying attention are ya?” . . . I guess I am over protective since
you know since he’s so little, so young, and everything else. You’re trying, you’re wanting the best of the best of the best, and we’re here. And that’s kinda you know, there’s no better place than here in this area at all. But you kinda, just for a split second . . . [referring to doubting Jett’s treatment as a result of the lack of communication between nurses] the attentiveness could have been a little bit more. . . . I just know how I felt.

Although Michelle had expressed she agreed with Jim in the concern about the communication between nurses, she revealed to me that she had a different perspective of the rash incident:

I guess we did perceive it differently because I looked at it as “I’m [referring to the nurse] seeing something, but let me make sure I’m seeing what ya’ll are seeing” . . . that’s how I took it. But it’s because I know she’s never been his nurse before.

Michelle followed this with describing that her constant presence at Jett’s bedside allowed her to know that this nurse is new and couldn’t have known about the rash prior to this experience. Although she was concerned the prior nurse hadn’t noticed it, she felt good that the second nurse quickly “got on it” and ordered ointment to avoid further skin breakdown.

Jim and Michelle had a more diverse experience to share than did the other parents in that this was their second NICU experience. Michelle described the comparison between their daughter’s NICU stay and Jett’s stay at ACH. Their daughter had been at their local hospital with a small NICU and limited resources compared to those at ACH. Michelle described that the smaller NICU allowed them to get to know the nurses and develop relationships with them. Their daughter had had the same nurses so there had been more consistency than what they had experienced at ACH. Jim finished their discussion on
multiple nurses with: “If she had been his nurse more than once she would have known a difference. It makes it difficult when you have a different nurse every day. Because they don’t know your child.”

Another factor to discuss is the experienced interpretation of what medical staff intend to convey. Sometimes when parents receive messages about their child’s health that they don’t want to hear, they may perceive the staff as “out to get them” or “not knowing what they’re talking about.” Although there is no way to know what staff actually said to the parents, one can only try to understand their experience of it and how they interpret the information doctors and nurses gave them. Much emotion influences how they process the suggestions and information from staff.

Yolanda described how she felt nurses perceived her questions:

[The nurses] give me the answers. Dey get tired of me asking the same questions. ‘Cause like all those monitors. I be asking, “What is dat? What is dat? What is dat over dere?” I really think they get tired of me asking questions. But I ask dem anyway.

It is unclear exactly why Yolanda perceived that the nurses did not want to answer her questions. Perhaps further exploration would reveal that their voice tone was harsh, they looked at her in a way that she perceived as negative body language, or perhaps their answers were very short which conveyed they did not want to spend the time explaining the equipment again. A consideration that is necessary in Yolanda’s case is that, with her limited understanding, perhaps the nurses were making an effort to give her minimal information so as not to overwhelm her. In their effort to simplify and offer the briefest answer possible, they may have been communicating to Yolanda that their time was not worthy of her
understanding. Yolanda followed the previous discussion with her comfort level at times of asking questions with: “I’m uncomfortable, but I wanna know. So I gotta ask if I want to know.”

It was also interesting to hear Yolanda then describe her experience each time she visited the NICU. She described being given all their status updates upon her arrival. This appeared to be contradictory in some respect to her previous comments of how she had access to limited information. Yolanda responded to my question about the amount of information she felt she had:

As soon as I come in [nurses] get to tellin’ me how [Tyrell and Monique] been, if dey vitals change, if dey increase, decrease, and all. [The nurses] be all ready, before I even have a time to ask. As soon as dey see me dey say, “How you been doin?” and get ready to tell me what the doctors done been changing.

This last statement presents a conflict in Yolanda’s perception of the nurses. She contradicted herself by saying the nurses were eager to provide information and welcomed her upon arrival to the NICU, but yet she also spent time explaining to me how nurses appeared to not want to answer her questions and she felt uncomfortable in their presence. Further examination is needed to explore contrasts in perceptions such as these.

Emergent Overarching Themes for Nurses

The 4 nurses who participated in this study comprised Mark, with 5 years of NICU experience; Janet, with over 20 years of NICU experience; Liz, with 1 year experience; and Molly, with 2 years of NICU experience. The nurse interviews were conducted during the same period as the parent interviews. The questions used to structure the nurse interviews were presented on page 66. These interviews were held in the same private waiting room as
were the parent interviews. There was little emotional response from the nurses, and they appeared to maintain an emotional distance from the phenomenon, as required by them professionally. Their perspective provided a more sequential presentation of the evolution of this dynamic. The overarching nursing themes were: (a) NICU responses perceived by nurses, (b) touch, (c) barriers to bonding, and (d) protection. At the end of each nurse’s interview, I asked what each felt the most important and influential way that parents bonded with their babies during this critical time. Every nurse responded by explaining the value of touch and its power for parents and babies as well.

**NICU Responses Perceived by Nurses**

Nurse reports revealed a process of emotional responses parents had as they first entered the NICU progressing to later stages when parents acquired more control and emotional security in the setting. Findings are listed in the order reported by the nurses as they described parental responses to touching their babies, allowing readers to see how parents feelings moved from being overwhelmed to more acquisition of control and comfort through the first weeks of their children’s admission to the NICU.

_Overwhelmed with emotion._ When nurses were asked about parents touching their babies and the emotional response to that interaction, they all responded that parents felt overwhelmed by the appearance of their fragile babies and the situations parents found themselves in. Janet illustrated the essence of their comments:

> So the first time they see the baby. . . . It’s very overwhelming. Usually they cry. . . . Because they’ve got tubes . . . coming out of everywhere, and um, you know we have a minimal [stimulation] protocol. The parents aren’t really supposed to touch and stimulate the baby very much.
She then began to describe the protocol to me. I found it interesting that, even though I explained myself and my position as a child life specialist at ACH upon our meeting, Janet responded to me as I perceived she would with some parents. She spoke slowly and provided much detail about protocols and policies. She also described medical conditions that occurred commonly as a result of excessive premature stimulation, thus necessitating the minimum stimulation protocol.

Mark described his experience and observations of parents by revealing his perceived role during this phenomenon:

Parents are afraid to touch so we have to make everything okay. We make them feel like it’s okay. This isn’t anything like they expected. Um, so yeah, my experiences have mainly been that parents are kinda standoffish at first and they need directions from the nurses.

Some of the nurses also described the dynamic between care and the parents’ feelings of being overwhelmed. I noticed that nurses all described a similar progression for parents. For the purpose of this study, I have chosen the term “parental role acquisition” to describe the process of parents gaining more control over the situation and experiencing more comfort in both the NICU setting and with caring and touching their infants. Molly described the comfort level of parents during those first few weeks of admission and experience in the NICU as well as her perceived role:

Very minimal [parental comfort level]. I know they’re always real, um, hesitant to do anything and it takes a lot of time and making sure they don’t want to hurt the babies, but that’s the thing that I see. They don’t want to cause the baby any harm. You have to kind of help them with what’s good and bad and help them with that.
Liz also described the dynamic of parental role acquisition and her perceived role as a nurse:

I think nurses can just get wrapped up in their job and start doing it and the parents are just watching. A lot of times parents are afraid to say, “Is there anything that I can do?” They’re overwhelmed by everything and they just feel like the nurses have to do everything. . . . I feel like I would like to help the parents as much as I can, just having the bonding, even if it’s just, “You can change the diaper,” or “You can take a temperature.” . . . so just enforcing, reinforcing to them, that it’s their baby and they can take care of them.

It was interesting that during this section of her interview, she also included a list of all the things parents could not do and differentiated that as well. This list included things like giving medications, suctioning, and tube feeds. I am not sure why Liz decided to add it in her description. However, I felt it was significant because Janet also reported a “list” of things parents could not do with their infants. These lists were spontaneously reported, so I felt it conveyed their perception of the differentiation of roles in the NICU between themselves and parents during this emotional time. Overall, nurses reported the same types of parental involvement such as changing diapers, wiping mouths, or assisting in bathing.

Another emotion that all nurses described was the emotion of fear. Some of the nurses even likened the parents’ experience to their own in an effort to explain to me the magnitude of the situation. Mark began his discussion of emotional responses with these comments:

At first the parents are gonna be scared, especially if they’re holding a child that’s on the ventilator, ‘cause I know that scares me, too, sometimes. ‘Cause there’s so much
support that has to go into that, you know. Making sure the tube stays in place . . .

maybe start there and then when they do it once they get more comfortable.

Liz said almost the exact same thing:

I can understand where they are coming from too, because I was a little like that when I was starting as a nurse. Like, “What have I gotten myself into?” you know, “What are all these lines” sort of stuff. So I can imagine how they feel.

Again and again nurses came back to feelings of fear and its influence on the relationship between the parent and the baby. Molly simply stated: “A lot of parents, they’re scared and they’re like, ‘I don’t want to hurt the baby.’”

The nurse interviews also gave insight into the common things parents ask and say during those crucial touch interactions that reveal their emotions. The parental association of fear with touch was revealed in each interview. Mark reported: “A lot of times [things parents say when touching their babies are], ‘I’m afraid I’m gonna hurt the child’ or ‘Is this okay? Are they in pain?’” Janet, with the most experience, phrased it as:

Parents are scared to death of their babies. They are scared to touch their babies, they’re scared to put a diaper on their baby, um, the parents that feel, and those parents are the ones that we really need to encourage.

Nurses continued to describe traumatic experiences that could further contribute to parents feelings of fear related to touch. Explaining the nurses’ contribution to the dynamic and the possible perception and experience of parents who have a negative touch experience, Janet continued:
We [nurses] are doing all these terrible things to this baby and then the parents come along and they touch and the baby may drop the pulse ox to 50, the baby may bottom out blood pressure. . . . So we do as little as we can. We touch as little as we can.

Nurses appeared to perceive themselves as a catalyst in the progression of emotional responses and interactions in the NICU. Modeling appeared to be a common practice that all nurses utilized in regards to this phenomenon. Mark shared a strategy to facilitate parents’ role and comfort level: “I’ll show them how to do it first, and from my experience, that helps them feel more comfortable doing it next time.”

The nurse interviews paralleled the parents’ reports that parents had all these feelings of fear and to have them realized by knowing that their touch caused their baby pain or danger further compounded that interaction and emotion. Liz related the feelings of fear with being sad as well: “I think a lot of times, they can be sad because you know they don’t want anything to be their fault if they you know, mess with their IV lines.”

The anecdotal experiences of the nurses also revealed differences in the perceptions of mothers and fathers. Janet explained mothers’ and fathers’ typical responses:

Mothers are very tearful and in tune to looking at the baby and “Does he have his fingers, does he have his toes, what color is his hair.” . . . Dad is more about “Um, what does this number mean? What does that number? Why does that way like that?” I mean that’s what dad’s do. They look at the monitors and stuff.

She further explained later in the interview:

Dads always respond with anger, most dads, not every dad. Some dads don’t, but it’s because they don’t have any control. They don’t have any say. That’s their baby, but
they can’t touch them, they can’t do anything for them. There are all these people around them. This isn’t what they planned.

Molly also shared her experiences with fathers as not being there as frequently as were mothers. She then proceeded to explain to me the possibility of that absence linked to their control and initiation in caregiving:

You will occasionally have a dad that will want to step up and take a temp or change the baby’s diaper or do mouth care or whatever it is, but generally it’s the moms that start out doing that sort of thing.

Additional research is needed to continue to examine the perceptions of fathers and their role in parenting a baby in the NICU.

*Grief and loss.* Similar to the parent interviews, nurses perceived some of the same losses with the experience of having a baby in the NICU. The loss of control was evidenced in each interview. Janet described why she thinks parents feel the loss of expectations and control:

It’s because they don’t have any control, they don’t have any say. They planned to go home and take a baby home and love on their baby. And they can’t do any of that. And depending on how sick [the babies] are, how premature they are, it’s even less that they can do.

Janet then returned to this issue as she further described parents’ loss of control:

This wasn’t what they planned. This wasn’t how they planned. You’ve taken control over something they created together. So I think that’s one thing we need to really be in tune to and to allow them to participate as much as possible.
As Mark explained his experiences in observing parental emotional responses in the NICU to touching their baby, he gave me an overview of the progression of emotional responses followed by the parents’ response: “Especially babies who are preterm and just admitted. This isn’t anything like they expected.” Mark reported this contributed to parents’ hesitant behaviors in the NICU which he coined as “standoffish.” This loss of expectations paralleled those reported by parents in this study as well as research studies such as Pohlman (2009) and Martinelli (2005) that evidenced feelings of loss.

Liz explained the importance of her role of in this phenomenon of helping parents assume parental role acquisition in caring for their babies during these times of loss:

If you just reinforce that everything is going to be okay and you are there and you’re going to help them. And I think that’s really important. So just reinforcing to them, that, it’s their baby, and they can take care of it, they can take care of them, even though they are sick.

In an earlier portion of Janet’s interview, she tried to help me understand parents’ emotional progression of being overwhelmed, fear, loss, and finally attaining more comfort. She talked about the lack of understanding as it connects to the issue of those lost expectations:

And it’s as simple as we put it [the special needs of their baby and the necessity for hospitalization], you can’t put it in their minds. They’re like “Well, when are they gonna get a bottle?” or “How long ‘til I can take them home?” They don’t really get it.

As previously reported in the section on parental experiences, mothers strongly desired to hold their babies and travel down the road toward health and recovery. As revealed by
Janet’s description of comments she has heard from parents, nurses appeared to understand the losses perceived by parents. That loss of expectation to hold and take their baby home and the goal orientation toward recovery were echoed in the reports from both parents and nurses.

When I asked Molly what she felt was the most difficult thing for parents, she replied: Just not having that perfect experience that you are supposed to, like you imagined . . . that your baby would be born and you’d take him home, and it’s just all of that is not happening, it didn’t turn out the way it was supposed to be. So for it to be there in an unfamiliar place with unfamiliar people, and then every 12 hours they have somebody different that’s taking care of their baby, that’s you know, they have to put their total trust into, I just feel like it has to be hard. It just wasn’t the way it was supposed to be. It’s just not the perfect picture of how the baby was supposed to come.

Molly’s comment revealed some of the same sentiments parents shared in the discussions on primary nurses, loss of expectations, and the unfamiliarity with the setting and experience. Parent reports described the difficult feelings of loss associated with those themes. Janet also described what she perceived as the most difficult experience for parents in this phenomenon: “Usually, the biggest problem we have with parents is when you, they feel like it’s not their baby.”

I believe the loss of control coupled with the loss of expectations make it difficult for parents to transition into this new experience of parenting a preterm infant. As evidenced in the parent reports, they had lost the ability to care for their infants, take them home, or, in some instances, even touch them.
Comfort level attained by parents. Nurses also connected parents’ level of comfort rising with more touch interactions occurring. Simply stated, Janet told me that letting parents participate helped them cope and adjust in the NICU. She described parent reactions to being able to participate in care activities such as bathing, diapering, or holding:

They are usually much more . . . it [makes] them more upbeat, and “This is real and this, I really [paused and began again] my baby. I got to do this with my baby,” and they start to feel like a parent when they can hold their baby or touch their baby or how I get to participate, even how little it is, and that’s what I’d like to encourage the newer nurses to just, it doesn’t matter what it is, just any little thing. To let parents participate, so I think it helps.

Janet continued her discussion to encompass the many physiological ways that parents could participate in their child’s care. This portion of her interview was lengthy and she provided me with much insight into her experiences and feelings about parental participation. “And I think as nurses, the most important thing we can do is to let a parent . . . to allow them to have some kind of choices or some kind of power after that seven days.” Janet described the beginning of the touch relationship for parents and their babies with this simple statement: “So it starts out with just a little touch.” I distinctly remember when Janet made this statement during my interview with her; I made mention of it in my field notes, and I reviewed it many times. She looked down and nodded as she said it, as though in reflection. She paused for a moment and then began to describe her experiences with various types of parental responses and potential contributing factors to touch responses. I contemplated the word “little” as I reviewed my notes. This particular description wasn’t specific as to the type of touch, although she described the typical progression in later
portions of her interview. At this point, she was introducing the topic. Her perception of little, it appeared to me, was the limited physical contact—most of these touch experiences involve reaching in and touching a baby’s hand. Both nurses and parents reported that those first touch experiences were such major events that to summarize it with the term “little” seems almost contradictory.

The progression of touch experiences is dynamic in that each family can experience a different progression or omission of specific types of touch depending on their baby’s medical condition and status. Some mothers cannot breastfeed for months and months because there may be gestational or oral motor issues that require a baby to have a feeding tube placed in its stomach or nose. These conditional issues also influence the typical progression. However the progression occurred—the touch, holding, and skin-to-skin contact—all were vital steps described by the nurses for the parents in this study.

Kangaroo care emerged as a touch theme in all the nurse interviews. Each of the nurses discussed kangaroo care in response to different topics. Skin-to-skin contact was seen as a powerful tool for both parents and their babies. Janet explained:

When you put a baby skin-to-skin, I’ve seen babies put skin-to-skin and they have all these little, I call them “not Christian” episodes, where they drop their heart rate, and they drop their pulse ox, and they hold their breath . . . and once you put a baby skin-to-skin, I mean a baby on the mom’s blouse on the mom’s breasts, and you cover them up and they can sit there, we say usually an hour, and it’s a lot on the baby, but once you get them there and you get them fixed, you see that baby’s pulse ox go up and you see that heart rate go down, and you see that mother, just the look on her face, then you know . . . you know it’s beneficial to both of them.
All the nurses agreed to kangaroo care was typically a step taken before mothers were able to physically breastfeed their babies because of physical issues in the development of the baby. Liz described her perceptions of how kangaroo care provides that skin-to-skin contact when mothers cannot breastfeed:

A lot of times if we can do skin-to-skin, we really promote that. That’s bonding where they hold them skin to skin and they are not normally breastfeeding, but it gives them that skin-to-skin time that they are not getting because they are not breastfeeding, they are not getting because they are not at home having that time, so that skin-to-skin gives bonding time that is really important. So we really try to promote that.

Nurses time and time again, came back to the aspect of the rewards parents felt when touching their babies through kangaroo care. Statements like this one from Janet were common during these portions of the interviews: “I think the skin-to-skin when they’re really sick . . . I think is very rewarding. So I would say, skin-to-skin” (referring to the most powerful and important forms of touch). Nurses described skin-to-skin time as significant for parents and discussed environmental issues and their role during that time to facilitate the experience for parents. Liz gave this example:

Especially if they’re doing skin-to-skin, we try to you know give them some privacy, always if they’re doing skin-to-skin . . . put the shields around them so they can have that special moment, ‘cause that usually is a special moment for them, we want to give them that.

Breastfeeding was also a common discussion point in my interviews and were brought up by both nursing and parent participants. Breastfeeding and kangaroo care are
closely related as both require skin-to-skin contact. Molly described breastfeeding,
explaining the ways parents could feel more in control or feel as though they were “doing
something” as discussed in the last section, which closely reflected the experiences that
parents shared in their quest to “do something.” Molly said, “And I know, a lot of times that
moms that are breastfeeding, they feel like they’re really doing something whenever the baby
is feeding and getting mom’s breast milk.”

Nurses perceived breastfeeding as a critical tool in bonding and in assisting parents in
gaining more control and acquisition of their role as parent. When I asked Janet what she
thought the most powerful form of touch was for parents, she discussed both skin-to-skin
time and breastfeeding. She described her perception of this dynamic as well as her perceived
role in this unique touch experience:

Breastfeeding, I think, is very rewarding. And you know, we encourage moms to
pump even if they don’t want to breastfeed because of the nutrients in the milk, but
yea, I think that skin-to-skin is wonderful if your baby can’t breastfeed. If they have
have issues and they can’t breastfeed or they have some kind of malformations. So I
would say skin-to-skin.

Liz described skin-to-skin contact as having great importance for mothers because
often these babies cannot breastfeed for a while. The eating patterns for these very premature
babies typically progress from tube feeds to breastfeeding. Liz described that experience as a
replacement for the loss of other experiences:

A lot of times we can do skin-to-skin. We really promote that. That’s the bonding
where they hold them skin-to-skin and they are not normally breastfeeding, but it
gives them that skin-to-skin time that they are not getting because they are not
breastfeeding yet, they are not getting because they are not at home having that time, so that skin-to-skin gives bonding time that is really important. So we really try to promote that.

Liz then described holding during tube feeds. Holding during feeds can be a way for parents to bond if they cannot breastfeed at that point. She explained: “Normally, we don’t start feeds quite that early, but if they are starting feeds, hold them while a tube feed is going on, so they can just bond with them feeding.”

Breastfeeding was closely linked to discussions of kangaroo care because they both require that skin-to-skin contact that is so vital for developmental progression. Nurses described breastfeeding as an ongoing process simultaneous with the other forms of touch. It appeared that they saw mothers pumping their breast milk as a form of pseudo touch because it was contributing to the mothers’ role and gave them hope that it would ultimately lead them to that skin-to-skin contact of breastfeeding.

The nurses also described the happiness and excitement most parents felt following touch interactions with their babies. Janet explained the dynamic following parents touching their baby:

They are very, very excited you know, and uh, now the way, uh, the media, all the different computers and all the way the different stuff is, they’ll take a picture and then they’ll have to text message it back then to their friends. . . . I had one family that I gave, they got to give their baby their first bath, and we did what we call a swaddle bath. And they had the video camera going and they put it on YouTube . . . it gives them more upbeat.
Liz described parents’ progression toward excitement and happiness as a result of those experiences in getting to touch and care for their baby:

They wish they were at home holding their baby . . . and they are getting used to [being in the hospital and limited in touch interactions] . . . and they’re excited to hold their baby, they’re excited to do things for it, because maybe they couldn’t before and now they get a chance to and they get very excited to do those things.

It was also interesting to me that nurses saw holding as the ultimate goal of parents as well, which yielded critical insight into the match between parents and nurses in understanding parental needs and desires at this point. The strong desire of parents to hold their baby was evidenced in the nurse interviews just as the parents had expressed in theirs. Lundqvist et al. (2007) reported that fathers felt a sense of realness when they first held or made eye contact with their infant. When I asked what their impression of the most powerful way that parents bonded with their babies in the NICU, the common response was “holding.”

Janet described her experience and joy in her career in reference to parents holding their babies:

Well, I think a sense of touch is just like if you have a newborn baby, well the first thing they want to do is pick up that baby . . . The best, the very best part of my job is, this part I love of my job . . . is a mom sitting at a bedside and can’t touch her baby and can’t hold her baby, her baby is so sick, and they’re not able to hold their baby so some of them can’t hold their baby for a month or two months. And there’s nothing more wonderful to me than even if they’re on a ventilator, and even no matter what, is to be able to put that baby in the mother’s arms for the very first time. That is just, just the most wonderful feeling. People say, “Well how do you do what you do?”
Well if you could just see that mother’s face for the very first time, some of them are so relieved and some of them will cry. It’s touching . . . but that’s the best part of my job.

I appreciate greatly that Janet shared this with me. It was candid and honest. It was the only time during her interview when she became tearful and appeared to let her emotional guard down. She smiled as tears filled her eyes and she reflected on those powerful moments in her life. I understood as I, too, have watched this phenomenon of parents holding and touching their babies for the first time. The overwhelming emotions of joy for that family are so intense that I personally have found it difficult to hide my emotions, which could easily manifest as “tears of joy.” It is almost impossible to describe the essence of its magnitude for everyone involved in the dynamic.

The emotion of happiness as described previously is also closely linked to the length of the stay as it progresses and parents become more comfortable. As their baby’s health progressed and allowed for more touch interactions and orientation to their surroundings, the parents appeared more in control. This could have contributed to their comfort level, allowing them to experience greater feelings of happiness. Although I did not have a sample that allowed me to see full progression over months of experience, as the babies of the parents in the study had been born within the previous two weeks and had only recently been admitted to the NICU, further studies could yield critical insight into contributing factors that continue to influence feelings of happiness and comfort. Common phrases shared by the nurses reflected those early feelings of happiness parents expressed. Liz gave a brief summary statement as she explained the experience of parents holding their baby: “They’re just excited to hold their baby.”
Unfortunately, there are also emotions of sadness that happen simultaneously with those moments of great joy. Liz described parents’ emotions connected to holding their baby: They’re sad because their baby is there and this is not the ideal place for them to be holding their baby. They wish they were at home holding their baby and . . . they’ve been here a couple weeks and their baby is getting better, they are excited to hold their baby, they’re excited to do things for it, because maybe they couldn’t before and now they get a chance to and they get very excited to do those things.

As Molly attempted to explain her perspective on touch between parents and babies, her perception of this phenomenon appeared to mirror those of the parents in that it appeared she was describing holding as a way parents were “there for their baby.” This was a recurring message in all the interviews. Molly’s response to my question about how parents feel following touch interactions was: “Probably awesome. You know it’s probably a really good feeling to get to know that you can be there for your baby. You know that you are important and can help the baby get better.” I found it interesting that Molly stated, “to get to know that you can be there for your baby,” as this comment closely aligns with those messages communicated by the mothers who, too, perceived that holding was the way they could “be there” for their babies.

**Barriers to Bonding**

Nurses described three subthemes that they viewed as barriers to bonding. Environment, communication, and presence all appeared to be obstacles that nurses perceived had the capacity to either facilitate or impede the bonding experience for parents trying to bond with their babies through touch.
Environment. The nurse interviews revealed a common perception of the NICU environment as a potential barrier to bonding. Nurses’ perceptions of the environment as a barrier was consistent with previous literature (Lundqvist et al., 2007; Pohlman, 2009). The NICU at ACH was divided into two units. The newer unit, which was recently remodeled, has a better design with more sound absorbing materials and other features that make it a more conducive and appropriate environment for this population. This portion of the NICU houses the extremely premature infants and those more critically ill. It is called the East Unit. Janet described the differences and dynamics involved with the environment:

If you’re in East, it is quieter and lights are lower, but if you’re in the main unit, it’s very noisy. It’s very loud. It’s not ideal, like it would be if we had private rooms with the new unit . . . we can offer them screens around for privacy or their shirt, put the baby in their shirt, or on their chest, but it’s very loud and it’s overstimulating for the nurses at times. And if you imagine a parent who is always stressed and then they’re sitting in this unit and all this stuff is going on around them. . . . And [parents] never get away from it.

Janet gave me a description of the environment’s affect on her personally as she explained her daily ride home and need for some reduced stimulation: “Just by the end of the day, when I go home, I don’t want to hear a radio or TV for at least 30 minutes. I want quiet time.” Janet then described that the environment, compounded by the stress that parents are already experiencing, can be monumental. She reported that the nurses are encouraged to silence the alarms and give parents curtain petitions as a way to reduce the stress and effect of the environment. Imagine, as Janet has described, being asked to expose part of one’s body in an effort to do skin-to-skin and know that any moment another parent going to see
his or her baby might walk by. Even with a curtain, there could be the fear that someone will walk around and see them exposed. It could be especially stressful if a mother is trying to breastfeed the first few times. It takes time to learn how to breastfeed, especially if the baby is having a latch-on problem that adds additional stress and frustration. The mother could experience embarrassment that she is doing something wrong because her baby is having problems. Then imagine someone walking by and looking at her. Having myself experienced the frustration of and disappointment in having a baby who had latch-on problems, I well remember nurses’ attempts to help me and how I felt. It can be such a vulnerable time. A private room would reduce that fear and anxiety for parents as it provides increased privacy and isolation from all the things happening in the NICU.

Mark echoed that perception as he described the environment. He also included his perception of the environment as being stressful for the babies as well:

Alarms, people talking, um, we just recently put around Christmas, really tried to concentrate on our noise level in the NICU, so we are cognizant of that. But the nurses do a pretty good job with advocating for their patients, making sure that, if there’s family in there, to be quiet and to set an example for the other nurses. So yea, they’re hearing alarms, people talking, doctor rounds, sometimes we get calls on our pods or things we wear. So yeah, it can be distressful for little babies. It’s really up to our management and the nurses to control that.

One difference between Mark’s perception and Janet’s perception was that of the control the nurse had in this dynamic. In his last sentence, Mark stated that it is management and nurses who have the control over those issues. But in Janet’s explanation, she reported that the nurses “had no control in the situation.” I would imagine that feeling of helplessness
and those perceived limits could be frustrating for nurses. Liz gave another example of that perceived helplessness by nurses regarding the environment:

Sometimes in our main unit it can be a little bit loud and noisy and bright and that’s . . . you wish it didn’t have to be that way, but sometimes it just has to be in order to take care of all the babies they way they need to be taken care of.

When Liz was explaining the environment, she made a comment that caught my attention. She appeared hesitant as she answered this section of the interview:

If they’re doing skin-to-skin, we try to you know give them some privacy, always if they’re doing skin-to-skin. I don’t know, put the shields around them so they can have that special moment, ‘cause that usually is a special moment for them, we want to give them that.

I find it interesting that she said she “didn’t know” and was hesitant in answering. At this point in the interview, she shook her head and slouched her body, body language that made it appear like she was expressing frustration to me. I felt it perhaps echoed that same helpless perception previously described. I can imagine this would present a unique problem when there are limited solutions, none of which accomplishes the desired end goal of the ideal NICU environment. I wondered if Liz’s “I don’t know” comment projected her having those feelings. Molly also described this dynamic and the potential effect on parents:

For parents getting to hold their baby it’s not the best environment, at all times.

Sometimes it quiet and dark and nice too, but there’s usually something across the way or whatever it may be, where the lights are on, or people are talking loud, it’s just not the best in the environment. . . . It would be distracting and not as good for that,
they can’t get the experience they want with their baby they need, there’s just too much going on.

I find it significant that all the nurses were aware of the environmental stressors and their influence on this phenomenon. This final statement from Molly depicts the overall goal for parents in FCC at this point in their NICU journey. Those first experiences with their babies need to be as positive and stress-free as possible. Parents are already dealing with so many emotions and concerns that making every attempt possible to alleviate some barriers that can be controlled is very important.

*Communication.* Oral language is the primary form of communication in the dynamic between medical staff and parents. Meeting with doctors and nurses to ask how their baby is doing is how most parents get their information about their baby. If parents cannot be present at the hospital, they can call the NICU and talk to the nurse about their child’s status and condition. There are seldom written documents sent to parents detailing progress or information about health conditions. Liz described the barrier of language when the nurse does not speak the same language as the parent of the patient:

Things like when I was talking to you about the people that don’t speak any English. That can be very hard and you know, as nurse we kinda do as much as we can without interpreters, and we have interpreters but they are not there at the bedside 24/7, so . . . even just trying to get them involved you try to, but you can’t always. You know? Say everything that you’d like to say and be as open as you’d like.

I have experienced this same situation in trying to comfort and educate families without the use of oral communication. Just as Liz described, you do not always have access to an interpreter. Even with the use of an interpreter, I have felt concerned that he or she may
not communicate the exact same wording I used. I carefully select my words to reflect compassion and to facilitate understanding. If I do not understand the discussion between the interpreter and the parent, how can I be assured that my message was effectively communicated in the way I wanted?

All the nurses voiced concerns that parents did not understand the surroundings or dangers of touch and care for their infants. Education for this lack of understanding presented itself in each of the four interviews. Janet explained typical parents’ desire and natural tendency in touching their baby for the first time, thus emphasizing the need for education of the parents:

[Parents] can’t just rub on the baby, the first thing they’ll want to do is pick up and play with their feet, which just irritates [the baby] to no end. So we need to do parent education to touch. They can touch or put your hand on his hand. Or put your hand in his hand and some babies can tolerate that much. . . . It’s real difficult for [parents] . . . when they first start out . . . with just a little touch.

Later in Janet’s interview she turned back to describing parents’ lack of understanding during those early weeks following their child’s admission:

I know when they first come they really don’t understand. A lot of parents don’t have any kind of way to really cognitively figure out what we are talking to them about when we describe “your baby is very little, your baby is very sick . . . it’s on a breathing machine.” And as simple as we put it, you can’t put it in their minds.

As previously reported, parents feel great frustration in not understanding what is going on with their child. Jim discussed his time with the nurse as it pertained to getting information about the monitors and equipment. Nurses also discussed the education levels of
individuals as an indicator for understanding. Janet described understanding as it relates to other factors:

If they, it seems like most people, the more educated people, the more middle class, upper middle class people tend to say, “can I,” after they get the through the understanding of you can’t touch your baby this much or that sort of thing.

Liz described “uneducated” parents and the lack of understanding and dangers she perceived for the baby:

Some are just very uneducated in that and their baby can be very, very sick and minimal stimulation and we’re barely touching the baby and they go, “Can I hold the baby?” and we just have to go, “No. Like, not right now. The baby is too sick to have us changing its diaper.” Sometimes they just don’t understand that and they have a hard time understanding.

Although these examples are anecdotal, as intended by this study design, it provides the nurses’ perception and experience with working with families. Biases and experiences shape the way one perceives and reacts to different families and situations. I had a unique experience that was opposite to those just described. I worked once with a mother who had graduate degrees in child development and special education. Her son was born prematurely and had the diagnosis of Down syndrome. As I began to talk with her and develop rapport, she expressed that staff assumed she knew more than she did. She told me that she did not feel prepared by her education to adequately understand a baby with special needs. She told me that it was different being in this new role. This example gives just a glimpse into the potential affect that assumptions might have. The mother I just described felt hesitant to ask for clarification and information because she was embarrassed that others would think she
should already know the answer since she had been “trained in this.” This kept her from gaining the information she needed and developing a deeper understanding of her child’s medical condition.

Continuing to explore this dynamic, I thought back to the experiences shared in the nurse biographies. Recall that Liz expressed her difficulties in serving families addicted to drugs or those parents who were very young. Individuals may need to explore more fully the potential impact of their biases on their choice of what to communicate to parents. If one assumes parents don’t care about their babies, or don’t deserve their babies, could this then make one hesitant to share information because one is angry at the situation? If an individual perceives that these parents do not deserve their babies, then why should they deserve to understand what is going on with their babies? Further exploration of this dynamic would allow for the gaining a deeper understanding of the role of biases in the effectiveness of communication with parents.

Understanding appeared to be connected to the way in which nurses perceived they communicated information. Janet detailed messages she used to communicate in helping parents understand the touch dynamics of their preemie:

You know at first it’s gonna take education in a very gentle way, otherwise you are gonna have problems from the get go. You know, “I feel how you feel” sorta thing. “I know how you feel and how much you would love to [hold the baby], but this is what might happen, this is what we’re worried about,” but instead of that, “Why don’t you put your hand right here under the plastic or in the port hole and you can touch your baby’s hand.”
Janet further described the differences she perceived between different age groups. She compared educated adults with teenage parents in this portion of her interview:

> Usually I’d say about 60 to 70% of the time, people with more education are more patient and have read more about what it means and that they know they’re gonna have their babies early and that sort of thing. Then I think they have more of an idea, but if you’re 14 years old, you don’t have an idea and you see babies as a little baby doll laying there. It’s either that, or they’re scared to death.

Mark described his role in helping parents understand by explaining teaching practices and methods utilized to help families get more comfortable and understand what is going on with their baby. He described the typical practice and progression for a family with a baby who will eventually go home:

> Of course teaching is going on from day one ‘til they are discharged. We have private rooms the babies can stay in, um, especially if they are first-time mothers or parents, and by that point they are going to be doing most of the primary care, temperatures, diapers. We are still going in to do our head-to-toe assessment, blood pressures, sometimes parents even do the blood pressures even though they won’t have to do it at home. Other than that, they’re doing most of everything. They should be.

He then explained that first-time parents require more teaching and repetition in practicing caretaking and medical needs of their baby. He compared those parents with parents who have multiple children, reporting that the parents who “have four or five babies” don’t typically need help learning how to give a bath because they already know. His comments led me to consider the experience of both sets of the parental dynamics Mark described. Even when a mother has four or five “healthy” babies at home, it does not necessarily mean that
she will understand how to bathe a baby who is hooked up to multiple machines or who has certain physiological accommodations that must be made. All parents must be provided with the same opportunities to gain information and individualized care for each family as they make progress toward parental role acquisition and understanding. Jones, Woodhouse, and Rowe (2007) reported that mothers emphasize the need for more encouragement in being treated as an equal partner in their infant’s care. Jones et al.’s (2007) findings revealed that communication strategies that support this need involve being more accommodative and interpersonal.

Molly related the acquisition of comfort with the lived experience of spending time in the NICU and gaining medical understanding. When I asked Molly when she though parents began to feel more comfortable in touching their babies she responded:

Usually, a lot of times whenever the baby has a lot of stuff going on with leads and everything is new, it usually takes several days before they understand what different things are and then once they know what they are, then they can do it and feel confident and not hurt the baby... so usually within a week or two.

When I asked Molly what she felt was most important for parents to be doing during those first few weeks, she discussed both understanding and presence:

Probably just to be there for the baby and to know what’s going on and to be knowing all the information and just to make sure that if they are supposed to be somewhere at a certain time, that they are there, like, meet with the doctor, then they should be there. You know, that’s as much as possible.”

In examining what Molly said, I reflected back on the experiences shared by parents. Further studies examining alternative strategies that could be used to facilitate bonding and
understanding for families who are not present at the hospital for uncontrollable reasons, such as work or other children to care for, would be beneficial. It must also be considered that parents may not be ready to understand what is happening with their baby, particularly if the prognosis is not favorable. In Yolanda’s example, I wonder if her hopes for Tyrell influenced potential denial about his condition or if it truly was her faith in God’s decision to end his life that was navigating her choices in Tyrell’s care.

**Being there.** Presence in the NICU appeared to be a common theme in the nursing interviews as well. Previous studies have revealed proximity to the hospital as an important facet to the experience of parenting a child in the NICU (Affonso et al., 1992; Cleveland, 2008; Holditch-Davis & Miles, 2000). Liz gave me a good description of how distance and location could influence parental acquisition and comfort levels:

Unfortunately I feel like there is less and less parent interaction just in the NICU in general, I think a lot of babies weren’t planned or babies, you know parents live far away and they can’t come or . . . the parents can’t, and parents have to go back to work, so parents can’t be here as often as they’d like. You know, parents do have, a lot of people don’t have the opportunity to come here and stay for weeks at a time, um, so for them to be here constantly is rare, but the parents that are able to do that, you find they are much more comfortable taking care of their babies, they are much more, um, willingness to just kinda, not take charge, but you know, go ahead and go in and change their babies diaper, um, and just do things like that and they become more comfortable with the nurses.

In an earlier passage on the comfort level attained by parents, Liz described ways that parents could still feel like they were “doing something” by leaving stuffed animals and
bringing items from home, describing those actions as a way to feel better about their
necessary absence from the hospital. Liz also described policies and dynamics related to
other family members being present while parents must be away:

A lot of times even if parents can’t be there, having a grandparent there or someone
that’s there with them. I think that’s kinda hard with our visiting policy, um, parents
usually have to be there in order for a grandparent to come back or a relative to come
back. And that’s something I’d like to see changed because sometimes parents can’t
always be here, but it reassures parents to know if someone can just be there. If
someone is available to come, I feel like they should be able to come, just sit at the
bedside, not make any decisions, but just know that someone is there.

Liz closed her discussion of this barrier by sharing the story of a family she is currently
working with:

I have a baby with spina bifida right now, it has a trach, it has a shunt, it has a foley, it
has a lot of stuff going on. He’s a little bit older, but he’s a baby that can be held, can
be interacted with, and mom is here all the time, and you can tell that that baby is
gonna go home with those things, but she is learning, she is getting involved and is
learning how to do those things and how to take care of them, because those things
are nursing things, how to suction his trach and it’s very important for parents to get
as involved as they can.

Although nurses reported little control in the environmental situations present and the
availability of parents to be present, they do have great control in their attempts to
communicate and facilitate understanding. FCC practices assist in determining how best to
facilitate understanding for diverse families and the various situations they are facing.
Protection

As I coded nursing themes, I found a recurring theme that was unrelated to the nursing reports of parental reactions. Again and again nurses seemed to covertly portray a form of protection for the baby from the parents. All nurses reported, as evidenced in the previous sections, that they placed a high value on facilitating parental involvement and bonding. However, the language that emerged from their reports appear to offer an unspoken dynamic of protection; I believe they were not conscious of its presence. Although the word “protection” was never used directly, the essence of the nurse reports conveyed the need to protect the baby. At first I coded this with the term “control,” but later, as I gained a deeper understanding, I interpreted their motivations as protection rather than mere control. The current findings are similar to those of Fenwick et al. (2001) who described nurses’ fear that releasing control of the infant and incorporating more parental involvement could be harmful to the infant.

Nurses frequently discussed things they did to protect the baby while teaching parents and allowing parents to participate in the baby’s care. This finding was consistent with studies such as that by Lupton and Fenwick (2001) who described nursing behaviors in the NICU as “teachers and monitors of the parents, protectors of the infants’ and experts by virtue of their medical training and experience” (p. 1017). As I attempted to explore what nurses were doing during times when parents were having touch interactions with their babies, Molly boldly described her protection of the baby:

Just to kind of be [the baby’s] advocate and make sure that [the parents are] not doing anything that is going to hurt the baby, or you know, babies that have, um, umbilical
lines, we can’t always let them hold the baby, but they can do several things for the baby. It just depends what is going on.

Molly later continued with this same idea as she explained what she does while parents hold their baby.

How safe it is, and the baby’s health comes first, and as long as I think the baby is okay, and looks like they aren’t going to pull lines out or anything like that, then I’ll let them take the initiative and do that. But always think of the patient first, like I want the parents to be able to hold, and for that is a very important part for me, but first and foremost is the baby’s health. ‘Cause I don’t want the baby to get cold or to risk blowing the lungs out ‘cause that would cause a lot more pain.

I can understand this dynamic of nurse protection because the baby’s care and medical treatments are typically their responsibility. The baby’s health and progress could be perceived by the nurse as a reflection of the quality of care they are providing. Allowing the parent to “hurt” the baby due to their lack of understanding and training, could be perceived as irresponsible and a failure to keep the baby safe on the part of the nurse. However, I think it is important to explore how this protection and control influences the bonding parents are attempting to experience and build. If nurses are perceiving parents as a danger to the baby, then the need to protect the baby from them could result in decreased opportunities for bonding. Molly is a younger nurse with limited experience, so perhaps her reference to this dynamic was more frequent as a result.

Protection appeared to closely linked to a form of authority I perceived from nurses. Parents also reported that nurses were a gateway to their babies. Previous studies support this finding, describing the influence of nursing behaviors on a mother’s relationship with her
infant (Jones et al., 2007; Lupton & Fenwick, 2001). All the information and understanding comes from nurses, and the parents depend on nurses to guide them through this experience. In exploring the nursing transcripts, it appears that nurses saw themselves the same way that parents did. They saw themselves as the authority over the baby, making decisions based on what they deemed appropriate for parental interactions. I think this facet to the phenomenon of parental bonding in the NICU deserves critical review and further investigation. It presents a conflict within the practice of FCC. If nurses perceive themselves as the authority over the baby, what implications does that have for parents in their role as caregiver for their child?

My interview with Liz led me to specifically ask the question as to whose responsibility it is to do routine care for the baby. She responded:

It’s my job to make sure it’s done, but as far as to what parents are able to do, it’s up to them really . . . but when it gets closer to going home, then it’s really more their role to do everything. But for the most part, it’s my responsibility.

I found it interesting that other nurses had statements similar to Liz’s, making reference to the parents assuming responsibility closer to the time of going home. I later wondered how that was communicated to parents and what messages they received from their perspective. Could parents perceive the message, “You aren’t competent enough to change your baby’s diaper because he’s on this unit, but once he goes across the hall tomorrow, it will be your responsibility?” Further investigations as to the pedagogical practices on routine care and facilitation methods in assisting parents to assume more caregiving responsibilities would give us more understanding into the perceptions and implications of this experience.
In short scattered sentences nurses frequently referred to themselves controlling touch interactions and parental participation. Mark described the acquisition of parental comfort in initiating touch experiences with their babies: “A lot of times nurses initiate it. Because we are familiar with what stage of growth and development the baby is at . . . [the parents] already talked with several nurses and they know what they can and can’t do.”

When Molly described the experiences parents had during those first few weeks in the NICU, she explained her role in helping them learn to do routine care activities. She described multiple activities she helped parents do, and then she said: “So yeah, as long as they’re gentle and know how to take care of everything, as long as I am watching them, I am okay with that.”

I wonder how this message is communicated both verbally and through body language to parents as they attempt to learn how to care for these very sick and fragile babies. If an individual sensed someone always watching over his or her shoulder could he or she truly ever feel comfortable? And if one has a constant feeling of discomfort, how does that in turn affect one’s ability to bond with one’s baby?

Janet talked at length about the first week after admission to the NICU and the dangers to the baby:

So when they come here, and of course they want to hold their baby, and they want to touch their baby . . . for seven days we really don’t allow them to do much. Because you can’t risk the baby. That’s just one more risk factor.

As previously presented in the nursing discussion on communication, Janet discussed the implications of the parents’ level of education. The role of control in protecting the baby appeared to be communicated by parents as they had to ask permission to have touch
interactions (both for comforting and bonding as well as for routine care like diaper changes). Janet described how parents “ask” for information: “The more educated people, the more middle class, upper class people tend to say, ‘Can I,’ after they get through the understanding of ‘You can’t touch your baby this much’ or that sort of thing.”

I considered little statements like this one from Janet: “To let the parents participate. When using the word ”let,” is one implying that it is a choice whether or not parents are allowed to participate? Shouldn’t that be their personal choice? How can medical staff position themselves as the determining factor of whether or not a willing parent is allowed to touch? I heard the terms “let” and “allow them” used frequently in all the nursing interviews. Although nurses described medical reasons cited in this study as well as in other studies, as evidenced by literature review, nursing staff must be cognizant of their motivations. Determining if a specific touch interaction is really a risk, an inconvenience, or perhaps personal insecurity or lack or experience might help nurses further understand their motivations and choices in controlling touch interactions. Pohlman (2009) reported that there was a perceived power dynamic between fathers of premature infants and nurses. The father in this study also voiced that nurses did not know or acknowledge his feelings of fear, frustration, and alienation.

Janet candidly admitted that sometimes it is difficult for nurses to draw a professional boundary for their relationship with the parents. She explained:

A lot of times, I think nurses can just get wrapped up in their job and start doing it and the parents are just watching. A lot of parents are afraid to say, “Is there anything that I can do?” They’re overwhelmed by everything and they just feel like the nurses have to do everything.
Liz shared a similar statement as she described primary nurses and the facet of different nurses interacting with families during those critical times: “You know a lot of times those [primary nurses], even though they felt comfortable, or those nurses come in and start taking over, so they have to find being comfortable with that nurse as well.”

These last two statements highlight the need for nurses to examine their own motivations and values in parental participation and FCC. Liz began to talk about “letting” parents do routine care practices. She then began to describe the differences between passive parents and those parents who tried to do too much in her perception: Passive parents “don’t want to interfere, they just want you to do your job which is great. You don’t want overbearing parents ‘cause that can sometimes get in the way of your actually taking good care of their baby.” This particular statement made me wonder what message is sent when medical staff perceive parents who participate too much as a problem. The overall goal that all nurses reported was to facilitate parental comfort in caretaking and bonding. However, messages such as this appear to communicate that nurses only want that “comfort” to a certain degree.

If parents sense that nurses are uncomfortable with their participation, perhaps parents would see that as a threat and danger for their child. As Kate shared, she believed some nurses resisted presenting a situation to her that required her to stand up for her son and protect him from them. Kate did not want to tell me what exactly nurses did to give her this impression, but I could tell that it was a highly influential experience. This presents a potential barrier that sets nurses against parents, which is in no way helpful to either party. It also does not align with FCC practices that all nurses should strive for. Understanding and teamwork should be critical components of the NICU experience and education of parents.
Liz later described the lack of understanding by parents referring to minimal stimulation and the critical status of their children’s health. She told me how she perceived parents asking to touch these babies: “We’re barely touching the baby and they go, ‘Can I hold the baby?’ and we just have to go, ‘No . . . like not right now.’ Their baby is too sick to have us changing its diaper.”

When I reflect on a statement such as this one, I am drawn to the word “we” in reference to changing the baby’s diaper. Does it communicate that it is more important for nurses to change a diaper than for parents? If training and assistance is provided, cannot parents change a diaper? Once parents learn about the equipment, tubes, and leads on their baby and are shown and scaffold in how to change a diaper, why would the nurse want to continue doing it if the parent is at bedside? Mark previously stated that “teaching starts from day one,” so why would there be resistance? Previous studies revealed a feeling of exclusion by mothers when they do not feel a sense of belonging in the NICU. When feelings of participation increase, there is continued communication between the nurses and parents (Griffin, 2006; Wigert et al., 2006).

This issue of protection is complex as reflected by Liz as she described her opinions of the most important ways that parents bond with their babies and she led into a discussion of her perceived role confusion:

And I think that’s the biggest thing, we get so wrapped up in our jobs sometimes that we truly forget that this is their baby. It’s not our baby. Not everything has to be exactly the way we like it. It’s more important for them to know they can take care of their baby.

It appears that, to some extent, nurses realize potential boundary issues.
One particular statement from Molly resided in my mind for some time after transcribing and coding the data. At first it did not seem to fit with the overall messages reported from the nurses. However, the more I tried to understand and reflect on the totality of this study, I felt it should be explored in this section of power and protection. When I asked Molly what she felt were the most important forms of touch for parents, she responded: “I would say holding . . . I think touch is very important. Even for the little bitty ones, as if they even know.” At the end of this sentence, Molly laughed and raised her eyebrows at me, shaking her head at me. I felt at the time she was communicating that she found it humorous that very premature babies neither knew or cared that their parents touched them. I realize that cognitively, 25-week-old babies cannot understand these dynamics—my concern is for the message that could be communicated to parents. I have concerns that perceptions, such as this one from Molly, could communicate to parents that touching their babies is not important because “they don’t know anyways.” However, the mothers in this study strongly expressed a desire to touch their babies. They reported it as the way they felt their babies would “know them.” This last statement from Molly also showed some lack of understanding and exposure to research regarding the multiple benefits from various forms of touch for premature infants (Ferber et al., 2005; Lappin, 2005; Lundqvist et al., 2007). Deeper exploration as to nurses’ perceptions of the value of touch is needed to better understand potential biases that could influence parental touch experiences. For example, if Molly laughs at the value of touching a preemie, why would she advocate for it? Who would be serving the parents at that point if the nurse did not validate and advocate for their intense need to touch and hold their baby?
This statement also concerned me in that it, perhaps, showed control over the situation. By belittling the parental need for touch and the significance it held for them, Molly might be asserting herself as the more knowledgeable person in this nurse/parent role dyad. I find it inappropriate to ever laugh at the needs of families. No matter how insignificant one perceives something, it perhaps holds a different value for the family that one is serving. To laugh at the needs of another person conveys disrespect and inequality in the relationship. If one likened this to an example of a therapist laughing at his or her client’s disclosure of a personal behavior, one would be outraged that the therapist could be so impudent to the feelings expressed by the client. There is a similarity in this situation as well. Although, I do not know to what degree this sort of bias is exposed or communicated to parents, its significance remains and needs to be explored in additional studies.

However, it must be noted that nurses overall did report a strong desire for parents to touch and participate in their baby’s care. Even Molly gave this description of her perceptions of parental involvement:

I think it’s best for the baby because that’s what they need. I’m just the nurse to take care of the baby. I can’t provide for them the way their parent can. So the touch and the care that the parent can give is something I can’t. ‘Cause I care about the patients but they’re not truly mine.

My intent in reporting this phenomenon of protection and control was not to disrespect the incredible work that the nurses do. However, I felt it necessary to present it to explore possible implications for its unspoken and unreported presence. Increased awareness of this phenomenon could facilitate FCC as parents are adequately supported and positioned as the caregiver for their children. I feel Liz stated it poetically when she told me, “It’s not
our baby. . . . It’s more important for them to know they can take care of their baby.” If both actions and words communicate that parents’ presence and role as primary caregiver for their babies are valued, parents could feel more support and more respected. I recall those feelings of insecurity as nurses were busy working on my son and I stood there watching or in instances when I would leave for a while to eat and upon my return discover that they had given him a bath. In my heart and mind I felt the pain as I said, “I missed it . . . his first bath.” Who gave them the right to take that away from me? Although I am sure it is not an intentional attack on parents to take away those special moments, simple modifications and communication could greatly reduce those instances when nurses take over the parental role. After all, the healthcare team is not the parents who will be parenting that child for the duration of his or her life.

Comparison of Themes for Parents and Nurses

Overall, nurse reports paralleled the experiences that parents shared in my interviews. However, parent and nurse interviews revealed different perspectives and expectations on a few of the themes that emerged, including: environment, primary nursing, and control.

Environment

The nurses in this study all reported the environment as a barrier for parents. Nurses discussed a variety of issues related to the aesthetics of the NICU environment. However, parents had little concern about the NICU environment and did not report any significant negative experiences as a result of the surroundings itself. Nurses reported that the NICU was a noisy setting for trying to bond with one’s baby, but parental perspectives were different, as Jennifer expressed in her description of the NICU to me:
There is a lot going on. It’s mostly dark. The nurses ask if I want the light on or off, and they are very considerate about the environment once they give him to us. . . . Then they’ll step away and let us spend that time with him. So it’s a pretty calming environment.

Jennifer then proceeded to describe the experience of touching and rocking her baby during those times and the relaxing feelings she had during those times. It is interesting to consider the fact that Jennifer then began to describe the aspect of touch and holding as it contributed to the environmental experience itself. Jennifer continued with how it was difficult when she was at the bedside and the alarms would go off or her son would have some bradycardic events. She described feelings related to the lack of control in the situation as well as the fear that something was going wrong.

Yolanda described the environment as different than she had expected it to be. She coupled the environment with the discomfort she expressed in seeing her babies back there: “It’s quiet. . . . It ain’t what I thought . . . ‘cause I ain’t really want it to be quiet. First thing, [the nurses] want you to see dey first babies. ‘Cause I done had all these plans for em.” Then she began to discuss grief experiences and loss of control as she described her babies’ “cages.” Yolanda was the only parent in this study who expressed the NICU was too quiet. Perhaps further exploration might reveal that Yolanda is accustomed to a noisy home life filled with a loud television set, lots of family conversation, and/or children playing. The experience of going from an environment filled with constant auditory stimuli would present a new experience that perhaps would be uncomfortable being that it was not the norm for her. All other parents reported the environment as a good place that was conducive to spending time with their babies.
Primary Nursing

Primary nursing perspectives varied between the two groups. All of the parents discussed their desire to have a consistent set of a few nurses who took care of their baby each day. The nurses who participated in this study also discussed the benefits of primary nursing but voiced concerns about the emotional stress it puts on the nurse of a long-term patient. All nurses did agree, however, that primary nursing was preferable for the patient and family.

Because nurses had a different perspective on the issue of primary nursing than did parents, it’s important to examine the experiences they discussed in the nurse interviews. Although the intent of this study was not to investigate primary nursing and there were no research questions that specifically related to this topic, it was a common discussion point that all participants referred to in their interviews. Molly explained her definition of primary nursing:

It’s when nurses can sign up for a baby and whenever they are working on shift, most of the time they will have that baby. And they will take care of that baby. And most of the time it’s great, when you do have a 28-weeker, you can watch them grow through their process, and you know that baby, and you know if something is not right. You know the family and that family can really learn to trust you.

As I explored the parents’ acquisition of comfort and interaction with their baby, I found nurses connected this with primary nursing. For example, Janet responded to my question of the length of time it takes for parents to become more comfortable touching and caring for their babies:
I think that’s when it’s good to have primary nurses, because every time a new nurse comes on shift, it’s like starting all over again. You know a lot of times those nurses, even though they felt comfortable, or those nurses come in and start taking over, so they have to find being comfortable with that nurse as well. So I think that’s our job as nurses to make sure we reinforce that every time we come on shift, we don’t know these parents, we need to let them know that we are going to treat their baby the same as the other nurse did.

Liz described her impression of a parent’s experience with the hospital in relation to comfort levels:

For [the baby] to be there in an unfamiliar place with unfamiliar people, and then every 12 hours [the parents] have somebody different that’s taking care of their baby, that’s you know, they have to put their total trust into, I just feel like it has to be hard.

Descriptions of the comfort level of parents rising were connected to the amount of time parents spent at the hospital. If one considers that parents’ comfort levels rise with primary nursing, as described by the parents who participated in this study, then the presence barrier described by parents in this study could be lessened if there was an increase in primary nursing. Liz described her opinion on primary nursing:

“I think [primary nursing] really helps when parents can’t be here all the time, you know, “Molly is taking care of our baby. She’ll let us know if something is going on. We know that.” . . . And too, if they come in and they know, the nurse knows that you know how to change a diaper, the nurse knows that you can take the temp, then that helps with the bonding as well.
When I explored the communication between nurses who were primary nurses for a patient, Liz explained the dynamics to me:

If mom and dad will probably come in and want to do this, so that helps to bring a continuity to care so it’s continued throughout so it’s not just a random bunch of nurses all the time. Um, some babies can have 3 or 4 primaries and some don’t have any.

Molly proudly described her personal experience with being a primary nurse three separate times in her career. Both her facial expression and body mannerisms conveyed a deep sense of emotional tug for her:

I think [primary nursing is] wonderful. I think it’s a good thing. It helps the baby, for everything to stay on the same page. I have had three primaries myself, and I know that it helps with doctors and nurse practitioners and for everybody to know what is going on. Even though it’s all on the paperwork, to kinda, it’s better for the patient I feel like to have that stability . . . especially for the families, too, to have somebody that is familiar to them, is always a good thing.

She also described the emotional implications for nurses who choose primaries:

I sometimes hesitate [to volunteer for primary nursing] because it’s a huge responsibility and a big commitment so it’s sometimes can be anywhere from 2 weeks to a year. So it’s whether or not you’re ready to have that kind of commitment. And it is a huge responsibility. I know it can be really hard on somebody if something bad happens or you get attached. So you have to think about whether or not you are ready for that.
It’s interesting that nurses have the control to decide if they want to have a primary patient or not. Molly continued, describing situations she had experienced where her emotions did not allow her to serve despite a parent’s request:

Occasionally there will be parents who ask the nurse [to be a child’s primary nurse], ‘cause sometimes you know, for a long time, I had a primary for a really long time and after he went home, I wasn’t ready for a primary again, but I had been approached by a family member to be a primary, but I just wasn’t ready to get attached again, and I just couldn’t do it.

She continued, explaining how this might make parents feel:

Sometimes I think that parents staying in the waiting rooms . . . or even other nurses mention [primary nursing]. They just kinda find out about it and it’s not that it’s a bad thing, but I think that parents sometimes get their feelings hurt when one baby has several primaries and another doesn’t have any.

What message does it send to parents when their child does not have primary nurses or are rejected when they request a primary? Does it denote that their baby is not as special because they do not have primaries? Could it lead them to wonder if their baby will receive the same quality of care, since they are not liked as well? Molly even went as far as to say: “I wish there was a way where parents didn’t find out about it. I feel bad whenever they do and they don’t have [a primary nurse].”

This last sentence again, relates back to who has the control in the situation. Nurses already have the control over signing up for primary nursing, but due to her own discomfort with rejecting parents, this nurse said she would rather parents did not know about primary nursing. Further investigation is needed to better understand this conflicting view of primary
nursing. The question raised is: Whose needs should better be served in this situation? Is it fair to put nurses in a situation where they have emotional ties to patients and thus experience loss when the patient dies or leaves? Does it blur the lines between professional objectivity and attachment? The opposing view would perhaps say that experiencing attachment to and loss of a patient is just part of the field. Themes emerged in this study from both nurses and parents that indicated primary nurses were desired and considered best practice, but in an effort to make nurses more comfortable, should this be kept a secret from parents, preventing what is best in FCC practice? Additional studies are needed to explore the degree to which primary nursing affects nurses and then, perhaps, hospitals would be better informed in designing protocols and policies addressing this need of parents.

Control Issues

The theme of control appeared in both sets of interviews, although the perspectives differed between the two groups. Nurses acknowledged in their interviews that they saw parents as having lost control of the situation and may perceive the nurses as taking control, as this statement by Janet revealed:

They’re mad. This wasn’t what they planned. This wasn’t how they planned. You’ve taken total control over something they created together. So I think that’s one thing we need to really be in tune to and all them to participate as much as possible.

Parents also reported having felt experiences of losing control over the situation. Frequent comments by parents contained statements communicating, “I can’t do anything.” Those helpless feelings then have the potential to hinder comfort levels and parental role acquisition. It was interesting to me that, overall, parents reported support from nursing staff.

Parents perceived nurses as helpful in their attempts to bond with their baby; however, they
also communicated that they wished there did not have to be a “third party,” as reported by Jennifer.

The protection theme that emerged from the nurse interviews, also further complicates this phenomenon of control. It presents the question as to how healthcare staff can best serve families and give them a sense of control, if staff are subconsciously keeping the power for themselves. Nurses also described themselves as the individuals who are the facilitators and mediators between the parent and the baby, thus necessitating their role as totally dedicated to helping parents take the primary caregiving role. These reports by nurses almost appeared to be contradictory because they all discussed the importance of parent participation in care as well as the benefits and importance of touch were for their bonding and comfort, and yet, they often described interactions with controlling tones.

As evidenced in the parent interviews, parents felt a great loss of expectations and anticipatory grief for fear of losing their children. Providing the opportunity for parents to participate in some of the same parental roles and responsibilities they would have experienced had their infant been born healthy at term, nurses may better empower parents during that time. Recognizing this dynamic could be critical in fulfilling a need for parents in a limited way. In contrast, it is also important that parents continue to gain more control of their children’s medical needs, as many of them will eventually provide medical care at home seeing as many preterm infants have a long road to full recovery even after discharge. Nurses appeared to verbally support parents’ participation in limited ways that would still provide needed safety in consideration of the critical status of the infants. As explored in this study, during these first two weeks their babies are in the NICU, parents reported intense feelings of fear with respect to the medical equipment and treatments of their children. Involving them
with medical care at this point may not be the most beneficial tool in fostering their bonding and acquisition of the parental role. It could be more stressful than beneficial to parents if they are encouraged to assist with medical care that they currently do not understand at this early stage. Additional studies that explore parental desires and experiences with medical care involvement would help in better understanding their feelings and perceptions of this issue.

Consistent with recent literature, one cannot separate the phenomena of care and comfort. I found it very difficult to separate control and comfort and place them in a sequential order based on the reports from parents and nurses. It is not clear whether helping parents feel more comfortable as the weeks pass results in their increased control or, rather, if giving parents increased control will then result in their increased comfort. It appears that they are both evolve simultaneously and can be dually facilitated by the methods reported by the nurses in their interviews. Further research on this topic would help in better understanding how best to target the issues of control and parental role acquisition.

Further investigations also are needed to explore how the phenomenon of protection and control influences the relationship among the triad of nurse, baby, and parent. The extent to which each parent or nurse allows control or perceives control given and taken needs further examination as it influences practice.

Limitations of the Study

As an exploratory study of the role of touch in the NICU, the sample size and demographics were limited. Unlike random sampling in quantitative studies, this qualitative study focused on a small population of parents with infants in the NICU. Although this sample was limited, it may have characteristics and valuable insight for other regions of the
country and groups of individuals who serve similar populations. A larger qualitative study would be of value to further investigate this group and this phenomenon of touch and bonding in the NICU both statewide and nationwide.

Data collection methodology was also a limitation. The use of journals would have provided a rich amount of data that could have deepened understanding of the parents’ perspectives in this study. However, the fact the journals were not returned suggests they were not an appropriate tool for this population. Further exploration of appropriate data collection for this population would be beneficial.

Because I was the primary tool in this investigation, potential personal bias must also be considered. As a parent with a child who had been hospitalized in the NICU at another facility, my personal experience may have influenced my responses to families and my understanding of their experience. I also work at the institution where the interviews were conducted, although I had no prior contact with these families and had no connections to them other than this study. There was no direct clinical interaction with any of the families who participated in this study.

I found the parental reports about support from medical staff very interesting because health care professionals are typically told to keep their personal lives separate from work. When healthcare professionals begin to discuss their personal lives, in essence they take the focus off the family or the patient they are serving. They may also be putting pressure on families to take the same paths they chose or bias the families’ own perceptions of the situation. I found this perspective unique in that it contradicts what I have been taught and practice professionally in my career. If a family asks me a question about my child or past experience, I make a point to briefly answer so as not to make a family uncomfortable, but
then try to return a question that focuses back on the family. Further studies investigating the influence of staff support as perceived by parents would be valuable. Studies perhaps would reveal that parents do gain deeper understanding and comfort through staff members’ personal experiences. In reflection, I could have shared more of my own experiences and journey as a mother to Aidan and Eli that perhaps could have influenced the rapport and relationship between myself and the parents participating in this study.

This study was intended to study parental perceptions; however, the majority of participants were mothers. Because only one father chose to participate, the results are limited in how one can understand a father’s experience. His statements were different in some respects than were those of the mothers, so I cannot assume his perspective is similar in all ways to the mothers. Additional studies that involve participants from various socioeconomic levels would also be beneficial. It would be helpful to examine if the level of economic resources and education has an influence on parents’ level of support. Also, if parents have more emotional support, are they better equipped to manage the intense emotions that are experienced while their young baby is hospitalized? This information could potentially help hospitals assess and individualize the level of support needed for families.
CHAPTER 5. SUMMARY AND CONCLUSIONS

Both the parents who told their stories and the nurses who provided valuable insight have exposed some interesting findings, as previously presented, with regard to the phenomenon of parents touching their babies and bonding in the NICU setting. The initial purpose of this research, to understand the role of touch in the parental experience of having a baby in the NICU, has been achieved by sharing the parents’ stories. The nursing reports also gave a perspective of the actual events and progression of emotional responses of parents touching their babies in the NICU. In totality, this study provides a better understanding of this phenomenon and emphasizes the need for positive touch experiences to facilitate parental bonding and acquisition of parental role and control in the NICU.

The stories shared by parents and the reports given by the nurses offered information that far exceeds the initial scope of the study. The narrative approach utilized in this study allowed me to tell these stories and develop a deeper understanding of what touch meant to each of these parents. Throughout the course of this study, themes also emerged regarding primary nursing and protection of the babies. This was an unexpected finding that has great implications for the practice of FCC as it presents potential barriers between the individuals involved in this dynamic. I now see a triad of interactions among the babies, the parents, and the nursing staff that I had not previously acknowledged. My personal perception had been toward that of the interaction between parents and the nursing staff. I had not considered the possible dynamic of both nurses and parents protecting the baby from each other. The nurses felt great responsibility for the babies’ progression toward health as well as perceiving the parents’ lack of understanding the physical dangers to the babies. Parents reported the need
to take more responsibility for their baby as they acquired more comfort and control in their experience of parenting a preemie in the NICU. The subtle messages of control echoed throughout the study and I found myself again and again referring back to them and their potential implications in the lives of these families as they were journeying toward the hope of recovery and survival of their babies.

As I spent so much time reading, transcribing, listening, and writing about this phenomenon as shared by the parents’ stories, I began to see a conflicting dynamic. I understand mothers saying that they perceive holding their babies as the way they “are there” for them. They reported the loss of control and their inability to do anything that could make their baby feel better except for when they had touch experiences. Except for when mothers had touch experiences that they saw as a way of “doing something” to “be there” for their baby, this dynamic presents a conflict between felt needs and reality for some families. If their child’s health is extremely fragile, they may not be allowed to or may choose not to touch their babies. This touch dynamic presents a significant problem for medical professionals striving to meet the needs of the families they are serving. How can they assist in meeting the felt need of mothers if mothers need to touch and hold their babies but cannot do so? Additional studies are needed to further explore ways that parents who have extremely fragile infants can feel connections to their babies. This may assist medical staff in helping these parents when touch is limited.

It was difficult to make a clear distinction between parental fears that were due to the appearance of their infants and to what degree staff influenced those fears. If members of the medical staff continually remind parents of everything to be afraid of, they could be encouraging fear rather than acquisition parental role and comfort. Staff motivations for
communication should be examined as to why they are saying certain things to parents and the potential implications for those statements eliciting fear. There are times when parents need to be reminded of the fragility of their infant, but at the same time, if they see their baby, voice concern, and appear afraid, does medical staff need to dwell on the situation? Both nurse and parent reports in this study described intense feelings of fear that parents had during those initial weeks and days in the NICU. A close examination of how information is given is needed. Although parents desire more information, nurses must consider the degree to which they further sensationalize the information and compound the pre-existing fears of parents.

I have personally changed and grown throughout the course of this study. I was amazed by the stories shared by the parents in this study. I also found it greatly beneficial to examine my own NICU and loss experiences. I do not think I had fully accepted and allowed myself to realize the magnitude of influence those events had on shaping my current views. Hearing the courageous stories of these parents as they openly talked about their fears, hopes, and losses, I found myself identifying with their stories on a personal level. Their stories impacted me in a way I had never anticipated. I now have a greater understanding of the parental experience and desires during those first weeks of their NICU stay as they learn to parent a preterm infant. I see a gap in care provided to these families, as their stories revealed a strong desire for primary nursing and, yet, current policies in place do not provide for that need. I also discovered that my own training and views regarding my choice to keep personal experiences from families is perhaps not always best practice in FCC. Some of the parents reported how powerful the shared experiences from medical staff were to their own journey in making meaning of this experience.
Implications

This study brings about several significant implications for policy, practice, and future research.

Policy

In my exploration of the phenomena of parental touch experiences in the NICU, I have identified a policy implication for the practice of primary nursing. Based on the findings of this study, particularly those themes related to perceptions of primary nursing from both parents and nurses, it is apparent that there needs to be a greater understanding of the need for primary nursing. All the parents in this study voiced they wanted a few nurses who knew them and their babies well. By instituting a policy that provides primaries for certain patients who have anticipated lengthy stays, we can provide for a critical need that parents have reported. Although specifics of the policy could vary, perhaps designing a rotation of nurses who provide primary care would allow much-needed breaks from the emotional stress that can result from the intensity of the relationship.

With respect to the concerns voiced by the nurses, it may be beneficial to provide personal days for nurses who work with a patient long term and then lose them. I know from my own experiences how difficult it is to develop a relationship with a patient and family and then watch them grieve the loss of that child. It is difficult to see a baby lose his or her fight when you have dedicated so much time to helping him or her toward recovery. However, one must remember that nurses not only grieve the loss of the patient, but that they often develop relationships with the family and in essence grieve for the family as well. Policies that better support nurses’ emotional needs during those times would be beneficial and would increase the number of those who choose to sign up for primaries.
Also, there should be additional policies developed that provide for touch opportunities such as infant massage instruction within the NICU. Providing a carefully trained NICU child life specialist who is certified to train in infant massage could facilitate further touch interactions. These touch interactions would be closely scaffolded and supported so that parents can slowly continue to develop those feelings of comfort and role acquisition. There is much research on the benefits of infant massage for this population, as cited in the literature review, which would provide increased support for this policy implementation (Ferber et al., 2005; Lappin, 2005).

**Practice**

Themes in this study also emerged that communicated a sense of protection from both the nurses and the parents. Providing more education on FCC practices for nursing staff could better assist in reducing the number of instances when professional boundaries are crossed. The boundaries surrounding whose role it is to parent, provide emotional support, and provide routine care for the child when the parents are at bedside need further deliberation and delineation. Fidler (2002) found that fathers reported staff as being seen as parent-like, resulting in important milestones being lost, such as first baths. As reported by nurses in this study, healthcare professionals are aware that parents differ in their emotional readiness to participate in care; carefully offering these choices to parents and providing appropriate support and modeling will greatly increase parental role acquisition. Additional studies have found that parents report that “best nursing behaviors” facilitate the parental role, reinforcing the family as a whole (Harbaugh, Tomlinson, & Kirschbaum, 2004). Similarly to Kenner and McGrath (2004), I found that there were control dynamics that
placed parents in a submissive role to the nurses. For example, parents felt they needed to ask for permission to do routine caretaking activities such as changing diapers.

Additional training on language selection and communication could also be beneficial in helping nurses be more cognizant of their word choices and facilitation of parental involvement, such as saying, “If you need any help, just let me know,” rather than, “If your baby needs something, come get me.” The focus should be to empower parents rather than placing importance on the nurse as the authority of the baby. Previous research by Fenwick et al. (2001) found that mothers perceive the nurse as a gateway to the information about their child’s health information, which influenced their experience as a mother. Nursing behaviors that are seen as facilitating the mothering role are consistent with FCC. These include actions that are nurturing and encourage parental participation in their infant’s care.

Advocating for touch is beneficial not only for attachment, but health as well in the evidence presented in the literature review. Touch is a free tool by which the hospital could utilize to improve patients health and recovery. Increased practice of nurturing touch could reduce costs by shortening hospital stays, stabilizing patients with lessened medications through the use of kangaroo care, and overall health benefits.

Finally, professionals should educate doctors, nurses, and other medical staff about the dynamics revolving around this phenomenon of parents touching their babies. Increased understanding of the fears and desires parents reported in this study could help staff better provide for their needs during those first few weeks following admission. More specifically, education should be provided to assist medical staff in supporting these parents within the context of staff’s word selection and actions witnessed by parents. Increased personal reflections could also assist medical staff in reducing bias and judgment in parents’ choices.
of whether or not to participate in their child’s care. By providing training to these staff, their level of sensitivity toward culturally diverse families as well as differing family compositions could be raised. For example, inviting a parent to participate is appropriate, but requiring them to change a diaper before they can hold their baby or manipulative language could be harmful to the nursing–parent relationship. Personal reflections of staff’s own biases and value judgments of family involvement should be monitored. Similarly, staff should not assume that parents’ choosing not to touch their child early in the NICU stay communicates they do not have that desire. As evidenced in the parental reports, all mothers had this desire, however, their emotional status and fears inhibited those desires. Careful consideration is needed to individualize expectations for each family served.

Future Research

There are many areas needing further exploration with regards to future research on the topic of parental experiences of touching their premature infants in the NICU. More ethnic diversity is needed in the sample groups. All participants except one in this study were White. The region of the country in which this study took place has a large Hispanic community. Due to language barriers, non-English speaking individuals were not chosen for this study. I do not speak Spanish and, due to the sensitivity of the study and my understanding of the interviews, the views of this population were not explored. One family selected was Hispanic and spoke English, but they did not return for the interview at the meeting time. This could still have been a limitation if their English was not fluent, as that would have presented challenges in communicating the research questions as well as in me fully understanding their story and what they meant to communicate. Another factor that limits diversity within the Hispanic population is the large number of immigrants who are
undocumented. In Arkansas there is a large population of undocumented immigrants. These families may have been fearful of participating in any study because they were afraid of being discovered and deported. This is a huge burden on these families and gaining a sample from this population would be very difficult. However, this would be invaluable information because the NICU serves so many in this population due to the poor prenatal care they receive and limited resources they have available during pre- and perinatal periods.

Additional studies should be done on fathers and their experience with parenting preterm infants in the NICU setting. Much research is on this topic has been gathered from mothers. They are typically more accessible and the primary caregivers for their children during NICU stays. Understanding the point of view of fathers would better help the health care community serve both parents in the clinical setting. Studies that yield more insight into the support available to different populations would also assist in providing additional support groups or organizations which could serve as a form of support for families who do not have access to their family or other support systems.

Future studies that investigate the nurses’ desire to protect the baby would be valuable. This was a theme that emerged during the interviews with both nurses and parents. This need to protect the baby from the parents can pose a barrier to bonding, so it needs to be more closely examined. Better understanding of this dynamic could increase FCC by reducing this potentially limiting interaction between the healthcare providers and parents who are trying to bond with their baby.

Touch continues to be a common desire that all the mothers expressed. Further investigation into how hospitals can advocate for more parental touch interaction is needed. Qualitatively examining hospital protocols from various regions of the country may yield
interesting data that shows trends in how various institutions vary in the level of value placed on this important aspect of bonding for parents. Most NICUs have touch protocols, yet some institutions offer infant massage classes, kangaroo care, touch education, and possibly other activities while at the bedside.

In respect to considerations for methodological approaches in future studies, I would recommend oversampling. The difficulty in accessing this population and gaining a sizable sample could perhaps benefit if the sample size was 25 instead of 15 which was used for this study. Since less than half of the participants returned for interviews, it appears that more parents need to be recruited. I would also recommend not choosing a journal as a form of data collection at this stage in the NICU. The transient life they are currently under as well as the incredible stress perhaps hinder the use of the journals. More appropriate methods such as additional interviews may prove more beneficial.

Further research could also be helpful in examining the doctors perspective in this phenomenon. Doctors are instrumental in hospital protocols as well as control the interactions parents have with their babies. A doctor must write an “order”, otherwise known as give permission, for parents to touch their babies. Gaining a deeper understanding of the value doctors place on touch as well as possible misconceptions regarding touch could help us advocate for families and serve as a catalyst for hospital policy changes.

Concluding Self-Reflection

Through my experience in completing this research, I have begun to make meaning of my role in this phenomenon. It is my hope that this study is a testament to the tremendous courage of both the parents living this phenomenon and the nurses who assist during those life-changing touch experiences. I see a greater meaning for the role I serve as both a CLS
and an infant massage instructor. This study has served as a catalyst for my continued advocacy of this powerful form of bonding and language between parents and their babies.

I have also been able to better understand and make meaning of my own experience of parenting a child in the NICU and in having lost a child. Although both those experiences were very difficult, they gave me insight into shared emotions I experienced with the parents in this study. I also greatly appreciate having the opportunity to hear the perspective of the nurses and see more clearly the role they play during this phenomenon. I have a greater appreciation for their emotional perspective of primary nursing. It was difficult for me to present the findings and advocate for primary nursing when I understand the emotional implications it has for the nurses who are already so emotionally impacted by the experience of caring for such fragile, precious babies. I hope that future policies and practices will provide support for the nursing staff and their needs in serving this population.

As I reflect back on the babies and families I have worked with whose journey ended in the NICU, I feel a great sense of reward knowing that the babies typically spent those last moments being held by the parents who loved them so much. It is a comfort to me to know that those strong desires mothers have to finally hold those sweet babies in their arms can at last come true, even if only for a brief time. It has been my honor to know you and provide support for you during those goodbyes. I hope this study has provided a voice for you to be heard and to provide remembrance for your journey and hope.
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APPENDIX A: INFORMED CONSENT DOCUMENT

INFORMED CONSENT DOCUMENT

Title of Study: Parental perceptions of touch between parents and their infants in the neonatal intensive care unit

Investigator: Crystal Y. Whittington

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION

The purpose of this study is to expose and analyze themes related to the perceived experiences of touch and attachment between parents their preemies. You are being invited to participate in this study because you are a parent of a baby in the neonatal intensive care unit.

DESCRIPTION OF PROCEDURES

If you agree to participate in this study, your participation will last for one month and will consist of three parts: a short written demographic survey, one audiotaped 90-minute interviews session at a site of your convenience, and a follow-up opportunity for you to proof the transcribed written dialogue from that session. The interview will be spaced approximately 4 weeks apart from the final phone conversation. You will also be asked to keep a journal about weekly experiences you have in touching your infant.

The audio recording will take place during the 90-minute session and will be erased following the submission of the research project. Your responses will remain confidential and you may skip any question that you do not wish to answer or that makes you feel uncomfortable.

RISKS

While participating in this study you may experience the following risks: There are no foreseeable risks at this time from participating in this study.

BENEFITS

If you decide to participate in this study there will be a small gift of books and toys provided for your infant. It is hoped that the information gained in this study will benefit society by providing valuable information about the relationship between parents and their infants in the neonatal intensive care unit.
COSTS AND COMPENSATION

You will not have any costs from participating in this study. You will not be compensated for participating in this study.

PARTICIPANT RIGHTS

Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. If you decide to not participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled.

CONFIDENTIALITY

Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, federal government regulatory agencies, auditing departments of Iowa State University, and the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis. These records may contain private information.

To ensure confidentiality to the extent permitted by law, the following measures will be taken: Identifiers will be kept with the data. The researcher and her faculty research committee will have access to this data. The data will be retained until submission of the research project, at which time the audiotapes will be erased. If the results are published, your identity will remain confidential.

QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study.

- For further information about the study contact Crystal Whittington (501)-278-5362 (cywhittington@hotmail.com) or Dr. Dianne Draper at Iowa State University (515)-294-4024 (dcdraper@iastate.ed).

- If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, IRB@iastate.edu, or Director, (515) 294-3115, Office of Research Assurances, Iowa State University, Ames, Iowa 50011.
INVESTIGATOR STATEMENT

I certify that the participant has been given adequate time to read and learn about the study and all of their questions have been answered. It is my opinion that the participant understands the purpose, risks, benefits and the procedures that will be followed in this study and has voluntarily agreed to participate.

(Signature of Person Obtaining Informed Consent)  (Date)

PARTICIPANT SIGNATURE

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

Participant’s Name (printed) ________________________________

(Participant’s Signature)  (Date)
APPENDIX B: DEMOGRAPHICS FORM

Family Information

Gender (please circle): Male   Female

Relationship to the infant: _______________________

City you live in ______________________

Is this your first baby? Y   N

Is this your first infant in the neonatal intensive care unit? Y  N

Are you able to stay close to the hospital during this hospitalization? Y  N

Were you able to touch your baby at birth? Y   N
APPENDIX C: PARENT INTERVIEW QUESTIONS

Questions were generated that would elicit meaningful responses from the parents. The questions are intended to facilitate open dialogue through semi-structured interviews. The researcher will be attuned to body language and verbal responses to determine the best approach to facilitate each interview. The study will address the following questions:

1. What are the experiences, perceptions and feelings of touching do parents have in the NICU?
   a. How do you feel about being in the NICU with your infant?
   b. What sort of touch experiences are parents anticipating most?
   c. What were the ways that you had physical contact with their infants?
      (kangaroo care, massage, breastfeeding, containment hold, or other)

2. How do parents feel after touch experiences?
   a. What staff near you during this time?
   b. What was the environment like during touch interactions?

3. Tell me about how you feel bonded to your baby?
   a. What sort of things make you feel closer to your baby?
   b. Do you think touching your baby makes you feel closer to him/her?

4. What is your relationship like with the nurses?
   a. What sort of things does the nurse do before you get to touch the baby?
   b. What sort of things was the nurse saying before, during and after these times?
   c. How do you feel about being involved with your babies care?
   d. How does staff respond to your presence?
APPENDIX D: NURSE INTERVIEW QUESTIONS

Questions were selected for interviews of the nurse who worked with each family during the initial touch interaction between the parent and their infant. Interviews will be semi-structured and the following questions will serve a guide to collect observations from the nurses perspective.

1. What sort of touch interaction do parents typically have with a baby at this gestational age?
2. What is the typical comfort level of the parents before the touch interaction?
3. What are typical things parents saying during this time?
4. What does their comfort level appear to be during the touch interactions?
   a. Did they appear excited, surprised, anxious, etc.?
   b. What sort of things were they saying?
   c. What was going on during this time in the environment?
   d. What were you during this time?
5. What is their typical mood like following the touch?
   a. What sort of things were they saying or asking?
6. Do parents ask to touch their baby?
   a. Who is usually the one who initiates touching the baby?
   b. Have they asked often about touching their baby (anticipation)?
7. How do you feel about parents touching their baby?
   a. Do you think they should do most of the routine caretaking?
   b. What is your role in helping families bond with their babies?
APPENDIX E: RESEARCH ANNOUNCEMENT FOR NURSES

Dear Staff,

I am a graduate student at Iowa State University seeking my PhD. I am also a child life specialist here at Arkansas Children’s Hospital. For my dissertation research I plan to study parental experiences and perceptions of touching their infants in the neonatal intensive care unit. I will interview parents who’s infant has been recently admitted into the NICU. I am also asking parents to keep a journal of their experiences. I will interview four experienced NICU nurses to gain your perspective of this dynamic as well.

I plan to leave a neon folder at the bedside to help you know who these families are as well as any information that you need concerning the research. This folder will hold my contact information and general information about the study. To facilitate this study, I would like to ask that you remind these parents to journal if you are present during a touch interaction. Thank you for your time in assisting this research. It will benefit the families here at ACH as it will allow us to better understand what the needs of our families are during this time. Please feel free to contact me with any questions you may have.

Sincerely,

Crystal Whittington
Child Life Specialist, Extension 41412
(501) 278-5362
cywwhittington@hotmail.com
Dear Parent,

Enclosed is a summary of our recent interview. I have typed the entire conversation, and have included portions of it in this letter. You are welcome read over the summary and portions of the interview and make any changes or comments that you feel I did not capture or may have misunderstood. If you do not want to make any changes, that is fine. I will call you to follow up and again discuss the summary that I have sent. I have enclosed a stamped and addressed envelop for you to return the journal. Please send that at your earliest convenience. I will collect the information I need and then send it back as soon as possible. Please expect it to be returned within two weeks.

Thank you for your time. I enjoyed our conversation. I look forward to talking with you again soon.

Thanks,

Crystal Whittington

Researcher